African and Caribbean people’s attitude to sickle cell and
the risk of having a child with sickle cell anaemia

By

Iyabode (Lola) O. T Oni

Submitted for the Degree of Doctor of Philosophy
September 2007

© Iyabode (Lola) Oni
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>i</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>ii</td>
</tr>
<tr>
<td>Glossary of terms and abbreviations</td>
<td>iv</td>
</tr>
<tr>
<td><strong>Chapter 1 - Introduction</strong></td>
<td></td>
</tr>
<tr>
<td>1.1 Aim of study</td>
<td>1</td>
</tr>
<tr>
<td>1.2 The Research Question</td>
<td>1</td>
</tr>
<tr>
<td>1.3 Familiarity with research environment</td>
<td>2</td>
</tr>
<tr>
<td>1.4 Central Ideas and Concepts</td>
<td>4</td>
</tr>
<tr>
<td><strong>Chapter 2 - Literature review</strong></td>
<td></td>
</tr>
<tr>
<td>2.1 Attitude</td>
<td>6</td>
</tr>
<tr>
<td>2.2 Cognitive Dissonance Theory</td>
<td>10</td>
</tr>
<tr>
<td>2.3 Culture</td>
<td></td>
</tr>
<tr>
<td>2.3.1 Culture in context</td>
<td>22</td>
</tr>
<tr>
<td>2.3.2 Culture and language</td>
<td>32</td>
</tr>
<tr>
<td>2.3.3 Culture, disease and perception of illness</td>
<td>34</td>
</tr>
<tr>
<td>2.3.4 African, Caribbean culture and religion</td>
<td>37</td>
</tr>
<tr>
<td>2.3.5 Culture and reproduction</td>
<td>44</td>
</tr>
<tr>
<td>2.3.6 Cultural beliefs and attitude to sickle cell in Africa and the Caribbean</td>
<td>48</td>
</tr>
<tr>
<td>2.4 Genetics</td>
<td></td>
</tr>
<tr>
<td>2.4.1 Political aspects of genetics and sickle cell screening</td>
<td>51</td>
</tr>
<tr>
<td>2.4.2 Research, genetic screening and impact</td>
<td>56</td>
</tr>
<tr>
<td>2.4.3 Perception of risk and genetic decision-making</td>
<td>61</td>
</tr>
<tr>
<td>2.4.4 Is non-directive genetic counselling possible?</td>
<td>71</td>
</tr>
<tr>
<td>2.4.5 Pre-natal diagnosis – to test or not to test?</td>
<td>75</td>
</tr>
<tr>
<td>2.5 Conclusion</td>
<td>82</td>
</tr>
</tbody>
</table>
## CONTENTS

**Chapter 3 - Human haemoglobin and sickle cell**

<table>
<thead>
<tr>
<th>3.1</th>
<th>Human haemoglobin</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1.1</td>
<td>Composition of human blood</td>
</tr>
<tr>
<td>3.1.2</td>
<td>Genetic inheritance of normal haemoglobin</td>
</tr>
<tr>
<td>3.1.3</td>
<td>Genetic mutations of haemoglobin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.2</th>
<th>Sickle cell disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.2.1</td>
<td>Structure of sickle haemoglobin</td>
</tr>
<tr>
<td>3.2.2</td>
<td>Epidemiology of sickle cell</td>
</tr>
<tr>
<td>3.2.3</td>
<td>Genetic inheritance of sickle haemoglobin</td>
</tr>
<tr>
<td>3.2.4</td>
<td>Bio-pathophysiology of sickle cell</td>
</tr>
<tr>
<td>3.2.5</td>
<td>Clinical implications and complications of sickle cell disease</td>
</tr>
<tr>
<td>3.2.6</td>
<td>Treatment and prevention of complications</td>
</tr>
</tbody>
</table>

**Chapter 4 - Philosophical approach, adoption of cognitive dissonance theory, methodology**

| 4.1 | Philosophical approach | 98 |
| 4.2 | Adoption of cognitive dissonance theory | 101 |

<table>
<thead>
<tr>
<th>4.3</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.3.1</td>
<td>Triangulation of data collection</td>
</tr>
<tr>
<td>4.3.2</td>
<td>Ethical approval</td>
</tr>
<tr>
<td>4.3.3</td>
<td>Instrument design</td>
</tr>
<tr>
<td>4.3.4</td>
<td>Pilot study</td>
</tr>
<tr>
<td>4.3.5</td>
<td>Recruitment &amp; distribution of questionnaires</td>
</tr>
<tr>
<td>4.3.5.1</td>
<td>Sample size</td>
</tr>
<tr>
<td>4.3.5.2</td>
<td>Recruitment process</td>
</tr>
<tr>
<td>4.3.5.3</td>
<td>Inclusion criteria</td>
</tr>
<tr>
<td>4.3.5.4</td>
<td>Exclusion criteria</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4.4</th>
<th>Organization of questionnaire and interview schedule (measurement tools)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.4.1</td>
<td>Section 1 – Knowledge of sickle cell</td>
</tr>
<tr>
<td>4.4.2</td>
<td>Section 2 – Attitude to sickle cell</td>
</tr>
<tr>
<td>4.4.3</td>
<td>Section 3 – Demography</td>
</tr>
<tr>
<td>4.4.4</td>
<td>Section 4 – Multi-dimension Health Locus of Control</td>
</tr>
<tr>
<td>4.4.5</td>
<td>Section 5 – Ethnicity &amp; cultural orientation</td>
</tr>
<tr>
<td>4.4.6</td>
<td>At risk women – Phase 3 questionnaire</td>
</tr>
<tr>
<td>4.4.7</td>
<td>At risk women – Phase 3 interview schedule</td>
</tr>
</tbody>
</table>
## CONTENTS

<table>
<thead>
<tr>
<th>Chapter 4</th>
<th>Philosophical approach, adoption of cognitive dissonance theory and methodology (continued…)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.5</td>
<td>Study Population</td>
</tr>
<tr>
<td></td>
<td>4.5.1 Study Population inclusions</td>
</tr>
<tr>
<td></td>
<td>4.5.2 Phase 1 - Respondents excluded</td>
</tr>
<tr>
<td></td>
<td>4.5.3 Phase 2 - Respondents excluded</td>
</tr>
<tr>
<td></td>
<td>4.5.4 Phase 3 - Respondents excluded</td>
</tr>
<tr>
<td>4.6</td>
<td>Process of Data analysis</td>
</tr>
<tr>
<td></td>
<td>4.6.1 Addressing the research question</td>
</tr>
<tr>
<td></td>
<td>4.6.2 Management of parametric and non-parametric data</td>
</tr>
<tr>
<td></td>
<td>4.6.2.1 Regression analysis</td>
</tr>
<tr>
<td></td>
<td>4.6.3 Qualitative data management</td>
</tr>
<tr>
<td></td>
<td>4.6.4 Presentation of participants’ voices</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter 5</th>
<th>Phase 1 Data - African Females/ Caribbean Females/ African Males and Caribbean Males</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>Demography</td>
</tr>
<tr>
<td></td>
<td>5.1.1 Ethnicity and gender</td>
</tr>
<tr>
<td></td>
<td>5.1.2 Ethnicity, gender and age group</td>
</tr>
<tr>
<td></td>
<td>5.1.3 Ethnicity, gender and marital status</td>
</tr>
<tr>
<td></td>
<td>5.1.4 Ethnicity, gender and educational level</td>
</tr>
<tr>
<td></td>
<td>5.1.5 Ethnicity, gender and employment</td>
</tr>
<tr>
<td></td>
<td>5.1.6 Ethnicity, gender and religion</td>
</tr>
<tr>
<td></td>
<td>5.1.7 Ethnicity, gender and knows someone with sickle cell disease</td>
</tr>
<tr>
<td></td>
<td>5.1.8 Ethnicity, gender and tested for sickle cell</td>
</tr>
<tr>
<td>5.2</td>
<td>Migration</td>
</tr>
<tr>
<td></td>
<td>5.2.1 Patterns of migration</td>
</tr>
<tr>
<td></td>
<td>5.2.2 Migration and religion</td>
</tr>
<tr>
<td></td>
<td>5.2.3 Migration and living with someone</td>
</tr>
<tr>
<td></td>
<td>with sickle cell disease</td>
</tr>
<tr>
<td></td>
<td>5.2.4 Migration and other variables</td>
</tr>
</tbody>
</table>
## CONTENTS

**Chapter 5 - Phase 1 Data - African Females/ Caribbean Females/ African Males and Caribbean Males (continued…)**

<table>
<thead>
<tr>
<th>Section</th>
<th>Subsections</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.3.1</td>
<td>Ethnicity – African and Caribbean</td>
<td>143</td>
</tr>
<tr>
<td></td>
<td>5.3.1.1 Ethnicity and enculturation</td>
<td>143</td>
</tr>
<tr>
<td></td>
<td>5.3.1.2 Ethnicity and general knowledge of sickle cell</td>
<td>144</td>
</tr>
<tr>
<td></td>
<td>5.3.1.3 Ethnicity and attitude to sickle cell and reproductive drive</td>
<td>145</td>
</tr>
<tr>
<td>5.3.2</td>
<td>Gender – Male and female</td>
<td>150</td>
</tr>
<tr>
<td></td>
<td>5.3.2.1 Gender and attitude to sickle cell and reproductive drive</td>
<td>150</td>
</tr>
<tr>
<td></td>
<td>5.3.2.2 Gender and Multi-dimension Health Locus of Control (MHLC)</td>
<td>151</td>
</tr>
<tr>
<td></td>
<td>5.3.2.3 Gender and other variables</td>
<td>151</td>
</tr>
<tr>
<td>5.3.3</td>
<td>Migration</td>
<td>151</td>
</tr>
<tr>
<td></td>
<td>5.3.3.1 Migration and enculturation</td>
<td>151</td>
</tr>
<tr>
<td></td>
<td>5.3.3.2 Migration and religion</td>
<td>152</td>
</tr>
<tr>
<td></td>
<td>5.3.3.3 Migration and general knowledge of sickle cell</td>
<td>152</td>
</tr>
<tr>
<td></td>
<td>5.3.3.4 Migration and attitude to sickle cell and reproductive drive</td>
<td>153</td>
</tr>
<tr>
<td></td>
<td>5.3.3.5 Migration and Multi-dimension Health Locus of Control (MHLC)</td>
<td>154</td>
</tr>
<tr>
<td></td>
<td>5.3.3.6 Migration and other variables</td>
<td>154</td>
</tr>
<tr>
<td>5.3.4</td>
<td>African Female / Caribbean Female</td>
<td>154</td>
</tr>
<tr>
<td></td>
<td>5.3.4.1 African Female / Caribbean Female – and enculturation</td>
<td>154</td>
</tr>
<tr>
<td></td>
<td>5.3.4.2 African Female / Caribbean Female – attitude to sickle cell</td>
<td>155</td>
</tr>
<tr>
<td></td>
<td>5.3.4.3 African Female / Caribbean Female – other variables</td>
<td>155</td>
</tr>
<tr>
<td>5.3.5</td>
<td>African Female / African Male</td>
<td>155</td>
</tr>
<tr>
<td></td>
<td>5.3.5.1 African Female / African Male – enculturation</td>
<td>155</td>
</tr>
<tr>
<td></td>
<td>5.3.5.2 African Female / African Male – attitude to sickle cell and reproductive drive</td>
<td>156</td>
</tr>
<tr>
<td></td>
<td>5.3.5.3 African Female / African Male – Multi-dimension Health Locus of Control</td>
<td>156</td>
</tr>
<tr>
<td></td>
<td>5.3.5.4 African Female / African Male – other variables</td>
<td>156</td>
</tr>
<tr>
<td>5.3.6</td>
<td>Caribbean Female / Caribbean Male</td>
<td>157</td>
</tr>
</tbody>
</table>
Chapter 5  -  Phase 1 Data -
African Females/ Caribbean Females/ African Males and Caribbean Males (continued...)

5.3.7 African Male / Caribbean Male
   5.3.7.1 African Male / Caribbean Male – and general knowledge of sickle cell 157
   5.3.7.2 African Male / Caribbean Male – Attitude to sickle cell & reproductive drive 158
   5.3.7.3 African Male / Caribbean Male – other variables 158
5.3.8 Analysis of other variables 159
5.3.9 Regression analysis 161
5.3.10 Analysis of qualitative response in questionnaire 162

5.4 Phase 1 Discussion 163
   5.4.1 Enculturation 164
   5.4.2 Educational level 165
   5.4.3 Impact of religion 166
   5.4.4 General knowledge of sickle cell 168
   5.4.5 Attitude to sickle cell disease
      5.4.5.1 Severity of disease 171
      5.4.5.2 Level of burden 174
      5.4.5.3 Reproductive drive 176
      5.4.5.4 Multi-dimension Health Locus of Control 178
      5.4.5.5 Test result and selection of partner 180
      5.4.5.6 Qualitative data in questionnaire 182
      5.4.5.7 Other concepts and variables 185
   5.4.6 Conclusion 185

Chapter 6  -  Phase 2 Data -
– African Antenatal / Caribbean Antenatal

6.1 Demography
   6.1.1 Antenatal - Ethnicity 187
   6.1.2 Antenatal - Age group 188
   6.1.3 Antenatal - Marital status 189
   6.1.4 Antenatal - Educational level 189
   6.1.5 Antenatal - Employment 190
   6.1.6 Antenatal - Religion 190
   6.1.7 Antenatal - Migration 192
   6.1.8 Antenatal - At risk group 192
## CONTENTS

<table>
<thead>
<tr>
<th>Chapter 6</th>
<th>Phase 2 Data -</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>– African Antenatal/ Caribbean Antenatal (continued…)</td>
</tr>
</tbody>
</table>

### 6.2 Inferential Analysis

6.2.1 African Antenatal and Caribbean Antenatal

6.2.1.1 African Antenatal and Caribbean Antenatal and enculturation 193

6.2.1.2 African Antenatal and Caribbean Antenatal and general knowledge of sickle cell 193

6.2.1.3 African Antenatal and Caribbean Antenatal and employment 194

6.2.1.4 African Antenatal and Caribbean Antenatal and attitude to sickle cell disease 194

6.2.1.5 African Antenatal and Caribbean Antenatal and migration 195

6.2.1.6 African Antenatal and Caribbean Antenatal and know someone with sickle cell disease 195

6.2.1.7 African Antenatal and Caribbean Antenatal and test result and selection of partner 196

6.2.1.8 African Antenatal and Caribbean Antenatal and genetic counselling experience 198

6.2.2 Analysis of Phase 2 qualitative response in questionnaire 199

| Chapter 7 | Comparative analysis of Phase 1 and Phase 2 Data - Non-Pregnant Females / Pregnant Females |

### 7.1 Non pregnant Female / Pregnant Female

7.1.1 Non pregnant Female / Pregnant Female

- Educational level 202

7.1.2 Non pregnant Female / Pregnant Female and employment 202

7.1.3 Non pregnant Female / Pregnant Female and religion 202

7.1.4 Non pregnant Female / Pregnant Female and general knowledge of sickle cell 203

7.1.5 Non pregnant Female / Pregnant Female and attitude 203

7.1.6 Non pregnant Female / Pregnant Female and Multi-dimension Health Locus of Control 203
## CONTENTS

### Chapter 7 - Comparative analysis of Phase 1 and Phase 2 Data - Non-Pregnant Females / Pregnant Females (continued...)

**7.2 African Females (non pregnant) / African Antenatal**
- 7.2.1 African Females / African Antenatal and enculturation 204
- 7.2.2 African Females / African Antenatal and general knowledge of sickle cell 204
- 7.2.3 African Females / African Antenatal and Attitude 204
- 7.2.4 African Females / African Antenatal and Multi-dimension Health Locus of Control (MHLC) 205

**7.3 Caribbean Females (non pregnant) / Caribbean Antenatal**
- 7.3.1 Caribbean Antenatal & Caribbean Females and general knowledge of sickle cell 206

**7.4 Discussion – Phase 1 and Phase 2 comparative analysis of Non Pregnant and Pregnant Females**
- 7.4.1 Pregnant and Non-Pregnant and enculturation 207
- 7.4.2 Pregnant and Non-Pregnant and educational level 207
- 7.4.3 Pregnant and Non-Pregnant and religion 209
- 7.4.4 Pregnant and Non-Pregnant and general knowledge of sickle cell 209
- 7.4.5 Pregnant and Non-Pregnant and attitude to sickle cell disease 212
- 7.4.6 Pregnant and Non-Pregnant and reproductive drive 212
- 7.4.7 Pregnant and Non-Pregnant and Multi-dimension Health Locus of Control (MHLC) 213
- 7.4.8 Pregnant and Non-Pregnant and test result and selection of partner preconception 214
- 7.4.9 Pregnant and Non-Pregnant - other concepts and variables 215
- 7.4.10 Conclusion 215
## CONTENTS

**Chapter 8 - Phase 3 Qualitative Data and Discussion – African Antenatal/ Caribbean Antenatal / African Male Partner / Caribbean Male Partner**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.1 Introduction</td>
<td>218</td>
</tr>
<tr>
<td>8.2 Attitude to procreation and childbearing</td>
<td></td>
</tr>
<tr>
<td>8.2.1 Importance of having children – a cultural perspective</td>
<td>220</td>
</tr>
<tr>
<td>8.2.2 Barrenness - Marital instability and stigmatization</td>
<td>232</td>
</tr>
<tr>
<td>8.2.3 Children – a pension plan for old age</td>
<td>239</td>
</tr>
<tr>
<td>8.2.4 Religion and procreation</td>
<td>241</td>
</tr>
<tr>
<td>8.3 Knowledge and perception of sickle cell disease</td>
<td></td>
</tr>
<tr>
<td>8.3.1 Nature and severity of sickle cell disease</td>
<td>244</td>
</tr>
<tr>
<td>8.3.2 Screening - choices &amp; responses to trait (carrier) result</td>
<td></td>
</tr>
<tr>
<td>8.3.2.1 Screening choices</td>
<td>248</td>
</tr>
<tr>
<td>8.3.2.2 Response to sickle cell trait result</td>
<td>249</td>
</tr>
<tr>
<td>8.3.2.3 Selection of partner pre marital and attitude to at-risk coupling</td>
<td>254</td>
</tr>
<tr>
<td>8.3.2.4 Selection of partner preconception</td>
<td>269</td>
</tr>
<tr>
<td>8.4 Factors influencing decisions about an at-risk pregnancy</td>
<td></td>
</tr>
<tr>
<td>8.4.1 Experience of genetic counselling</td>
<td>276</td>
</tr>
<tr>
<td>8.4.2 Personal experience of living with sickle cell disease</td>
<td>282</td>
</tr>
<tr>
<td>8.4.3 Partners and significant others</td>
<td>284</td>
</tr>
<tr>
<td>8.5 Prenatal Diagnosis</td>
<td></td>
</tr>
<tr>
<td>8.5.1 Factors influencing rejection of prenatal diagnosis</td>
<td>288</td>
</tr>
<tr>
<td>8.5.1.1 Risk of miscarriage</td>
<td>289</td>
</tr>
<tr>
<td>8.5.1.2 Religion</td>
<td>291</td>
</tr>
<tr>
<td>8.5.1.3 Social and moral aspects</td>
<td>293</td>
</tr>
<tr>
<td>8.5.1.4 Advanced age of pregnancy</td>
<td>295</td>
</tr>
<tr>
<td>8.5.1.5 Other reasons</td>
<td>296</td>
</tr>
<tr>
<td>8.5.2 Acceptance of prenatal diagnosis</td>
<td>297</td>
</tr>
<tr>
<td>8.5.2.1 Opposition to termination of an affected pregnancy - preparing for a potentially sick child</td>
<td>297</td>
</tr>
<tr>
<td>8.5.2.2 Support of termination of an affected pregnancy</td>
<td>300</td>
</tr>
<tr>
<td>8.6 Influence of religion in decision making</td>
<td></td>
</tr>
<tr>
<td>8.6.1 Dilemmas posed by religion</td>
<td>305</td>
</tr>
</tbody>
</table>
## CONTENTS

Chapter 8 - Phase 3 Qualitative Data and Discussion – African Antenatal/ Caribbean Antenatal / African Male Partner / Caribbean Male Partner (continued…)

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.7 Possible impact of having a child with sickle cell anaemia</td>
<td>311</td>
</tr>
<tr>
<td>8.7.1 Impact on marital / intimate relationship</td>
<td>311</td>
</tr>
<tr>
<td>8.7.2 Impact on other relationships</td>
<td>314</td>
</tr>
<tr>
<td>8.7.3 Impact on decisions about family size</td>
<td>314</td>
</tr>
<tr>
<td>8.8 Conclusion</td>
<td>317</td>
</tr>
</tbody>
</table>

Chapter 9 - Overall Discussion

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.1 Phase 1, 2 and 3 overall discussion</td>
<td>321</td>
</tr>
<tr>
<td>9.1.1 Ethnic group – cultural and social similarities and differences</td>
<td>321</td>
</tr>
<tr>
<td>9.1.2 Knowledge of sickle cell &amp; attitude to testing</td>
<td>324</td>
</tr>
<tr>
<td>9.1.3 Importance of having children</td>
<td>340</td>
</tr>
<tr>
<td>9.1.4 Attitude to sickle cell disease</td>
<td>348</td>
</tr>
<tr>
<td>9.1.5 Decision making in Pregnancy</td>
<td>357</td>
</tr>
<tr>
<td>9.1.6 Impact of religion</td>
<td>363</td>
</tr>
<tr>
<td>9.2 Reflection on theoretical models</td>
<td>369</td>
</tr>
<tr>
<td>9.3 Implications for future practice</td>
<td>379</td>
</tr>
<tr>
<td>9.4 Implications for society</td>
<td>382</td>
</tr>
<tr>
<td>9.5 Limitations of study</td>
<td>383</td>
</tr>
<tr>
<td>9.6 Suggestions for future research</td>
<td>386</td>
</tr>
<tr>
<td>9.7 Personal reflection</td>
<td>388</td>
</tr>
</tbody>
</table>

References | 392 |
## Illustrations

<table>
<thead>
<tr>
<th>Boxes</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Box 1 – Study population</td>
<td>121</td>
</tr>
<tr>
<td>Box 2 – Phase 3 interview population</td>
<td>121</td>
</tr>
<tr>
<td>Box 3 – Composition of groups analyzed</td>
<td>124</td>
</tr>
<tr>
<td>Box 4 – Variables Analyzed</td>
<td>124</td>
</tr>
<tr>
<td>Box 5 – Qualitative data coding strategy</td>
<td>129</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Charts</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pie Chart 1 Phase 1 - Ethnicity and gender</td>
<td>133</td>
</tr>
<tr>
<td>Pie Chart 2 Phase 2 - Antenatal ethnic group</td>
<td>187</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagrams</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagram 1 Normal red blood cells and haemoglobin molecules</td>
<td>84</td>
</tr>
<tr>
<td>Diagram 2 Double helix and adult haemoglobin tetramer</td>
<td>85</td>
</tr>
<tr>
<td>Diagram 3 Autosomal recessive Mendelian inheritance of the sickle cell gene</td>
<td>91</td>
</tr>
<tr>
<td>Diagram 4 Sickled red blood cells and abnormal stacking of haemoglobin molecules</td>
<td>92</td>
</tr>
<tr>
<td>Diagram 5 Clinical implications and complications of sickle cell disease</td>
<td>96</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Graphs</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Graph 1 Ethnicity, gender and age group</td>
<td>134</td>
</tr>
<tr>
<td>Graph 2 Ethnicity, gender and marital status</td>
<td>135</td>
</tr>
<tr>
<td>Graph 3 Ethnicity, gender and educational level</td>
<td>136</td>
</tr>
<tr>
<td>Graph 4 Ethnicity, gender and employment</td>
<td>137</td>
</tr>
<tr>
<td>Graph 5 Ethnicity, gender and religion</td>
<td>138</td>
</tr>
<tr>
<td>Graph 6 If a couple both have sickle cell trait I think they should not have children together</td>
<td>145</td>
</tr>
<tr>
<td>Graph 7 Having a child with sickle cell disease can be a blessing in a family</td>
<td>147</td>
</tr>
<tr>
<td>Graph 8 Having a child with sickle cell disease can cause financial hardship for the Family</td>
<td>148</td>
</tr>
<tr>
<td>Graph 9 It is important for ALL healthy men and women to have children</td>
<td>149</td>
</tr>
</tbody>
</table>
Illustrations

Graphs

Graph 10 People should tell their partners their blood test result before having children 149
Graph 11 Antenatal and age group 188
Graph 12 Antenatal and marital status 189
Graph 13 Antenatal and educational level 191
Graph 14 Antenatal and religious practice 174

Maps

Map 1 Incidence of sickle cell trait 89

Tables

Table 1 Haemoglobin type at stages of human development and globin chain present 86
Table 2 The most common incidence of sickle cell trait 89
Table 3 Ethnicity, gender and age group 134
Table 4 Ethnicity, gender and educational level 136
Table 5 Ethnicity, gender and religious faith 138
Table 6 Ethnicity, gender and religious denomination 139
Table 7 Know someone with sickle cell disease/ tested for sickle cell/ chose or not choose partner preconception 141
Table 8 Ethnicity and language 143
Table 9 Ethnicity, attitude to sickle cell and reproductive drive 146
Table 10 Migration and enculturation 151
Table 11 Migration, attitude to sickle cell and reproductive drive 153
Table 12 African Male/ Caribbean Male, attitude to sickle cell and reproductive drive 158
Table 13 Qualitative data obtained from questionnaire 162
Table 14 Antenatal and age group 188
Table 15 Antenatal and religious faith 191
Table 16 Antenatal and religious denomination 191
Table 17 Antenatal and migration 192
Table 18 Antenatal at-risk couples in Brent Centre 195
Table 19 African Antenatal / Caribbean Antenatal and Know someone with sickle cell disease 195
Table 20 African Antenatal / Caribbean antenatal and selection of partner pre-marital / pre-conception 196
## Illustrations

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 21</td>
<td>African Antenatal / Caribbean Antenatal selection of partner based on own haemoglobin status</td>
<td>197</td>
</tr>
<tr>
<td>Table 22</td>
<td>African Antenatal / Caribbean Antenatal and mode of result notification and notifier</td>
<td>198</td>
</tr>
<tr>
<td>Table 23</td>
<td>African Antenatal / Caribbean Antenatal and experience of genetic counselling</td>
<td>198</td>
</tr>
<tr>
<td>Table 24</td>
<td>Qualitative data obtained from questionnaire</td>
<td>199</td>
</tr>
</tbody>
</table>
Abstract

The project aimed to identify socio-cultural factors influencing attitudes to sickle cell disease (SCD) and decisions about a pregnancy at risk of producing a child with sickle cell anaemia; and to identify differences between African and Caribbean respondents.

Sample: Phase 1 – General public African and Caribbean men and women; Phase 2 – Pregnant African and Caribbean women with sickle cell trait (HbAS) Phase 3 – Pregnant women from Phase 2 and their partners, who have HbAS, placing the couple at-risk of having a child with HbSS.

Methodology: Phase 1 and 2 – a questionnaire (appendix 1) examining - knowledge of SCD and five attitude variables – importance of having children, locus of control in genetic decision-making, prevention of birth of children with SCD, perception of the burden and severity of SCD.. Phase 3 - semi structured interview (appendix 3), which examined attitude and response of pregnant women and their partners to their being at-risk of having a child with sickle cell anaemia.

Result: Statistically significant differences were observed between African and Caribbean respondents in areas which include - knowledge of SCD p=0.005; perception of a high level of burden of SCD, p=0.000; importance of having children, p=0.000; with Africans having a higher mean score in all these categories. Unexpectedly the age at which an individual migrated to the UK had an impact on attitude supporting the hypothesis that culture influences attitude. Significant differences were observed in those born/ migrated <15 years of age and those migrated >15 years of age – importance of having children p=0.000; perception of severity of SCD p=0.002; perceived high level of burden of SCD p=0.000, in all these areas those migrated >15 years of age had higher mean scores.

Discussion: The increasing demand for individuals to seek genetic testing and avoid the birth of children with genetic disability has placed greater pressure on members of society, especially pregnant women, and raises many dilemmas which few people are prepared for or able to manage. The pressure to have children and the society’s opposition to having children with a disability, especially in some African communities contributes to increasing anxiety and tension.

In this study in responding to being at-risk of having a child with SCD few African or Caribbean respondents opted for prenatal diagnosis with the intention of terminating an affected fetus. There often arises a tension between, a cultural demand to produce offspring, society’s stigmatization of those who produce ‘sickly’ children and the religious conviction that it is not appropriate to interfere with God’s creation (fetus) and its outcome. The cognitive dissonance that this tension creates was amply demonstrated in this study and the way which individuals attempt to deal with this has included obfuscation of knowledge, reducing the importance of the dissonant cognition and adding a consonant element in order to justify behaviour and reduce dissonance. The application of dissonance theory has helped to explain some of the reasons behind some African and Caribbean peoples’ reluctance to seek information or testing for sickle cell before marriage or having children; and declining the option of prenatal diagnosis with a view to terminating an affected pregnancy.
Acknowledgements

I wish to thank all those who have contributed in various ways to this project without their commitment and support it would not have been possible to achieve my ambition.

My sincere appreciation is extended to all the participants who completed the questionnaires and especially to all the pregnant women and partners who also volunteered to be interviewed and gave permission for me to present their stories.

I also thank the following individuals and groups:

Project supervisors: Professor Ian Robbins, Professor Geoff Hunt, University of Surrey and Professor Sally C Davies, Director of Research and Development, Department of Health.

Funding bodies: The Health Foundation (formerly PPP), North West London Hospitals NHS Trust, The Thomas Page Legacy Fund

My long suffering Family: Olatunde Owoyemi, Mrs. Tanimowo Oni, John Oni, Olufunmilayo Caulcrick, Oluseye Caulcrick and Bunmi Aiyede

My church leaders and members: Special Apostle Prophet Pastor (Dr) S.O Aiyegbusi, M/S/M/I/I Prophetess E.A Adeeko and all members of Amazing Grace C&S Church Movement, London Branch

Brent Sickle Cell & Thalassaemia (Lead) Centre Relay of Research Assistants: Orla Cummins, Tanya Dasgupta, Matsui Izawa, Emma Lawrence

Other Members of staff: Dr. Kofi Anie, Beatrice Babalola, Vesna Graham, Elizabeth Okuyiga, Linda Joseph, Gira Patel, Sonia Patel, Brent Sickle Cell and Thalassaemia Centre, London

Participating centres and facilitators:

- Collis Rochester-Peart, Hilda Castillo-Binger, Jean Mullen, Shirley Samuel, Jeneh Burns, SE London Sickle Cell & Thalassaemia Centre, Lambeth PCT
- Dr. Lorna Bennett, Nkechi Anyanwu, Camden & Islington Sickle Cell & Thalassaemia Centre, Camden & Islington PCT
- Bernice Burton, Comfort Okolo, Newham Sickle & Thalassaemia Centre, Newham PCT
- Sherrill Gregory, Rhonda Foster, Croydon Sickle & Thalassaemia Centre, Croydon PCT
- Professor Swee Lay Thein and Dr David Rees, Haematology Department, King’s College Hospital, London
- Dr Mary Petrou, Department of Obstetrics & Gynaecology, Fetal Medicine Unit, University College Hospital, London
Other professionals:

- Professor Theresa Marteau, Genetics Department, Guy’s Hospital, London
- Peter Williams, Statistician, Mathematics Department, University of Surrey, Guildford

Community organizations:

- Monica Cameron, Project Coordinator, Friends of African and Caribbean Carers and suffers of Dementia, Brent, London
- William Gemegah, Project Manager, Community Health Action Trust, Brent, London
- Linda McDonald, Senior Specialist Nurse Manager, Genito-Urinary Clinic, North West London Hospitals NHS Trust
- Dr. Asaah Nkonkwo, Director, Sickle Cell Society, London
- Ike Odina, Director, Cancer Black Care, Brent, London
- Phil Sealy, Chair, Black Mental Health, Brent, London
- Tony Warner, Coordinator, 100 Black Men, Voluntary Organization, UK

Other supporters and contributors *(in alphabetical order)*:

Kofi Agbolegbe, Tolu Ahmed, Olu Akinyemi, Hazel Alexander, Obrey Alexis, Dr. Sandra Anglin, Lekan Ayinde, Chris Baguma, Elaine Beresford, Eileen Bowen, Simone Bowman, Iris Brown, Cynthia Coker, Tayo Daramola, Delphyne Evans, Clementine Femiola, Pippa Gilham, Cynthia Gill, Theo Harris, Aisha Khan, Dr Mark Layton, Linda Liu, Abim Mabadeje, Dr Ashiorkor Meshe, Norman Mitchell, Folake Ogunojemite, Rotimi Ogunojemite, Yomi Ogunsanya, Janice Omar, Evelyn Otako, Emma Quarshie, Marina Rossi, Margaret Sanyu, Stephanie Suilaiman, Delsie Thomas, Dorothy Turner, David Udo, Joan Walters, Carol Webley-Brown, Christine Williams
Glossary of terms and abbreviations

**Aplastic crisis** – A temporary cessation of the bone marrow producing red blood cells, often as a result of infection by the parvovirus

**Dactylitis** – Swelling of the hand, foot or digits due to inflammation of tissues occurs most commonly in children with sickle cell disease

**Diploe expansion** – An abnormal expansion of the skull bones

**Genotype** - The specific genetic constitution of an organism, what is inherited through the perm and egg at the moment of conception; a set of DNA molecules, the genes contained in the nucleus of a fertilized egg

**Gnanopathy** – protuberance and gaping of the teeth

**HPFH** – Hereditary Persistence of Fetal Haemoglobin

**Phenotype** - Observable properties or attitudes, these include morphological, physiological or behavioural characteristics. All aspects of the organism that are NOT inherited, they develop thorough lifetime partly as a result of genotype partly not. The phenotype is subject to a degree of change under the influence of genetic evolution. For example, those with HbAS are phenotypically the same as those with HbAA, the observable characteristics of HbAS are the same as that of HbAA.

**Prenatal diagnosis (PND)** – An invasive procedure conducted to obtain fetal DNA for genetic analysis.

**Pre-implantation genetic diagnosis (PIGD)** – A process of fertilizing an egg with a sperm external to the human body; conducting genetic analysis to determine that the fertilized egg is free of the genetic condition, implantation of the fertilized egg in a woman in order to establish a pregnancy

**Priapism** – An involuntary erection of the penis due to sickling in the corpora cervosa

**RBC** – Red Blood Cell, the oxygen carrying component of blood

**Sequestration** – Pooling of blood in an organ e.g. spleen, liver

**Sickle Cell Disease (SCD)** – A genetic disease affecting red blood cell haemoglobin

**Tactoids** – Stiff rods of clumped haemoglobin molecules within the sickle red blood cell

**TIA** – Transient Ischaemic Attacks, blockage of small blood vessels in the brain, occurs most commonly in children
# CHAPTER 1 - Introduction

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Aim of study</td>
<td>1</td>
</tr>
<tr>
<td>1.2 The Research Question</td>
<td>1</td>
</tr>
<tr>
<td>1.3 Familiarity with research environment</td>
<td>2</td>
</tr>
<tr>
<td>1.4 Central Ideas and Concepts</td>
<td>4</td>
</tr>
</tbody>
</table>
Chapter 1 - Introduction

1.1 Aim of study

The aim of this study is to gain insight into socio-cultural factors that influence attitudes to sickle cell, particularly the decision-making of pregnant African women and Caribbean women, and their partners, when at risk of having a child with sickle cell anaemia (HbSS) a form of sickle cell disease (SCD). It also aims to ascertain whether social and cultural factors have any influence on the pregnancy outcome of the two ethnic groups.

Medicine and genetics have advanced dramatically in the last few decades such that it is now possible to offer people opportunities to prevent the birth of children with disabilities. Yet few women and couples from minority ethnic communities appear to avail themselves of this opportunity. As a clinician working in a highly specialist field of medicine and observing this phenomenon I wanted an opportunity to examine factors contributing to it. In view of the UK government’s proposal to provide national comprehensive screening for sickle cell to women and all newborn infants in England (DoH 2000) I felt this was an opportune time to examine this important issue and contribute to our understanding of how African and Caribbean people make decisions in respect of the genetic choices available to them in modern-day society.

1.2 The research question

i. Is the attitude to sickle cell influenced by cultural outlook and other social experiences?

ii. Are decision-making and pregnancy outcome influenced by culture and other psychosocial factors when a woman or couple is at risk of having a child with sickle cell anaemia?
1.3 Familiarity with research environment

I migrated to the UK from Nigeria in western Africa at nine years of age before completion of my enculturation. There were few people of African origin in the area where I lived in southwest London. The vast majority of those I associated with were of Black Caribbean origin, a few white English and Asian. Following migration to the UK I had no association with people from Africa, except my nuclear family that was until my early-twenties. In view of this most of my ‘outside the home’ experiences and cultural influences were derived from the Black Caribbean youth culture of southwest London, therefore, my attitude reflects primarily African and subsequently Caribbean culture and to a lesser degree English culture. I obtained most of my English perspective through exposure in school, college and latterly professional training and interactions with my local Anglican church where from the age of nine I attended regularly.

As a specialist nurse in the field of sickle cell and thalassaemia since 1995 I have developed an expertise in this specialist field. I was instrumental in the development of the first professionally accredited nurse training programme in the UK and was the specialist module leader at the Florence Nightingale School of Nursing and Midwifery, Kings College University of London. I have written extensively on the specialist subject and contribute to the development of policies at national and international level.

This familiarity with the research population and the specialist subject will invariably influence my approach to the research question, data analysis and interpretation of the data. I am aware that this familiarity with the research environment has the potential to create bias and limit objectivity, this was reflected upon frequently during formal supervision and all attempts were made to remain objective and maintain the integrity of the project.

As a researcher I am conscious of the dilemmas inherent in ones attempt to retain the philosophy of a feminist researcher which aims to promote the empowerment and liberation of women by presenting the women’s stories and voices in a way which is in keeping with honesty, truth and a shared empathetic understanding of women’s experiences in a male dominated society. Spalter-Roth and Hartman (1999) suggest that feminist researchers need to resist the temptation of merely producing data which fails to influence or improve the lives of those they have researched hence they should produce policy relevant research which can be used by policy
makers, feminist researchers and the women affected by the policies. I suggest that the same can be said of researchers who conduct research on black and minority ethnic people who have a genetic condition that is almost peculiar to their specific group and who may have little or no opportunity for their voices to be heard about what it feels like to live with the condition or the experience of the condition and its impact in their community. These voices need an opportunity to be heard by those who produce policies and by the wider society who have not been exposed to the reality of being at-risk of having a child with this debilitating and unpredictable condition.

I acknowledge that I share certain characteristics with the research population. I share being black with all the participants; whilst I share being a woman, African and a Christian with some of the participants. This as described by Ann Oakley (1981) depicts the ‘insider’ aspect of being a researcher. As highlighted by Parr (1998) this could pose a double-edged sword which can enable or limit the participants’ ability to share their experiences with the researcher. As an ‘outsider’ to the study population I am an academic, researcher and policy maker and need to recognize that I am also influenced by an already existing body of knowledge in these professional worlds and to a certain extent need to adhere to rules and the regulations and the expectations of these roles. Hence the ‘insider’ and ‘outsider’ roles could conflict unless efforts are made to identify and limit areas of potential conflict. I experienced the benefits as well as the negative impact of being an insider, this I discuss further in the reflection in section 9.2.
1.4 Central ideas and concepts

The researcher's experience and observation in the clinical field led to the formation of the opinion that there may be differences in attitude to sickle cell disease (SCD) among African and Caribbean people and that this influences the pregnancy outcome of women and couples who are at risk of having a child with sickle cell anaemia. Clinical observation also led to the opinion that a greater proportion of African women opt for PND and termination of an affected pregnancy compared to women of Caribbean origin. Petrrou (1992) reviewed factors affecting the uptake of PND for sickle cell, and following the review they recommended that studies which examine factors that influence decision-making would promote a better understanding of relevant issues in this specialist field. The majority of studies which have examined genetic decision-making have explored pregnancy outcome, but few have examined the socio-cultural factors influencing these decisions and the consequent impact on the outcome of pregnancy. Two studies were found that examined socio-cultural aspects of SCD specifically (Dorticos-Balea 1997, Alkurayyah and Kilani 2001.)

Sickle cell is a genetically inherited disease of red blood cell haemoglobin and belongs to a group of conditions collectively known as haemoglobinopathies. It primarily affects people of non-northern European origin and this includes people from Africa, Asia, Mediterranean, Middle East and Sub-Saharan regions. Due to migration and intermarriage it is also seen in people of the Caribbean, South America, North America and many parts of Europe. SCD is debilitating, associated with a high rate of handicap, morbidity and mortality (especially infant mortality), predominantly in underdeveloped and developing countries (Konotey-Ahulu 1992, Steinberg 2001, Serjeant and Serjeant 2001). In some parts of West Africa 80% of children born with the disease die by the age of five years.

Haemoglobinopathy antenatal screening aims to identify women and couples who are potentially at risk of having a child with SCD and other genetic disorders of haemoglobin (Thomas, Oni 2005). Once identified, the woman and her partner are offered genetic counselling and the option of having the unborn fetus tested through PND; an invasive procedure, which poses a 0.5% to 1.5 % risk of miscarriage (Kirkham 2005). Where PND confirms sickle cell anaemia or any other serious disease of haemoglobin the couple is offered the option of terminating the pregnancy.
Following an extensive literature search and review several issues have been identified as contributing to decision-making in respect of pregnancy outcome when a couple is at risk of having a child with SCD. These include previous knowledge of the disease, gestational age of the pregnancy at first presentation, maternal age, gender, religious beliefs, previous experience and relationship with someone who has or had SCD, having a previous child with the disease, and access to affordable PND.

This exploratory study will attempt to examine knowledge of sickle cell and the socio-cultural factors contributing to attitude toward sickle cell disease. It will also explore and interpret the subjective attitude of pregnant women and where accessible their partners when they are at risk of having a child with sickle cell disease and their decision to accept or decline the offer of prenatal diagnosis and continue or terminate an affected pregnancy.

A three phased approach was adopted in order to determine whether being pregnant and or being at risk of having a child with sickle cell disease influenced an individual’s knowledge and attitude to the disease. Phase 1 will provide quantitative data on knowledge and attitude to sickle cell disease using a convenience sample of African and Caribbean men and women of child bearing age from the general population. Phase 2 will provide similar data using a convenience sample of pregnant African and Caribbean women with sickle cell trait. The Phase 3 interview will provide qualitative data on a convenience sample of African and Caribbean women and their partners’ who are at risk of having a child with sickle cell anaemia, measuring their attitude to childbearing, decisions regarding the offer of prenatal diagnosis and the outcome of the potentially at risk pregnancy. It is anticipated that each of these phases will provide very different data which will help address the overall research question, which is, to determine whether there are socio-cultural differences in attitude and decision making, taking account of difference that may occur as a result of being pregnant and or being at-risk.
# CHAPTER 2

## Literature Review

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td><strong>Attitude</strong></td>
<td>6</td>
</tr>
<tr>
<td>2.2</td>
<td><strong>Cognitive Dissonance Theory</strong></td>
<td>10</td>
</tr>
<tr>
<td>2.3</td>
<td><strong>Culture</strong></td>
<td></td>
</tr>
<tr>
<td>2.3.1</td>
<td>Culture in context</td>
<td>22</td>
</tr>
<tr>
<td>2.3.2</td>
<td>Culture and language</td>
<td>32</td>
</tr>
<tr>
<td>2.3.3</td>
<td>Culture, disease and perception of illness</td>
<td>34</td>
</tr>
<tr>
<td>2.3.4</td>
<td>African, Caribbean culture and religion</td>
<td>37</td>
</tr>
<tr>
<td>2.3.5</td>
<td>Culture and reproduction</td>
<td>44</td>
</tr>
<tr>
<td>2.3.6</td>
<td>Cultural beliefs and attitude to sickle cell in Africa and the Caribbean</td>
<td>48</td>
</tr>
<tr>
<td>2.4</td>
<td><strong>Genetics</strong></td>
<td></td>
</tr>
<tr>
<td>2.4.1</td>
<td>Political aspects of genetics and sickle cell screening</td>
<td>51</td>
</tr>
<tr>
<td>2.4.2</td>
<td>Research, genetic screening and impact</td>
<td>56</td>
</tr>
<tr>
<td>2.4.3</td>
<td>Perception of risk and genetic decision-making</td>
<td>61</td>
</tr>
<tr>
<td>2.4.4</td>
<td>Is non-directive genetic counselling possible?</td>
<td>71</td>
</tr>
<tr>
<td>2.4.5</td>
<td>Pre-natal diagnosis – to test or not to test?</td>
<td>75</td>
</tr>
<tr>
<td>2.5</td>
<td><strong>Conclusion</strong></td>
<td>82</td>
</tr>
</tbody>
</table>
2.1 Attitude

In exploring cultural differences in attitude to sickle cell among people of African and Caribbean origin it is an important pre-requisite to define attitude and examine attitude theories.

Walker (1995) defined attitude as an inferred disposition which influences an individual’s thought and behaviour, which in themselves are influenced by how past experience has impacted on the person’s cognitive perception and emotional response to an issue. Attitude is a set of values and beliefs developed through personal experience or socialization in the family, community and wider society. Oppenheim (2003) defined attitude as:

…a state of readiness, a tendency to respond in a certain manner when confronted with certain stimuli… reinforced by beliefs (the cognitive component) and often attract strong feelings (the emotional component) which may lead to particular behavioural intents (the action tendency component)…a wider compound of values, beliefs and feelings…everything in life depends on people’s attitudes

(Oppenheim 2003: 174 - 5)

In a similar vein, Foster and Parker (1997) suggested that attitude consists of three components: ‘… cognitive, what you believe about the object; affective, how you feel about it; behavioural, how you act towards it’. Garmonsway (1991) describes attitude as ‘a mental disposition, opinion and judgement’.

Oppenheim (2003) highlighted a distinction made by social psychologists between the differing levels of being at the surface level is opinion, at the second level is attitude, at the third values and at the fourth and deepest level personality. The deeper the level the more difficult it is to influence: an individual’s opinion and attitude stems from their underlying personality. Psychologists generally claim that personality is a composition of environmental influence, life experiences and genetic predisposition, which themselves are influenced by cultural orientation, especially enculturation (primary culture acquired through interactions in the family) and socialization. Unlike opinion, which is easier to influence and can fluctuate with social trends, attitude is more pervasive. Depending on the weight that that an individual attaches to that object or subject, attempts to alter an attitude may meet with resistance because it is a component of a
person’s values, beliefs, personality and feelings. Evidence of this can be found in the strong attitudes of fundamentalist religious leaders and their followers.

Attitudes are not always logically consistent, nor do they follow a logical sequence, hence the same individual may express a strong opposition to having a child with SCD and advocate abortion of an affected fetus whilst also having a strong social conviction and religious attitude and belief that God created all human beings and each human is precious and has a right to live. Attitudes can change with life experiences and other environmental influences, for example, the teenage Greenpeace protester of the 1970s may become an advocate of nuclear power in later life due to persuasive circumstances that have evolved over time.

In examining attitude and its influence on behaviour Kashima et al. (1992) argued that the two concepts, ‘attitude’ and ‘behaviour’ relate, although they are not synonymous they argued that consistency between attitude and behaviour is dependent on whether individuals originate from an interdependent or independent society and culture. In an interdependent society the individual will take into consideration the impact that his action will have on the family, cultural group, community and perhaps wider society. As a result they may behave in a way that is inconsistent with their personal belief, attitude and values, preferring to sacrifice consistency for the sake of interpersonal accommodation. In support of this theory of society Wrightson and Wardle (1997) claim that individuals from an interdependent society tend to have an inherent psychological and cultural desire to maintain social harmony and their decisions will be based on this mode of being rather than their own desires and preferences; in these communities an individual is likely to respond positively to a given situation even where he or she has a personal negative attitude towards it. This will be observed later in the attitude and decision-making of respondents in this study, especially in respect of procreation and decisions made about an at-risk pregnancy.

Many African, Asian and non-western societies demonstrate this interdependent mode of being. The lack of government social support systems in many African countries perpetuates such a mode. Reliance on kin and friends for social, financial and other support especially in time of need is inevitable. In making a decision about having a child with a potentially fatal genetic condition, individuals will invariably consider the possible impact of that decision in the context of living in their particular society and their ability to maintain the child independently. But more importantly in a society where there are no government initiatives providing affordable health care and other welfare benefits, they may also consider the reaction they may encounter if there
is a need to seek the financial support of close and extended family and wider society during a
time of crisis. Conversely in an independent society, as reflected in many western societies
where such welfare systems exist and especially the UK factors that influence decision-making
focus on the individual and perhaps their nuclear family and it may require legal sanctions to
force an individual to consider the wider society when making decisions. There is no financial
reliance on nuclear or extended family hence the perpetuation of interdependence is
unwarranted. In an independent society a person who acts in opposition to their values and
beliefs will often experience and demonstrate a certain degree of dissonance, whilst one from an
interdependent society will feel comfortable with inconsistencies provided he has done what he
or she perceives is the ‘right thing’ not just for his or her own benefit but for that of the family,
kin and society. In the majority of independent societies there are government systems and
mechanisms for provision of social support, so that the dependence on kin and friends is
diminished hence their opinion about an issue may be considered irrelevant or ignored during
decision-making.

Foster and Parker (1997) argued that behaviour is not always consistent and will not necessarily
reflect attitude and vice versa. For example, a positive attitude to the rights of the unborn child
may not be reflected in an individual’s choice when confronted with having to make a decision
about continuing or terminating a pregnancy diagnosed with a serious genetic disease. In a study
of 42 expectant women offered prenatal testing for Downs Syndrome, Marteau (2001) found that
18 women made what they classified as an ‘informed’ choice, that is the women’s values and
attitude toward the test was consistent with their eventual decision about being tested. Conversely
24 women did not make an informed choice, in that their values and attitude did not
match their eventual decisions about testing. The authors concluded that the inconsistency in
decision-making and attitude in the latter group is the result of women being poorly informed
about the condition and the test. However, if one considers the Foster and Parker (1997)
argument, it is possible that the women in the latter group were making decisions based on their
perception of what their nuclear and or extended family, community and society will consider
the ‘right’ choice even where this conflicts with their own values, beliefs and attitude. In other
words they are making the choice not for themselves (independent) but for the kinship and wider
society (interdependent).

In exploring what constitutes knowledge, Garmonsway (1991) defined it as an act or process of
knowing, cognition, perception, awareness, experience, information, learning and body of facts
socially acquired or gained through study of a subject. Hughes and Sharrock (1997) proposed that knowledge is social and cannot be divorced from the social circumstances that produced the knowledge. Knowledge is a social construction and receptivity depends in part on socio-cultural attitudes to the subject-matter. Knowledge and attitude to sickle cell is a shared social construct. An individual may be receptive or dismissive of the subject depending on their social environment and their community or society’s attitude to the subject. The importance of this collective attitude became evident when analysing peoples’ reluctance to attend for genetic testing for sickle cell.
2.2 Cognitive dissonance theory

In developing a theory of cognitive dissonance Festinger (1957) proposed that cognitive dissonance is the uncomfortable tensions that occur when an individual or group have conflicting thoughts about the same thing or engage in behaviour that conflicts with their values, belief or attitude to an object. The theory is based on the premise that pairs of cognitions can be relevant or irrelevant to one another and whether they are either consonant or dissonant is dependent on whether the two cognitions are relevant or irrelevant to each other. If they are irrelevant to each other a discrepancy between the two or more cognitions would not cause any dissonance however if they are relevant to each other such a discrepancy would create cognitive dissonance. Cognitive dissonance theory rests on the assumption that man is not necessarily a rational being however he is capable of rationalizing his thoughts and actions in order to appear rational to him self and to others; it assumes that inconsistency between attitude and behaviour will be experienced as an ‘unpleasant’ state which motivates an individual to seek consistency.

The key feature of the theory is any inconsistency or tension between attitude, belief and behaviour (Cooper 2007). The level of tension is dependent on the amount of value that an individual places on the issue or object. Contradictions in cognition or in cognitions and behaviour create a degree of psychological dissonance, which eventually acts as catalyst for belief modification. In order to reduce dissonance and bring about the preferred state of consonance the individual will feel compelled to modify or change their belief so as to support or justify their behaviour. The higher the number of cognitions contributing to the dissonance the greater the psychological pressure and the degree of dissonance experienced, this will determine the amount of effort required to reduce the dissonance and bring about the preferred state of consonance. As stated by Festinger ‘the magnitude of the dissonance increases as the importance or value of the elements increases’, (1957:18). An individual will seek information that will help change their belief and thus justify their behaviour and consequently reduce or eliminate the dissonance whilst avoiding or discounting information, persons or situations that may increase the dissonance further.

Dissonance can be reduced by: removing a dissonant cognition, adding new consonant cognitions, reducing the importance of the dissonant cognitions or increasing the importance of the consonant cognitions. However, cognitions that are difficult to change or that are resistant to
change will yield less easily. Dissonance can be reduced by adding positive attributes to a chosen option and negative attributes to the rejected option.

In decision making Harmon-Jones and Mills (1999) outlined the common paradigms that have been developed and widely used in dissonance research, these are: **The free choice paradigm** - following a selection between two or more options individuals will experience a certain degree of dissonance, the negative aspects of the chosen alternative will be dissonant to their having chosen that alternative, whilst the positive aspects of the rejected alternative will be dissonant to having rejected it. In order to regain consonance an individual will add positive attributes to the alternative selected and reduce its negative attributes. Conversely they will reduce the positive attributes of the rejected alternative whilst adding negative attributes. The more difficult a decision the more dissonance is aroused.

Dissonance theory has relevance for decision-making when individuals are making choices between elements especially difficult elements frequently encountered in the field of medicine and genetics in particular. Festinger (1957) argued that most people are open minded and wish to make good decisions yet once the decision is made they often feel pressured to justify the decision, the source of this pressure is dissonance, especially when there is no clear cut right decision and there are often two or more acceptable options. Whatever decision the individual makes there will often be elements of good and bad in both outcomes. However, second-guessing the decision made creates dissonance and the individual will need to find bolsters to justify the choice made.

Eagly and Chaiken stated, ‘the attitudes and beliefs that people communicate to others do not always reflect their private convictions; self presentational concerns, social norms, and the requirements and constraints inherent in social roles often lead people to say things they do not genuinely believe’, (Eagly and Chaiken 1993: 499).

In decision making where a choice has to be made between two objects when an individual has a negative attitude or thought about the choice made they may experience dissonance in order to reduce or eliminate the dissonance the individual attempts to identify and emphasize the positive attributes of the choice made whilst deemphasizing the negative attributes, and they apply the converse to the item that was not chosen.
In criticism of alternative explanations and counter arguments of dissonance theory Harmon-Jones and Mills (1999) argued that the impression management theory that was proposed as a possible viable alternative is flawed. Impression management theory suggests that people’s attitude reflects their inert desire to manage the impression that other people have of them; they attempt to create a favourable impression of themselves whilst avoiding creating an unfavourable impression, preferring to demonstrate attributes that are consistent with favourable behaviour. This suggests that individuals are deceitful and they are not genuine. Counter to this argument Harmon-Jones and Mills (1999) argued that the result of several cognitive dissonance experiments have demonstrated that individuals have made genuine cognitive changes and the impression management theories cannot account for the findings of experiments where even in private situations dissonance occurred, when attitude change measurements were taken by those who did not appear to be connected with the experimenter or who observed the original behaviour genuine changes were reported (Harmon-Jones et al 1996).

Another common paradigm is the belief–disconfirmation paradigm - dissonance occurs when people are confronted with information that is inconsistent with their belief. There are a number of possible options for reducing the dissonance, for example, the individual or group may seek the support of other believers so as to strengthen and maintain their original belief and seek to convert others to share their belief, they can refute the counter arguments that is threatening their belief or they can reject the original belief based on the evidence in front of them, the latter is often less likely. Where the original belief is not rejected the dissonance can cause the individual or group to misinterpret the information they have been given, information that is causing the inconsistency between their belief and the evidence or information in front of them. This paradigm was tested by Festinger et al (1956) as participant observers in a group which believed in a prophecy given by a Mrs. Marion Keech a woman who claimed that her hand was spiritually controlled to write a prophecy given to her by beings from planet Clarion in outer space. The prophecy is that their continent would be engulfed by floods on 21st December 1955, however, all those who believe in the message will be regarded as the ‘chosen’ and will be saved by being transported in a flying saucer into outer space on the eve of the impending catastrophe. In preparation for the event many of the believers sold their properties, resigned from their jobs, some divorced their non-believing partners (Cooper 2007) and the group engaged in a small degree of proselytizing whilst they awaited the event date. The group did not seek to attract attention to themselves and were reported to actively shun any form of publicity. Festinger
(1956) named the believers ‘Seekers’. On the eve of 21\textsuperscript{st} December 1955 the group gathered to await the spacecraft that would transport them to safety.

When the prophecy did not occur Mrs. Keech reported receiving another spiritual message, which stated that God had intervened by averting the catastrophe because the group of believers, were a force for good and because of them the continent has been saved. It was observed that the group members who were alone did not maintain their faith whilst those who were together as a group did. Following the failure of the prophecy the group courted publicity in order to explain to critics, skeptics and others why the prophecy did not occur, the level of proselytizing increased dramatically, the group attempted to persuade others to adopt their belief and help maintain its future; this as observed by Festinger was the group’s attempt to maintain their integrity, they added consonant elements in order to reduce the state of consonance that the reality of the failed prophecy brought. This observation of Seekers in 1956 acted as catalyst in Festinger’s development of cognitive dissonance theory in 1957.

The \textbf{effort-justification paradigm} – occurs when an individual participates in an unpleasant activity in order to achieve a desirable outcome. The more unpleasant the task required in order to obtain the desired outcome the greater the dissonance. However, the dissonance can be reduced by highlighting the positive attributes of the desired outcome. A number of researchers tested this paradigm one of these is Aronson and Mills (1959) who conducted a study on women who wanted to join a social group. The women were divided into two groups, the first were given the task of performing a mildly unpleasant and embarrassing initiation task to perform whilst the second set were given a severely unpleasant and embarrassing initiation task to perform. The second group evaluated joining the group more favourably than those who were given a mild initiation task to perform. Other researchers who tested this paradigm include Beauvois and Joule (1996).

The \textbf{induced-compliance paradigm} - occurs when a person says something that is contrary to a former belief or attitude. Festinger and Carlsmith (1959), in conducting the first experiment to test cognitive dissonance theory formally, asked students to participate in an experiment where they were given tedious and mundane tasks to perform, the first was to turn pegs and the second is to put spools onto a tray empty the tray and refill it with spools. The two tasks lasted one hour. In order to make it convincing that that this action was the active part of the experiment the experimenter remained in the room observing the subject and took observation notes. However,
unbeknown to the students these activities were not the active research it is their rating of its enjoyment that constitute the experiment. Each student was asked to independently rate the level of enjoyment of the task and as anticipated the tasks were rated negatively by the students.

As each student was leaving the experiment room two-thirds of them were approached by the experimenter and asked to assist further with the project. They were told that the project research assistant was unable to attend on that day but his or her role is crucial to the experiment. Each student was then asked if he or she is willing to assist by filling in for the research assistant. The job entails informing another student, who is waiting to perform the experiment, that the task they are going to be asked to perform is interesting and enjoyable; this being contrary to his or her own experience and rating of the tasks.

There were two experimental groups the first were offered an inducement of $1 to tell the lie, whilst the second group were offered $20 and a control group were not offered any inducement or asked to lie about enjoyment of the tasks. The findings of the study demonstrated that there was a high level of dissonance among those who were asked to tell a lie about their enjoyment of the task. However, those who were offered only $1 were more persuasive in telling the next participant that the task was enjoyable, even more so than those who were offered an inducement of $20. In explaining the findings Festinger and Carlsmith (1959) proposed that those who were offered $20 had external justification for their behaviour, that is, payment of $20, which in 1959 is a huge sum of money Cooper (2007) suggest this is equivalent to $200 in modern day currency. Those in the $1 group did not have sufficient monetary justification to feel comfortable with telling the lie and the dissonance it caused, this group had to internalize the lie in order to be able to reduce the dissonance that telling the lie would bring. This internalization of the lie that the task was ‘not boring’ enabled the individual to reduce the dissonance because his or her belief that the ‘task was boring and mundane’, their self perception that ‘I am not a liar’ and the behaviour ‘I have lied’ are in conflict, that is, they are dissonant. By internalizing the lie they are able to change their belief from ‘the task is boring and mundane’ to ‘task is not boring and mundane’ in order to justify their behaviour and thus reduce the dissonance. The participants attempted to relieve their dissonance by changing their own attitude and belief about the task and this allowed them to believe genuinely that the task was ‘not boring and mundane’. Hence the $1 group was more enthusiastic about persuading the other students than the $20 group, who had a monetary incentive and justification for telling the lie.
Reflecting on thirty years of cognitive dissonance in a transcript of remarks by Festinger, he was reported as having stated, ‘in order for dissonance to be large enough to exist there has to be minimal pressure on the person to do what the person does. If there is too much pressure, there is too much justification for having done it and it is all consonant with having done it, (then) there is no dissonance’ (Harmon-Jones and Mills 1999: 383).

Festinger and Carlsmith (1959) concluded that where an individual has been persuaded to lie but not given sufficient justification or inducement they can only carry out the task by actually changing their own belief and convincing themselves that their belief needed modification anyway. There is an alternative to changing belief in order to reduce dissonance ‘denial’ and a failure to seek further information about an issue. The researchers also suggest four situations where dissonance can arise, these are: logical inconsistency, inconsistency with cultural mores, inconsistency between a single cognition and a general more encompassing cognition and finally inconsistency between present and past experiences.

Reality constraints can prevent elimination of the dissonance since the individual may not be able to change the cognitive element, for example, the reality of being at risk of having a child with sickle cell anaemia. In this instance an individual or couple may address the issue by adding ‘consonant elements’, which do not remove the dissonance but help reduce its magnitude. Abelson (1959) describes this as ‘bolstering’. An example is an expectant couple who are at risk of having a child with a genetic disability, and they do not want a child with a disability but are opposed to termination. The reality of being opposed to abortion constrains their ability to eliminate or reduce the cognitive dissonance. In order to reduce the dissonance and its impact they may add justification or consonant elements of morality or religion as factors that prevent their ability to choose to terminate an affected pregnancy. In some instances the bolstering element could reduce the importance of the dissonant cognition, for example, the importance of being at risk of having a child with a serious genetic condition. The woman or couple may convince themselves that sickle cell disease is not as serious as the doctors report it to be and there are examples of those who live useful and productive lives even within the constraints of the illness.

Draycott and Dabbs proposed that, ‘the effects of dissonance manipulations are maximized when a behavioural commitment is made, when the individual is responsible for this behaviour, when the behaviour result in consequences which are experienced as aversive, and when the
inconsistency involves an important cognition, such as the self-image’ (Draycott and Dabbs 1998:349).

Other studies have examined cognitive dissonance theory and adaptations have been made to the theory. Studies such as Aronson and Carlsmith’s (1963) the ‘forbidden toy study’, Hendricks (2000) ‘political television advertising’ study. In support of Abelson’s (1959) proposition Sherman and Gorkin (1980) elaborated on the cognitive dissonance theoretical model further and argued that in a state of dissonance people seek information to help ‘bolster’ or justify their behaviour and reduce cognitive dissonance.

Eagly and Chaiken (1993) proposed three modes for the resolution of dissonance the first is changing the elements (elements being the amount of value that an individual places on the attitude, belief or behaviour) adding consonant elements and reducing the importance of the dissonant elements. The authors assert that where dissonance is present perceivers do not only seek to reduce it, they also attempt to avoid information that might result in further increments in its magnitude. Avoidance of situations or persons that may increase the dissonance and questioning the information giver’s integrity are tools used commonly to reduce dissonance. Others include defensive modes of behaviour, inattention to detail given, feigning misunderstanding of information given, these are used as attempts to prevent the ‘cognition’ from becoming fully established. For example, failing to attend an appointment for genetic counselling may be an attempt to avoid information that may increase dissonance especially where personal beliefs and the reality of the situation places a constraint that makes it difficult for the individual to eliminate the dissonance. It is possible that Hill’s (1994a) report of obfuscation of medical knowledge of SCD among low-income women is an example of a response to dissonance; although they have a child with SCD already many of the women claimed that in a subsequent pregnancy they were not aware that they could access genetic services without being recalled by the health care providers. However, by the time they were recalled the at-risk pregnancy had advanced by several weeks possibly to the point where they may find difficulty accessing the option of prenatal diagnosis or possible termination of an affected pregnancy. This obfuscation I suggest exemplifies a common response to cognitive dissonance.

Many critics have attempted to discredit cognitive dissonance theory. In challenging the theory Aronson (1969) proposed that dissonance did not occur merely as a result of conflict between
two or more cognitions but rather as a result of people seeing their action as conflicting with their self-concept or self-image. Therefore, in the experiment conducted by Festinger and Carlsmith (1959), Aronson (1969) argued that the dissonance which occurred between ‘I am an honest person’ and ‘I lied that the task was not boring’, is dependent on whether the individual perceives him or herself as a liar, if the latter there would be no dissonance and the individual will feel perfectly comfortable with telling the lie, irrespective of any monetary or other incentive. This criticism is somewhat superfluous since Festinger (1957) did acknowledge that self perception can be powerful, and depending on the depth of this an individual may be oblivious or resistant to dissonance or to changes that would enable consistency.

Tedeschi, Schlenker and Bonoma (1971) argued that the maintenance of cognitive consistency is for the purpose of protecting one’s public self-image and has nothing to do with dissonance per se. Rosenberg (1965) in a critic of dissonance theory argued that the Festinger and Carlsmith’s (1959) experiment failed to acknowledge the interpersonal dynamic that occurred between the experimenter and the participant that this was responsible for producing the psychological effect observed and cannot be explained using the claims of dissonance theory. This argument was echoed by Schlenker (1980) who suggest that the interpersonal dynamics of the experimental situation may have led to the effect observed by Festinger and Carlsmith.

Rosenberg (1965) argued that the students in the Festinger and Carlsmith (1959) experiment probably had preconceived ideas about the intentions of the researcher, they are aware that psychologist researchers tend to focus on examining attitudes, it is possible that these students perceived that the experimenter was inadvertently assessing the ease with which they can be bribed (bought), secondly the sum of money on offer may have aroused the students suspicion since this would have been perceived as a large sum of money in 1959 terms and $20 was not justifiable payment for such a small task, perhaps the inducement of money was merely a trap, the real experiment is to assess their personal integrity and whether they can be bribed, hence the $20 group, in order to protect their personal integrity were less likely to alter their attitude compared to the $1 group.

In addition Rosenberg (1965) argued that rewards affect behaviour as supported by learning theorists, the more the inducement or reward the more a person will come to like what they have been asked to do. To prove this hypothesis he conducted an experiment where students were asked to volunteer for a study which aimed to assess attitude. On arrival the student were
informed that the experimenter is delayed and whilst waiting for his arrival could the student participate in another experiment which is being run concurrently by another investigator who is unrelated to the experiment that the student had volunteered for, on completion of that first experiment the student should return to the original attitude assessment experiment. The concurrent study that the students attended asked them to write a compelling argument in support of a controversial issue that was affecting their university at the time, a proposed ban of the Ohio State Campus football team from the forthcoming Rose Bowl football tournament. This was a contentious issue that the students did not support personally. The students were offered small (50 cents), medium ($1) or large incentives ($5) to write the essay supporting the ban, once completed the students returned to the original experiment that they had volunteered for. The important issue in Rosenberg’s experiment is that two separate experimenters must be seen to be dealing with the students and the two studies must be perceived by the students to be totally unrelated, thus eliminating the idea that the same person will see the result of both studies.

On arrival at the original experiment room the students were given a questionnaire which aimed to examine their attitude to a broad range of issues included in this was questions about their attitude to the proposed ban of Ohio State Campus football team from the Rose Bowl tournament. The result demonstrated that those given the larger financial incentive for writing an essay in support of banning the team their essay concurred with their attitude in the questionnaire even more so than those given the smaller incentive. Rosenberg (1965) argued that the higher the reward the more favourable the attitude towards the objective of the reward; once the anxieties about a possible open evaluation of their integrity was removed the participants contrary to their original opinion about the ban were in favour of the ban because they had been given a financial reward to be in favour of the ban.

However, Linder, Cooper and Jones (1967) argued that Rosenberg’s study failed to consider freedom to choose. The students had volunteered for the first experiment not the second, in essence they had been coerced into taking part in the essay writing experiment and told exactly what to do; they were not given a choice whether to write the essay for or against the ban, they were merely told to write in support of the ban, therefore they did not have a free-choice, this loss of autonomy was sufficient justification which eliminated any dissonance the students could have experienced. If asked why he/ she wrote the essay supporting the ban the student will inevitably state, ‘the experimenter told me to’, that cognition of lack of self-will is powerful enough to eliminate any dissonance that could have arisen. Cooper (2007) argued that variance between attitude and behaviour can occur only under certain conditions, this includes a freedom
to choose, if there is a ‘high-decision freedom’ dissonance can occur between attitude and behaviour if there is ‘low-decision freedom’ the inability to choose eliminates dissonance.

Dissonance theory applies where there is a freedom to ‘choose’ and cannot be applicable where an individual or group does not have free will, the experience of dissonance depend on ‘free choice’; a lack of control or responsibility for behaviour or choice may result in the individual not experiencing dissonance since they will not regard themselves as culpable. The need to seek justification elements will only be relevant where there is freedom to choose. Eiser and van der Plight argued that ‘the more we feel personally responsible for, or can foresee, negative consequences of our behaviour, the more we change our attitude to (be in) accord with it’, (Eiser and van der Plight, 1988:35). This suggests that perhaps dissonance has little to do with inconsistency in itself but with a perception of the consequences of the behaviour and the inferences that others may draw about us as an individual when observing the behaviour. The change in attitude or behaviour is perhaps an adaptation, a public response in order to protect ourselves from possible criticism from observers. Gaes, Kalle and Tedeschi (1978) reported greater attitude change when participants in an experiment confirmed a public commitment to a statement than when they made the statement anonymously.

Cooper proposed, ‘dissonance occurs following induced compliance, but only when an unwanted consequence ensues. Several follow-up studies showed how necessary it is to have some unwanted event occur following counter attitudinal behaviour in order for dissonance to occur’ and ‘dissonance will occur only if the consequences of a freely chosen behaviour was foreseeable when the person chose to commit the behaviour. Surprise consequences that you could not have anticipated do not produce dissonance’ (Cooper 2007: 67 and 68).

Bem (1965 and 1967) argued that self-perception theory is a viable alternative to dissonance theory. He argued that if a person’s action is controlled by others or situations external to themselves they will not judge their actions as being within their power to control. He proposed that people merely inferred their attitudes from their behaviour and the factors influencing that behaviour, for example, the reason for acting in the first place, the environment in which they have acted and other peoples response to the action. He also argued that that some individuals do not even have access to their own attitudes in order to recognize that there is any conflict between two or more cognitions (Bem 1965, 1967). Reflecting on this argument I suggest that because many cultural practices are embedded into an individual’s psyche acting against personal values may not be as anxiety provoking as acting in contradiction to ones cultural
values and beliefs, even where these are in conflict. Individuals may not perceive any dissonance or be aware of their experiencing it as an unpleasant state if culturally they accept inconsistency between their personal values and the values of their family, society and cultural group. Within some traditional societies there is little or no opportunity for self-will, an individual is expected to adhere to collective cultural beliefs irrespective of personal preference. I argue that in such a context contradictions and inconsistencies may not result in psychological distress necessarily or act as an incentive for an alteration of attitude or behaviour. However, where one is immersed in a dual cultural environment it is possible that dissonance in decision making can occur, for example, migrating from one cultural environment such as Africa or the Caribbean to western society where individuality and liberalism is the norm. It is possible that making a decision in a dual cultural environment can create dissonance.

The need for consistency I suggest is dependent on an individual or group’s cultural view of the world and socialization plays a pivotal role, it determines whether there is an inherent need for consistency or whether an individual or group can maintain and accept inconsistency without having a desire to alter this state of being.

A weakness of dissonance theory is its inability to define the limits of the theory and how predictable it is when applied to several data; it would be easy to define dissonance observed in psychological situations that create a state of dissonance however but it will be difficult to apply the theory to logical situations.

It appears that after more than fifty years of cognitive dissonance theory some researchers continue to refute the validity of the original theory whilst avid supporters such as Beauvios and Joule (1996), Harmon-Jones (1999), McGregor (1999) and Mills (1999) continue to defend the theory, especially in its developed, tested and mature state. Festinger proposed that, the only theory that will remain unharmed over the years is a theory that is not testable. If a theory is testable it is inevitable that it will be subjected to change during its growth and development. Theories are neither right nor wrong, they are merely theories, the question is not whether they are right or wrong but whether they can be tested empirically and adapted as new evidence emerges. Harmon-Jones and Mills stated, ‘although the revision of dissonance theory have produced serious challenges to the original version of the theory, other theorists maintain that the original version continues to be viable and it can explain the evidence generated by the revisions’ (Harmon-Jones and Mills 1999:15).
In applying cognitive dissonance theory to the current study I examined whether cognitive dissonance is reflected in the attitude and behaviour of the African and Caribbean respondents interviewed in Phase 3, especially in relation to selection of a partner, reproductive choices, decisions with regard to prenatal diagnosis of an at-risk pregnancy and the outcome of an affected pregnancy. Where relevant I identified and commented on the ‘bolsters’ that individuals used to justify their choices and decisions.

I suggest that cognitive dissonance theory is of particular relevance to this current study because it offered a unique opportunity to examine how individuals have dealt with the psychological conflicts that arise from societal cultural expectations, personal attitudes and preferences and the often painful dilemmas which the new genetics and advances in medicine has created in modern times. The application of this theory has been useful and highlighted that this is a previously unexplored territory and this study will contribute to our understanding of how people respond to health, disease and illness. Future studies can build on the findings of this current in order to promote an increasing body of knowledge on the subject.
2.3 Culture

2.3.1 Culture in context

Definitions of culture abound in social science and a myriad of definitions can be found in anthropology, where the focus is on the study of humans, including their social and cultural milieu. From a sociological perspective, culture is the factor which influences the attitudes, beliefs, values and actions of individuals, the way in which individuals perceive their environment and the wider world. Helman (2001) provides a valid rationale for my intention to utilise anthropological theories as the basis for a discussion on culture and its relevance to the current study. There are two dimensions of anthropology, social anthropology which is the study of human societies and their cultural systems however emphasis is placed on social interactions. The second is cultural anthropology which relates to the way humans view the world that they inhabit, the external and internalised features of a group, the focus of this dimension is culture, the internalised way of perceiving the world, which consequently influences behaviour. The interpretation given to a phenomenon and the way the individual reacts to it is in part determined by their cultural orientation and cultural view of the world.

Laird’s (1998) criticism is that society uses the terms culture, gender, race, ethnicity, social class and sexual orientation as if they had consistent definitions with a universal agreement on their meaning, whereas they do not. I intend to extract some useful explanations from literature and apply this in a way that will help elucidate the complex concept we call ‘culture’.

Haralambos and Holborn (1991) asserts, ‘culture has two essential qualities; firstly it is learned, secondly it is shared [and] without it there would be no human society’. Kaplan and Manners claim that man is one but culture varies, and without cultural diversity the discipline of anthropology would not be a viable discipline in the social sciences. Anthropology allows an exploration and comparison of one or more cultural groups to enable a better understanding of internalized systems, including attitude of individuals within a cultural group or community. In view of this I felt it is appropriate to utilise anthropological theories to explore African and Caribbean peoples’ attitude to health generally and to SCD in particular.
A society is defined as a separate population with its own culture, dominant ideology, and political, religious and economic systems. Culture encompasses a number of concepts: belief, ritual, custom, practice, ethical and moral values, things acquired by virtue of belonging to a group within society. Culture is the transformation of information by behavioural means, most particularly by the process of teaching and learning. It is the body of information, which shapes our perceptions, values, beliefs and attitude to the environment and the people within it. Enculturation, which is the absorption of the primary culture, occurs from birth whilst an individual is immersed in a cultural group, primarily within the family unit and subsequently within a wider society where there is gradual learning of the wider pervading culture (Collier 2004). Atkinson (2004) describes the process of enculturation as ‘learning that takes place in one’s indigenous or home culture’. This learning and absorption of culture promotes individual conformity to the group’s beliefs, values and practices and serves to promote group cohesion.

Durham (1991) argued that there are five properties attributable to culture, cultural orientation and how individuals within a group collectively determine how to respond to a given phenomenon, having done so individuals retain this information and pass it on to future generations. These properties are described as

1) **Conceptual reality** - members of the group whilst experiencing a phenomenon develop a mental interpretation of it and determine how to respond to it then and in future; future response becomes fairly predictable for the cultural group.

2) **Social transmission** – because of transmission future generations will be expected to demonstrate a similar response to that phenomenon in future.

3) **Symbolising** - the use of symbolic codes shapes an individual’s knowledge and attitude to life. Durham argued that this is the most effective method for transmission of culture and the most poignant symbol in the majority of cultures is language.

4) **Systemic organization** - culture is constructed of interdependent systems of ideas and codes, which are used to interpret observed events or concepts, shared symbols and meanings. Systems include schools, places of employment, use of computers, television, tangible and non-tangible items.

5) **Social history** - is the final property consisting of time and life experiences. Associating with other cultures may have an influence and cause an individual or group to question, modify or change a cultural interpretation of a phenomena and their response to it.
Like biological systems culture is subject to an ageing process, it is evolutionary, symbiotic and
dynamic - it is constantly open to internal and external forces that ultimately initiate its
adaptation and change. The more complex a society is the more diverse its cultural groups will
be. For example, multicultural societies, such as that observed in major European cities, are a
melting pot of complex cultures. There will always be a combination of old and new cultural
creations, depending on the stability of its inhabitants. A constant influx of other cultures creates
instability of the original culture and initiates greater and more rapid change to culture.

The issue of a cultural group response to a phenomenon and future generations’ assimilation of
their forefathers’ attitude and response was well illustrated in the current study, especially in
respect of attitude to procreation, childbearing and a social response to SCD. A shared collective
cultural attitude transmitted from generation to generation will be seen to have a major influence
on the decision-making of most at-risk individuals despite advances in scientific knowledge and
medicine, that is until other factors such as genetic and health counselling modifies the
individual or couples’ cultural view point.

Culture is a cognitive construct; it is whatever a person has to know or believe in order to operate
in a manner that is acceptable to members of their group. It is not a material phenomenon but the
organization of things, behaviour and emotion, the way people perceive, relate and interpret
things in their environment. A failure to ‘know’ what one ought to ‘know’ about the cultural
expectations and in order to function in the cultural group may result in cultural dissonance and a
failure to remain comfortably in the cultural group.

Geertz (1973) claims that symbolism is a fundamental aspect in the transmission of culture from
one generation to another and symbols come in many forms, including use of language; members
of a group gain knowledge and their attitude is shaped in part through inherited concepts but,
more importantly, through transmission using symbols.

Helman (2001) describes culture, as a system of shared ideas, concepts, rules and meanings that
underlie values and beliefs and is expressed in the way that we live as human beings. It is a set of
guidelines that are inherited as well as learned, telling individuals within the cultural group how
they should view the world, how to experience it emotionally, how to behave with regard to
other people, supernatural forces or gods and the natural environment. The way in which the
group views the world is transmitted to the next generation using symbols such as language, art and cultural rituals.

MacLachlan asserted that a belief is not a universally applicable concept:

(A) particular belief may not be universal but it may lie at some point along a dimension which has wide relevance…An individual’s rating on culturally salient dimensions will reflect the impact which his or her culture has had on him or her with regard to that dimension. Thus a German culture may not endorse the idea of mystical causation of illness but the opinion of an individual German may not be that of the ‘average’ German. … individuals have their own opinions regarding certain dimensions within the context of their culture.

(MacLachlan 1997: 49)

Caution should be applied and in generalizing about cultural views, practices or responses to a given phenomenon; an individual will display their cultural orientation but this will be within a range of possible responses and not just one predictable and static response. Other factors also play a role in the response: for example, level of education, social exposure to cultural diversity, travel experience, social class, religious belief and other social factors. Hence in the current study although the majority of the respondents reflect an overall cultural attitude, a few were not typical of their cultural group and demonstrated divergent attitudes to some of the concepts.

Membership of a cultural group in many instances can only be tenable where individuals adhere to cultural norms and expectations and a failure to do so may result in the non-conformist being excommunicated. A non-conformist may attempt to change or modify a pervading group culture, but where this attempt fails the individual may be forced to relinquish their membership of the group or they may find themselves relegated to physical, mental or emotional isolation whilst still remaining a member of the group. Where the group has strong cultural rules it becomes almost impossible to remain a non-conformist; this became apparent in the current study where one respondent had to change her attitude to procreation in order to maintain cultural acceptance.

Most cultural groups are heterogeneous and in complex societies there is a mixture of a large number of sub-cultures resulting in a melting pot of values, perceptions, ideas, beliefs and practices (Pulis and Szwed 1999, Helman 2001, Collier and Fleischmann 2004, Puri 2004). The majority of multicultural societies co-exist sometimes amiably but sometimes precariously,
perpetually borrowing from each other’s culture. Intolerance may result in ‘racism’ and ‘racialism’, which may cause racial tensions and consequent conflict. If these tensions are compounded by ‘institutionalized racism’ (MacPherson 1999) it may result in community breakdown, as was witnessed in British cities of Toxteth, Brixton and Manchester during the 1980s and 1990s when disenfranchised, mostly British-born, Black youths reacted to their perception of being treated as second-class citizens in what they consider their own country (Phillips and Phillips 1998, Fenton 1999).

The advent of satellite and other technologies has resulted in globalisation and Americanisation of many cultures. History tells us that this is a fairly recent phenomenon. During the colonial era of the 17th to 19th centuries English culture was dominant worldwide and the relics of this persist in the many practices of African (Mazrui 1986, Rodney 1988), and other world cultures, such as that seen in Northern India, South and North America, Australia and New Zealand. The impact of this is amply demonstrated in an unpublished article by Dr A’daudu director of a Nigerian company in which she reflects on a youth talent competition she attended in Nigeria, where she was expressing anguish at the increasing Americanisation of Nigerian youths resident in Nigeria:

Where was the Nigerian in all these children?...We watch helplessly as our culture is slowly dissipated, our values diluted and our heritage replaced by an imported relativism that does not, and cannot distinguish between right and wrong, good and evil, black and white. When our children are ashamed of who they are and their very heritage then we are simply lost as a people…a time will come when they will have to visit museums to know who they are and where they come from.

(A’daudu 2006: 1 and 2)

Globally, culture is dynamic, constantly undergoing change. Perhaps the African youths described in this quote and their subsequent generations will demonstrate being American more and more and African less and less; what impact this will have on African culture will need future examination. The portrayal of Africa and African communities in the media, including in Africa itself, I argue is contributing to the African youths’ dissociation from their African culture. Young people living in a democratic society by virtue of their immaturity, youthfulness and socialisation experiences are less likely to have acquired the patriotism of adulthood and will tend to have little or no allegiance to a society or cultural group that is perceived as failing and not a leader in the global scheme of development. The images they see portrayed and perpetuated
by those around them support the perception that Africa is lagging behind, ravished by poverty and famine and always in need. Youths will not wish to associate with such a continent but will associate with success, the successful country whose leader is known and respected worldwide; the winning footballer or football team, hence the popularity of David Beckham and Manchester United football club worldwide, even in Africa and North America. However, I suggest that where a significant proportion of the culture becomes lost future generations will seek to reclaim it. This is a phenomenon observed anecdotally among second- and third-generation children of African migrants in the UK. A number of young people although comfortable with being British and with the European culture, are beginning to question their parents’ integrity in not allowing them to embrace their original culture, resulting in their loss of what they perceive as their cultural heritage, especially their language, and many are expressing a desire to explore this aspect of their being.

It will be interesting to see the impact of this newly emerging cultural awakening in the coming decade and whether it will initiate a reversal of the trend described with such anguish by A’daudu (2006). As argued by Sowell (1994), ‘it has in fact been a common social phenomenon around the world that those who have lost a culture have often been its most strident apostles’. Further Sowell (1994) asserted that an individual’s cultural orientation is not easily altered, even where they cross continents through migration, nor is it changed in subsequent generations of migrants despite their adoption of the host country’s social structures, such as dress, language and other modes of being. However, if one is to support this line of argument how does one account for the increasing loss of culture among African slaves transported to various parts of the developed world and who consequently lost a significant proportion of their original culture, especially their language and other cultural practices. Culture in Africa itself is dynamic and the population is exposed to a barrage of European and other Western cultural influences, it is therefore difficult to measure how much of the original African culture has been retained by indigenous Africans in Africa and among the early migrants in the African Diaspora. I argue that a lack of constant exposure and reaffirmation of the original culture has resulted in a gradual decline of some African cultural practices among the Caribbean and possibly African Americans, especially during periods of enslavement when cultural practices were opposed vehemently by slave masters in an effort to enforce control. The slaves’ use of their original African languages as well as cultural practices that would have promoted their emancipation were not allowed; with subsequent generations there is increasing loss of the original African culture and a high degree of modification to the little that has been retained. In view of this apparent divergence between
the Africans and the Caribbeans it is anticipated there would be differences in their cultural attitude to sickle cell and to being at risk of having a child with SCD. Perhaps the attitude of the host community plays a pivotal role in determining how well migrants accept the host culture and its values and practices; where the host community is not amenable to difference and migration it becomes more difficult to absorb the migrant, and for the migrant to learn about the indigenous culture in order to accept its practices and doctrines.

Berry and Kim, in Maclachlan (1997), describing the impact of migration on culture, explained that acculturation is a process whereby individuals encounter more than one culture and respond to the interplay between them in a number of ways. Individuals may adopt an *integrated* mode, whereby they are able to balance identification with their original culture and the host culture simultaneously without undue anxiety. This is most common among those who migrate before the age of puberty (Rosenthal and Feldman 1992, Tsai  2000) since this age group are often more adaptable and adventurous, willing to take risks and embrace new concepts and ideals.

Other migrants *separate* themselves from the new culture and retain their original culture refusing to adopt the host culture and its alien practices. This is most common among older migrants. A third group *assimilates* the host culture fully and relinquishes their original culture. This may be observed in some individuals even within their own country of origin. Examples of this can be observed in some Asian and African countries where individuals wishing to portray western elitism and social class superiority will adopt western cultural practices whilst relinquishing their own native language and culture. It is not uncommon to meet an Asian or African who, although they have never left their country of origin, are unable to understand or speak their native language or associate with its cultural practices. I argue, however, that even where this occur their cultural orientation and deep-rooted cultural attitudes will remain, for example, attitudes to procreation, disease and illness. The fourth mode described by Berry and Kim are those who reject the original culture as well as the host culture and remain on the fringes of both cultures; this *marginalized* group is often rejected by both cultures and feel a sense of not belonging to any cultural group and may become culturally and socially isolated. In view of this, it is anticipated that in the current study the age of migration will have an impact on cultural identification, and that the Caribbean respondents, being mainly second- third- and fourth-generation migrants will identify less with Caribbean culture and demonstrate more of the assimilation cultural mode of Europe, whilst the African respondents, mainly first- and second-
generation migrants will identify more strongly with being African and demonstrate more of the integrated or separation cultural mode.

In a discussion on multicultural school psychology and children’s response to cultural change, Collier (2004) describes similar concepts of integration and assimilation. However she labels the separation concept as rejection, which she argued can work both ways, where the individual intentionally rejects their original home culture and adopts the host culture or vice versa. In a similar vein Collier viewed the marginalization concept as a process of deculturation, which is non-acceptance of the original or host culture and or language. Despite differences in terminology, Collier’s (2004) four types of adaptation to acculturation and based on Berry’s (1986) model, where these concepts are described in terms of a psychological, social response to cultural environmental change.

In a lecture entitled ‘In search of measures of acculturation’, Atkinson (2004), claimed there are differences in rate of acculturation, with younger people being able to adapt more easily and quickly than older people, and males acculturating more rapidly than females by virtue of having to interact with indigenous groups in the work place, since first-generation women, being of childbearing age, tend to remain at home as housewives.

Cultural practices are contextual: a person’s behaviour is usually influenced by their social environment (Laird 1998). For example, attitude to disease and illness is culturally defined but can be influenced by social environment, and adaptations may be made to underlying values and belief because of the pervading cultural attitude to the given phenomenon. How an individual will respond to a situation can be subject to modification, depending on environmental factors.

As outlined by Helman (2001) there are three levels of culture. The primary level consists of observable rituals within a cultural group, for example, mode of dress, language spoken, food eaten and traditional practices, such as the way in which a wedding or burial ceremony is conducted. The secondary level is represented by the underlying rules, assumptions, beliefs shared by the group but not with outsiders. For example, among the Yoruba tribe, in Southern Nigeria, it is a taboo to eat with the left hand, because the left hand is regarded as the ‘dirty’ hand, in the absence of toilet paper the left hand is used for washing private parts after using the toilet. The majority of foods in many African and other cultures are consumed using one’s fingers. In rural areas access to clean running water is a luxury that few possess and it is not
uncommon to travel many miles to the nearest stream to fetch water each day. Therefore this cultural practice has a practical purpose. It is instilled in early childhood and becomes the norm, even among those who have migrated to areas where there is toilet paper and an abundance of clean running water. In some African cultural taboo extends to the use of the left hand for performing other activities, including giving or receiving of items, especially from elders, children are chastised repeatedly until they learn to adhere to this cultural way of behaving. Those who are born left-handed in this culture experience great difficulty as they are forced to learn to use their right hand, even for writing. The third and deepest level is tertiary, which comprises of shared beliefs and rules that are known and obeyed but rarely articulated even within the group. This level of culture is the most difficult for researchers to penetrate as the individuals being observed will often not be able to articulate the behaviours stemming from such deep-rooted beliefs.

An example of the tertiary level is the how individuals deal with news of a pregnancy. Unlike western cultures, an African woman will generally not share news of a pregnancy with anyone except her husband, and perhaps her mother. Even her mother-in-law may be viewed with suspicion. Where a woman appears pregnant and an observer asks she will deny it vehemently until the pregnancy becomes so advanced that it becomes futile to conceal the fact. This practice is unspoken among many African cultural groups yet, the majority practice this mode of behaviour and everyone knows they ‘should’, but many who are not within the environment for example those who have migrated to other countries often do not know why, yet they adhere to the cultural norm. The reason behind such secrecy is the inherent religious belief that those with ill-will may harm the pregnancy, causing a miscarriage or allowing an evil spirit to enter the unborn child, who is subsequently born with a handicap or malevolent spirit. Since it is believed that one cannot know who is a potential enemy, secrecy is usually maintained even in respect of extended family. In contrast, in many European cultures news of a pregnancy is shared with family, friends and colleagues as soon as the pregnancy is confirmed or at least as soon as the period for a naturally occurring early miscarriage has passed, which is believed to be eight to twelve weeks.

Durham (1991) claimed that there is a genetic element to acquisition of culture. However, the author does not provide any empirical evidence to substantiate this claim. If this argument is to be believed, how will Durham account for the loss of cultural orientation and loss of the original native cultural traits of Black African slaves of the eighteenth and nineteenth century and
subsequent generation African and Caribbean migrants living in the UK? Genetic dilution may be offered as a plausible but highly unlikely explanation. Durham’s genetic hypothesis of culture will require further investigation which is beyond the scope of this study. Evidently the degree of exposure to other cultures influences an individual’s cultural attitude and it can be argued that it is nurture (environment) not nature (biology) that determines an individual’s cultural orientation and consequent perspective.

Researchers observing a culture which is different from their own often fail to appreciate the depth of the roots of culture and how effective many cultures are in compelling members of the cultural group to adhere to its rules, values and practices (Read 2001). Many individuals feel socially and psychologically coerced into behaving in a way that reflects their culture and is acceptable to their culture rather than reflecting their own individual values, beliefs and opinions. This becomes relevant when comparing and contrasting the attitudes and actions of different cultural groups and attempting to interpret their mode of behaviour. A researcher who does not share the culture of those being researched needs to use caution in interpreting the data to avoid using the wrong cultural lens to interpret what is observed, which can lead to forming an invalid judgement about the individual or groups mode of behaviour. This is one of the inherent dangers of cross-cultural research.

Krauss and Chiu (1998) proposed that there is a ‘possibility’ that people exposed to a dual culture are capable of developing multiple psychological processes, which enables them to switch their mode of behaviour depending on the culture they are dealing with. In observing many dual-culture individuals, especially children, in the UK I argue that this is more than a mere possibility. Many young dual-culture children demonstrate the ability to identify appropriate cultural ways of behaving, depending on the person they encounter. For example, many Yoruba children, even those as young as six years of age, quickly recognise those who share their own native culture, and custom demands that they be greeted in a culturally appropriate manner, (girls kneel and boys prostrate in greeting elders) and many do this instinctively because they have been taught through an association with their culture through their parents. However, when they encounter, for example, a White elder they instinctively offer a handshake, assuming often rightly that this is the correct mode of greeting associated with a White European elder’s culture. Admittedly when they encounter a Black Caribbean there may be some confusion and many young children are observed attempting to mentally classify the individual.
Whether direct exposure in country of origin and degree of exposure to that culture determines levels of ‘Africaness’ and ‘Caribbeaness’ is uncertain, and whether this makes a difference to an individuals’ attitude to sickle cell requires some exploration. Whether dual-cultural exposure influences attitude to disease and illness and to sickle cell specifically is one of the issues that will be analysed, since this may impact on attitude to procreation and choices in respect of being at risk of having a child with SCD.

2.3.2 Culture and language

Language is one of the most significant symbols of a culture and one of the most effective methods for the transmission of culture to future generations. Madu (1994) argued that the use of language is a demonstration of cultural maturity since it is through the use of language that a group is able to pass on their cultural values, beliefs and norms, suggesting that a lack of language is a demonstration of cultural immaturity.

Krauss and Chiu (1998) asserted that there is a close relationship between language use, shared meaning and cultural identification. In recognition of the importance of language and its effectiveness in transmitting culture, white slave traders and masters made every effort to eradicate the use of African languages among African slaves transported to Europe, North America and the West Indies during the notorious Black African slave trade between the sixteenth and eighteenth century (GLC 1986).

There are words and concepts in one language that one cannot translate effectively into another language, and it is these elements especially that best promote and explain any given culture and the uniqueness of cultural diversity. Many would argue that language is power, and this was well recognised by the slave masters: take away a man’s language and ability to pass on his culture and you are better able to control not only his body but his mind. Language is therefore synonymous with culture. The power of language was well recognised as a potent symbol for promoting group cooperation and cohesion, and as a potential source of empowerment. If slaves were not forced to relinquish their native language they could pose a threat to their master’s wealth. As highlighted by Wesling, ‘once a symbol evolves in a person’s subconscious, that person uses the symbol with high frequency and has little or no necessary conscious
understanding of its meaning. A shared symbol speaks volumes, although contained in a relatively small visual or auditory package’ (Cress-Welsing 1991: xi).

Unlike the newly migrated Asian and Chinese migrants, the majority of Black Africans born and living in the Caribbean are not able to identify with their original African native culture or language. New languages and dialects have evolved, which has enabled cohesion of the newly formed nationalistic group (Collier and Fleischmann 2004). These languages combine remnants of the original African language with local Carib Indian languages and the slave masters’ European language. This forms the island’s patois, a dialect customized to suit the cultural background of the people of that island. Derivations of European languages and other languages result in the formation of patois: in Jamaica, Guyana and other English-speaking islands, English is the foundation, in contrast to Martinique and Guadeloupe where French is the foundation.

In the UK the majority of those originating from the Caribbean speak mainly English and a few speak Patois. The Commission for Racial Equality (1999) highlighted that 22% of Caribbeans in the UK speak Patois, the older generation especially. Since only a small proportion of the childbearing age Caribbean people in the UK speak Patois I anticipate that only a small proportion of respondents in this current study will speak any other language than English and since it is likely the majority will be second- or third- generation migrants few will feel able to identify with their original Caribbean cultural language and this in itself will influence their view of the world and their attitude to disease and illness.

In a worldview of culture Sowell (1994) proposed that individuals who have been deprived of their cultural roots through self-migration or enforced slavery have a tendency to identify more strongly with their lost culture and seek ways of reintroducing the lost cultural practices. This was observed commonly during the 1960s and 1970s where the Black Power movement of African Americans radiated to Black Caribbeans in the UK, creating a striving to identify with Black African culture. Many Black Caribbean people adopted African mode of dress, both men and women rejected Europeanization, for example, straightening of the hair with a hot comb, a common feature of the 1950s, and many donned natural afro hair styles, and used such phrases as ‘Black and Proud’ creating a shift in mindset. The production of the famous film Roots, an adaptation of Alex Haley’s (1977) book based on historical research which traced his family’s ancestry from Africa through the slavery era of the seventeenth century to modern-day America, further promoted the desire of many African Americans and Black Caribbeans to seek their
African cultural roots and embrace them with greater passion than the indigenous Africans they found when many of them visited Africa on pilgrimage during that era. They were surprised that many of the indigenous Africans were emulating European and American cultural practices and the Africans were bemused by those who wanted to relinquish the American and European culture and embrace Africanism.

The African and Caribbean culture, like any other, is transmitted through exposure to language in the nuclear and extended family, friends and the wider cultural community. However, in the UK, with each passing generation there is increasing assimilation of western culture and this is reflected in the cultural practices of subsequent generations of migrants. This is more prominent among the Caribbeans by virtue of their earlier migration. There are fourth- and even fifth-generations living in Europe. Conversely, the majority of Africans are first-and second-generation migrants and have had less time to assimilate western cultural practices. In view of this it is anticipated that differences will be observed in the African and Caribbean respondents’ attitude to health, disease and illness and to SCD in particular.

I argue that since the majority of native Africans have a distinct African language the transmission of African culture is easier to achieve than it is among those of Caribbean origin who have assimilated European languages and modes of being. Secondly, because of the large melting pot of cultures in the Caribbean and extensive exposure to European culture it is likely that a person of Black Caribbean origin is likely to reflect European, Asian, Chinese and Native Caribbean Indian culture, belief, values and attitudes and this may make comparison of the African and Black Caribbean group difficult.

2.3.3 Culture, disease and perception of illness

Culture impacts on health and social beliefs, behaviour, perception, attitude to disease and illness, emotions, language, religion, ritual practices, family structure and size, diet, mode of dress, body image, concepts of space and time, attitude to pain and misfortune (Henley and Schott 1999).
Marteau and Senior (1997) maintain that there is considerable variation in the cultural attribution of disease and illness. Non-Western cultures have a tendency to include interpersonal relationships and supernatural beliefs in their view of illness causation. Reflecting on the findings of Sisson Joshi’s study of Hindu people, Wrightson and Wardle (1997) reported ‘Hindu people regarded cultural rules with respect to social roles and obligations to be important, even when this was clearly acknowledged to be detrimental to [their] health’.

Landrina and Klonoff in Marteau and Senior (1997) asserted that Western cultures tend to attribute illness to one of several causative factors, the majority of which are, bio-physiological. These include diet, genetic orientation and consequent propensity to a particular illness, weight (obesity and underweight), smoking, alcohol use, stress and a lack of exercise. Conversely, many non-Western cultures attribute disease to other possible causative agents: violation of interpersonal norms, violation of the demands and expectations of social roles and the emotions evoked by such transgressions (e.g. guilt, sadness, envy, jealousy) which consequently cause illness, violations of moral and religious taboos, natural agents, such as type of food consumed and the weather and state of the individual’s blood. In the context of many African communities, and to a certain degree in traditional Caribbean cultures, the supernatural aspects plays a pivotal role and many ailments, especially in Africa, are ascribed to the machination of evil forces, including witchcraft.

Marteau and Senior (1997) argued that causal beliefs are influenced by cultural orientation and these consequently affect behaviour. A failure to take these cultural differences into consideration when offering health services to a multicultural society may account for some non-western clients’ failure to adhere to prescribed western medical care. It should also be noted that assumptions should not be made that western education and immersion in western culture will totally eradicate a non-western individual’s cultural attitude, belief or behaviour; many demonstrate dual and sometimes complex cultural attitudes and behaviour. And whilst western medical training may instigate a questioning of a cultural health belief, it may fail to change or eradicate the cultural belief since it is perceived that western science does not offer a full explanation for the cause and effect of health, disease and illness. These causal beliefs influence attitude and an acceptance or rejection of scientific explanations for disease and illness. A physician may find it inconceivable that an individual believes that evil spirits are causing his ailment, whilst the patient finds it inconceivable that the physician does not understand that science cannot explain the cause of all ailments nor offer a cure for diseases that have a spiritual
cause. This issue is very pertinent when examining African and Caribbean responses to being at risk of having a child with SCD.

In a study of 277 Asian, Chinese and Caribbean peoples’ attitude to health and illness in the UK, Dickinson and Bhatt (1994) demonstrated that most of the Caribbean women sampled agreed with the statement that ill health had a divine purpose while most Caribbean men did not agree with the statement. And the Caribbean respondents believed that serious illness is not the fault of the individual; this fatalistic attitude of the Caribbean respondents was also highlighted by other authors, who compared people of Caribbean origin with those of the indigenous white population (Howlett 1992).

In a study of perceptions of health, disease and illness, Morley and Wallis interviewed male and female heads of households among the Yoruba tribe of a town in Ibadan, in southern Nigeria. They observed, ‘although 65% would proclaim they were modern whilst the remainder would profess Christianity, traces of paganism still persist with its connotations of Orisha (lesser gods e.g. metal god, fire god, water god and others) worship, faith divination and a belief in witchcraft. The advent of serious illness or misfortune is especially liable to encourage a return to the traditional specialists and remedies, which have sustained generations of their forefathers’ (Morley and Wallis in Maclean 1978:154). Although this study was conducted three decades ago, more recent studies demonstrated that these cultural practices and beliefs persist in contemporary African society.

In a similar study of traditional definitions of concepts of health, illness and disease among the Ijaw tribe of North Eastern Nigeria, Jegede (1998) observed that a belief in ancestral worship was common irrespective of the individual’s religious beliefs. The combining of traditional as well as western beliefs is demonstrated in the common practice of using both orthodox western medicine and the help of a traditional herbalist. Jegede (1998) noted that the Yoruba people hold two concepts of illness: physical and mental, un wholesomeness, which they call ailara and cultural illness, manifested in misfortune or bad luck, oriburuku. I propose that the latter does not necessarily involve physical illness and certainly not illness as perceived by western societies. It is often an illness of misfortune which has its symptoms in the spiritual realm, and spiritual outcomes may include, for example inability to make progress in life socially, monetarily and educationally. Often oriburuku requires prayer or other such interventions to heal the spiritual ailment or bad luck.
Illness is stigmatising within many African and Caribbean societies. In the Ijaw group described by Jegede, illnesses that are perceived as being contagious or hereditary are particularly stigmatising and individuals may be isolated and excluded from mainstream society. The exclusion may include other members of the nuclear and extended family, especially in respect of marriage prospects. Because of this stigmatization there is a tendency to conceal ailments, particularly hereditary conditions, such as sickle cell, or contagious ones, such as leprosy.

Within the group studied by Jegede, and as seen in several other African cultures, before a marriage proposal is formalised the two families investigate whether there are any ailments within the family that could be potentially detrimental to the couple or their future offspring. This fact-finding exercise includes obtaining information from neighbours and those who know the family well. If the known ailment is considered serious the marriage proposal is invariably rejected and the enquirer is advised to seek an alternative. The rejected individual however may experience future difficulty finding a partner. A family history of early adult deaths, mental illness, birth of malevolent reincarnate children (abiku), hereditary diseases (such as sickle cell and epilepsy) and history of barrenness or long-term infertility in the family will often constitute reasonable grounds for rejection of a marriage proposal. Therefore where sickle cell is identified in the family this may impact on the marriage prospects of its members.

There is compelling evidence that culture plays a significant role in attitude to disease and illness. It is likely that African and Caribbean people’s attitude to SCD and the risk of having a child with the condition will be influenced by culturally determined attitudes, values and beliefs. If one is of the opinion that culture shapes an individual’s perception of health then it becomes untenable to apply a one-glove-fits-all approach to health service provision in a multicultural society.

2.3.4 African, Caribbean culture and religion

Exploring a theory and philosophy of religion, Thakur (1981) argued that religion is not in the sphere of reason but of faith and that one cannot apply the criteria of judgement borrowed from one sphere to apply to another that is distinctly different from it. It would be inappropriate and disingenuous. Religion is in the metaphysical and faith cannot be rationalized, otherwise it ceases to be faith. Thakur (1981) argued that religion is a ‘process rooted in experience and tends
to command deep, personal commitment to certain beliefs and attitudes, which is reflected in
the religious practices of its members. And it is the feeling evoked by passionate commitment,
feelings and the attitude of the religious followers that places religious belief beyond what he
describes as ‘mere intellectual assent’.

Frazer in Jegede (1998) claimed that religion is a conciliation of powers superior to man, which
are believed to direct and control the course of nature and human life. In a study of the Yoruba
tribe of Southern Nigeria, he observed that the belief in deities, supernatural beings and ancestral
worship is common and a belief in a benevolent all-powerful creator God who has control over
the entire universe unquestionably tenable.

In support of belief in supernatural causes Kondor (1993) observed that in traditional Ghanaian
culture there is a cause for every mishap, in many instances attributed to a spiritual influence,
and for most people every action has a religious significance. Despite modern western religious
influences, fortune telling (soothsaying) still thrives in the majority of African countries, even in
countries where extensive European influence has changed the landscape of culture, such as
South Africa and Zimbabwe.

In many African cultures there is a general belief that deities are closer to God than human
beings and therefore they are able to intercede on behalf of man. To initiate this plea-bargaining,
rituals such as sacrifice, prayer, dancing, libation and other forms of religious ceremonies are
performed in honour of the deity, lesser god or ancestor. Many African people, including some
Christians, use libation at the beginning of any significant ceremony, such as weddings,
christenings and dedication of a new house. This is to appease the ancestral gods and seek their
blessing on the venture. There is a belief that these practices are not opposed by the higher
supreme God of Christians, Moslems or others and such practices do not limit or prevent
worshiping of the higher supreme God. Deity worship it is believed is merely to assist in
appeasing the greater supreme God. Many believe that mystical and other religious experiences
are important aspects of their religious practices. For example, glossolalia (speaking in tongues),
going into a trance and other forms of religious behaviour are common in many modern-day
African and Caribbean charismatic churches, and can be observed in Pentecostal and African
Spiritualist churches (Beit-Hallahmi and Argyle 1997).
In an exploration of culture and religion, Henley and Schott (1999) observed that the majority of Caribbean people in the UK who practise a religious faith are orthodox Christians, of the Pentecostal, Seventh Day Adventist, Anglican, Baptist, Methodist and Roman Catholic denomination. A few are Jehovah’s Witnesses, whilst a small number of young people are practising Rastafarians and Moslems. Although many African Christians are within mainstream Anglican, Pentecostal and other orthodox denominations a significant proportion are in Black-led groups such as Cherubim and Seraphim and Celestial, which are white garment charismatic African churches.

Read (2001) claims that religion is a major component of a people’s culture and typifies a belief in a supernatural being that demonstrates the complexity of man's relation to nature, to his fellow man and to the supernatural powers that control him and the universe in which he lives.

Collier & Fleischmann (2004) discussing the creolization of cultures in the Caribbean, described the practice of voodoo, a fetish religious practice seen primarily in Haiti but also in other parts of the Caribbean. Voodooism has evolved since slavery era. It is based mainly on fetish African religions and has incorporated elements of Catholic religious practice, for example, the use of prayer incantation as part of the religious ceremony. The fusion of Catholicism and African religion may seem unlikely but it is related to the history of slavery in the Caribbean. Black people, brought from Africa during the slave trade of the sixteenth to eighteenth centuries, were forcibly baptised into their Spanish master’s Catholic religion. However, many slaves continued to practise their African religion surreptitiously. In time certain parts of both religions became fused. The practice of voodoo religion has been transported to different parts of the world, including New York, where there is a significant following of worshipers. The religion often involves dancing to rhythmic drumming, incantations, worshipping of spirits, performance of rituals and other religious activities, which are performed by voodoo priests, priestesses and other followers. However, the fetish practices of voodooism have earned it a bad reputation, so that many of its followers are reluctant to admit membership of what is now considered a cult.

In the last ten years a significant number of Caribbean young people in the UK have converted to the Islamic faith, influenced by a belief that it is the authentic religion of ‘Africa’. Moslem Clerics such as the infamous Louis Farrakhan, who originated and still lives in North America, has contributed to promoting this belief among the youth. Farrakhan claims that Islam will provide spiritual fulfilment and promote social cohesion and uplifting of the Black community.
Farrakhan argued that Islam is the religion that is most suitable and culturally acceptable for people of the African Diaspora. It is perceived as the religion which will address the inappropriate way of thinking that has resulted in the underachievement of many generations of Black men in the western world. It will enable the empowerment of the Black community by reinstating the Black male, as God intended, to the position of the head of his family and community. It is perceived that this will ultimately rebuild the broken infrastructure of the Black family and community.

In a few traditional Caribbean groups, particularly those living in the Caribbean, relics of their Black African ancestry remain in terms of a belief in witchcraft and consequent fetish practices (Pulis and Szwed 1999). Evidence of this can be seen in the many traditional religious shops that have become established within the last ten to fifteen years in many parts of London and other major cities in the UK and these shops are frequented by traditionalist religious African and Caribbean people. These religious shops retail items such as Bibles, crosses, holy soap, candles, incense, holy water, special perfumes to ward off evil spirits, charms for good luck, charms to appease the gods for success in exams and similar religious items. It is not uncommon to retail both orthodox and unorthodox religious items in the same shop. Retail outlets that are similar to these were seen by the researcher during a visit to Brazil and the Caribbean. These cultural beliefs and practices influence people’s attitude to the cause and required treatment for illness or a social predicament.

Alkuraya and Kilani (2001) in a study of 32 Saudi families who already had one or more children with SCD or other major haemoglobinopathies, examined couples’ attitude to PND, termination of an affected fetus and the influence of the Islamic religion in decision-making. Interviews were conducted with 26 mothers and 5 fathers independent of each other, and with one couple together. They noted that health carers often assume that strong Islamic values would be a strong predictor of women’s acceptance or rejection of PND and this perception influenced the health carer’s intention to offer or not offer the procedure to some at-risk women. The study highlighted that the majority of the families interviewed accepted the idea of having PND but rejected the idea of a possible termination of an affected pregnancy because they believe that the Islamic law (Fatwa ruling) does not permit abortion even in cases of confirmed fetal abnormality. The researchers found that although religion played a critical role in the decision-making of the study population there was a lack of understanding about the Fatwa ruling on termination. 28 (96.4%) of the sample said they would not accept PND because of their
The families had assumed that the objective of PND is for the termination of an affected fetus. The researchers subsequently offered the families information to clarify the Islamic ruling as stated by the Islamic Jurisprudence Council (12th session in Makkah, 10–17 February 1990), which stated that abortion is permissible where a fetal abnormality has been identified provided the abortion is conducted before ensoulment, which is calculated as 120 days of pregnancy. Following this clarification 13 (46.4%) of the families who were originally opposed to PND and abortion changed their minds and said they would opt for PND and abortion, one person (3.4%) was unsure and the views of 14 (50%) remained unchanged. Of those who rejected PND and abortion even after the Fatwa clarification, one family felt the risk of having or not having a child with a disease is in the hands of God and individuals should not interfere with Allah’s will, which is perceived as one that should not be violated. The researchers did not clarify whether those who declined the offer of PND following receipt of accurate information about the Fatwa ruling had a mildly or seriously affected child from a previous pregnancy which could have been influencing their unchanged attitude to PND and termination.

Alkuraya and Kilani (2001) did not comment on the Islamic ethic, which claims that suffering promotes strength and human endurance. Many other religions, including Christianity, see suffering as God’s way of enabling humans to achieve human perfection. Suffering in many non-western cultures and religions is not necessarily seen as negative state of being but part of the fabric of the human experience, and a prerequisite for attaining human perfection.

In a study of attitude to reproductive choice of parents of children with cystic fibrosis Henneman et al. (2001) stated that it was religion and not the clinical severity of the disease that had influence on intention to use PND. This suggests that those who regard God as the master creator whose design should not be interfered with are less likely to opt for PND. It is assumed that the sole objective of PND is to identify and terminate an affected pregnancy.

Petrou et al. (1992) reviewed factors affecting the uptake of PND among 170 couples at risk of having a child with SCD. They identified that only a few women declined offer of PND based on religious grounds, but did not specify the number. It should be noted however that most of the women who refuse on religious grounds would not have been referred to the tertiary centre, and are in the cohort of women who continue their pregnancy without any interventions.
In his study of the Ijaw Yoruba cultural group in Nigeria, Jegede (1998) observed the popular belief that some diseases are caused by evil spirits and the treatment necessitates appeasing the spirits by seeking the assistance of church elders for prayer or attending traditional healers who may prescribe and or perform the appropriate ritual (ebo), intended to appease the spirits and thereby rectify the problem. Rituals often involve preparing special foods, animal blood sacrifices, reciting special incantations then placing the items at a cross road for the deity. After a time if the food or items get consumed (disappear) this confirms that the gods or spirits have been successfully placated and there will be improvement in the individual’s state of health or perceived misfortune. It is interesting to note similarities in the concept of the blood sacrifice in the Christian doctrine, which has its background in Judaism, where communion red wine represents the blood shed for the atonement of sins and drank in remembrance of Christ’s sacrifice of himself to purify and cleans the believer from their sins.

Although modern western medicine does not consider supernatural powers as relevant in diagnosis and treatment of illness, traditional healers and those who consult them in many African communities do, they sometimes perceive it as being just as viable as orthodox western medicine (Kondor 1993, Madu 1994, Beit-Hallahmi and Argyle 1997). It is with interest that one is able to observe the emergence of traditional African healers that have recently been established in many major cities in Europe and it is not uncommon for African and some Caribbean patients to utilise their services, sometimes combining western orthodox medicine, traditional African medicine and spiritual invocations (prayer).

Many educated people have broken away from traditionalism, but those who have not severed the ties fully will integrate traditional African and western medicine. This is the group that will tend to attend spiritualist churches, not wishing to be seen as naïve or uneducated yet maintaining their cultural values and beliefs. Read (2001) noted that although western orthodox medicine maybe fully developed in some countries yet traditional healers continue to attract a wide spectrum of clientele many of whom describe themselves as educated. In view of this one should consider whether these individuals when migrated to a western society reject the traditional views and practices of their culture of origin and adhere to the orthodox practices of the west. I argue this is not necessarily the case since there is evidence that the use of traditional healers has grown in many European countries. Evidently this will be demonstrated in migrants’ attitudes to disease, illness and being told that they are at risk of having a child with SCD. I suspect many will embrace western orthodox medicine whilst resorting also to their traditional
ways of dealing with such life events, such as visiting a soothsayer or spiritualist for visions about what the future holds, or prayer to avert possible mishaps such as the birth of a child with a disease or illness.

Because of extensive migration of minority ethnic groups into the UK, especially those of African, Asian and Caribbean origin, the number of mosques, temples and spiritualist churches and other traditional worship venues has increased dramatically in the last decade. Spiritualist churches such as Pentecostal, Cherubim & Seraphim, Celestial, Church of God, Mount Zion Ministries and others have powerful symbols in their preaching and rituals which attract those who do not wish to be perceived as reverting to paganism but seeking divine intervention to address problems of ill health, poverty, misfortune or lack of progress in their personal lives.

Jegede (1998) observed that many churches claim to have powers to initiate and ensure healing and this power is a key aspect for attracting people to those churches. This belief in the spiritual power of the church or other religious establishments is crucial to understanding the attitude of many African, and to some extent, Caribbean people. Their belief will invariably have an impact on their response to being at risk of having a child with SCD.

Because of ethnocentrism, many people in so-called developed western societies have a tendency to regard those who do not conform to their way of believing or behaving as ignorant and or superstitious. ‘Folk medicine has mistakenly been thought to be peculiar to some ignorant segments of the world’s population when in fact it is the kind of knowledge which characterises in one way or another almost everyone in the (human) species’ (Adams in Jegede 1998). This includes religious attitudes, doctrine, belief, values and practices.

Whilst membership of many orthodox churches, for example Anglican and Catholic, is declining that of the new movement Black-led churches is increasing at a dramatic rate and tending to attract the educated, progressive, professional members of the Black community. Some Pentecostal, Redeem movement churches boast a congregation of five to ten thousand congregants attending a Sunday service. Many charismatic churches are zealous in promoting and encouraging their members to adhere to the Christian ethic of tithing (giving 10% of their income to God); as a result many have amassed a substantial amount of wealth. The church leaders are often accused of amassing wealth through the exploitation of members of their congregation, who are regarded by many members of the wider society as naïve and therefore
vulnerable. Accusations of misappropriation of funds are regularly levied against church leaders and this is often the basis for criminal investigation of these new age rapidly growing charismatic churches.

Jegede (1998) noted that most people in Nigeria still believe in the ancestral deities and in the witchcraft explanation for disease, which invariably influences their response to illness and health-seeking behaviours. However, he noted that some changes are occurring as a result of Christianity and western education.

In the African context, the Islamic religion, unlike Christianity, encourages the use of traditional medicine and there does not appear to be a conflict between Islamic practices and traditional healing practices. It is reported that many of these rituals are supported by the doctrines of the Islamic religion.

In a study of attitude to acceptability of PND and termination of an affected pregnancy Durosinmi et al. (1997) examined the attitude of 433 Nigerians (204 males, 210 females and 19 where gender was not recorded) with normal haemoglobin (40%), sickle cell trait or haemoglobin C trait (16.6%), sickle cell disease (2.2%) and those who did not know their Hb status (35%). Although avoidance of the problems associated with having SCD was the most common reason for approving termination of an affected pregnancy of the 55% who were opposed to termination 73% stated religion and moral values as the basis for their rejection of this option.

### 2.3.5 Culture and reproduction

Pearn (1979) hypothesized that a person’s, especially women’s, reproductive drive is inherently overwhelming, even the risk of genetic disease may be unable to suppress it because it is likely that it is fixed during early childhood. Pearn did not indicate whether the reproductive drive is also influenced by nurture. In support of this theory in a case study of three mentally retarded women Finucane (1998) argued that for the majority of women there is a motivation and desire to nurture and love a child and leave a legacy for the next generation and a real or perceived constraint on childbearing does not reduce this desire. In support of this Cote (1982) argued that
anticipated health and social problems do not nullify the reproductive drive but that they will co-exist and sometimes clash with each other. Marteau & Anionwu (1996) claim that the desire to have children has a stronger influence on procreation than the perceived risk of being a carrier of a genetic condition and this knowledge does not necessarily influence the decision to have children, however, it influences decisions about PND and termination of an affected pregnancy. Is there a difference in response to perceived risk and the reality of having experienced living with or caring for someone with a genetic condition like SCD? Will such personal knowledge and experience affect decisions when selecting a marital partner, and is it able to suppress the desire of African and Caribbean men and women to have children, and the number of children they choose to have?

Is Pearn’s (1979) reproductive drive theory plausible? If so how do we account for the significant number of career men and women in western societies who actively choose not to have children? Secondly, how do we account for the significant number of women who opt for PND and termination of an affected fetus? For example, in Durosinnmi et al.’s (1995) study of those at risk of having a child with sickle cell anaemia in Nigeria a significant proportion of the study population advocated PND and termination of an affected fetus. If reproductive drive is so compelling why do these women not accept having a child with SCD? Why did the ‘biological drive’ not influence the genetic choices of women and couples at risk of having a child with beta thalassaemia major, where a significant proportion are reported to opt for PND and termination of an affected fetus (Petrou et al. 1990, Zeuner et al. 1999)? Do men have this innate desire to reproduce themselves? The biological drive theory raises many unresolved questions.

I propose that there are other more compelling influences than the biological reproductive drive theory, and proposes culture as a more plausible factor, especially with regard to the perceived role, function and status of women within society. In African, Asian and other cultures there is pressure on women to have children, irrespective of their being at risk of having a child with a genetic defect. An individual’s cultural perspective will influence their response to this societal pressure to procreate. Other factors that could influence reproductive drive and subsequent reproductive choice are the perceived social and economic burden of caring for a child with a life-limiting condition, especially in an environment where access to adequate and accessible health care is sparse, where there is no hope of ameliorating or eradicating the condition in future and where the prospects for the child’s future appear bleak; one can argue that these factors
become more relevant in reproductive decision-making than the biological reproductive drive theory.

Attitude to childbearing varies across cultures, but the majority of the world’s people perceive having children an essential part of adulthood, especially for women. Lips (2003) highlighted that in developed countries a certain proportion of heterosexual couples choose not to have children or are involuntarily infertile, but even in such western cultures there is a common belief that a woman who is childless is unfulfilled in this important aspect of womanhood. Societal response to the predicament of infertility also varies, which we shall observe later in the findings of this study, and has a direct link to the dilemmas which many couples at risk of having a child with SCD encounter.

In a study of choices of treatment among the Yoruba tribe of Ibadan, in Western Nigeria, Maclean observing the attitude of 106 heads of households interviewed (58% men and 42%) and noted:

> It is felt to be disastrous for someone to die without sons to carry (on) the spirits of the ancestors…women…are preoccupied with their capacity to bear children and barrenness is a profoundly unhappy state.

(Maclean 1978: 159)

In support of this observation Madu (1994) argued that in most African cultures marriage is perceived as an undertaking to which all adults must subscribe and bachelorhood is seen as an aberration that cannot be condoned. The Igbo tribe of Eastern Nigeria have a popular adage, which state, ‘he who marries has paid the debt he owes to his lineage’.

Basden in Madu observed:

> The idea of a celibate life finds no favour whatsoever to the traditional Igbo it is ranked foolishness as well as being utterly contrary to the laws of nature. Except in peculiar cases (for example, it is acceptable for a nun, or Catholic priest) men and women and particularly the latter are scorned and mocked if they remain unmarried… childlessness is seen as having missed one of the essential goals of human existence… a childless woman is regarded as a monstrosity.

(Basden in Madu 1994: 152)
In many cultures motherhood is considered the only viable purpose of womanhood, a state of being that will fully satisfy society’s expectations even in the absence of any other life-affirming roles. Lips (2003) concluded that infertility is as high as 5 to 7% in some African countries; in many traditional African societies a woman’s status is totally dependent on her ability to bear and have children, in later life the children are commonly the only source of sustenance for the parents and other members of the extended family. Women who are unable to fulfill their role in this regard are often abused physically, mentally and emotionally. Such women may become objects of ridicule and stigmatization by their community, and they are often rejected and abandoned by their partner. Within such cultures the notion that a woman would deliberately choose not to have children would be considered total insanity. This is a common phenomenon observed among Africans in Phase 3 of this study.

Among Nigerians a common taunt levied at unmarried but highly educated women is, ‘What is the point in your having an MSc or a PhD if you don’t have your MRS (Mrs) certificate? Marriage and procreation, the latter particularly, are regarded as God’s purpose for humans. In the African context the main objective of adulthood is marriage and the sole objective of marriage is procreation of children. The notion of deliberately choosing not to have children is an alien concept to the average African and those who deliberately embark on such a course are not tolerated and become objects of ridicule. This strong cultural belief in the virtues of marriage and parenthood permeates the majority of African, Asian and other traditional cultures, especially in developing countries where children are also considered a parent’s insurance policy against economic hardship and social deprivation in old age. It is unclear whether acculturation to western values alters these opinions among African, Asian and other traditionalist cultural groups living in the UK. Is marriage and parenting as compelling for the Caribbean as it appears to be for many African and Asian communities? The exploration of this question will possibly impact upon the attitude of individuals and couples to SCD and to the risk of having a child with sickle cell anaemia.
2.3.6 Cultural beliefs and attitude to sickle cell in Africa and the Caribbean

Cultural belief about sickle cell influences people’s attitude to sickle cell and the prospect of having a child with this genetic condition. It is possible that this cultural dimension is a key factor that needs to be examined in respect of African and Caribbean people’s attitude to the condition.

Akinyanju (1989) highlighted that of the 1000 newborn babies that were tested in one rural village in Nigeria, 30 were diagnosed with SCD. This gives an indication of the average number of babies born with SCD annually in that area. In view of this one would anticipate a fairly significant number of people with SCD in the child and adult population. However, when tested there were no children above fourteen years of age or any adults with sickle cell anaemia, since those affected had died in early childhood.

It is proposed that many infant deaths, which were attributed to cultural beliefs in re-incarnation among the people of Western Africa, could be attributed to SCD and its associated complications. The high infant mortality in many African societies was and still is frequently attributed to witchcraft or to the presence of a malevolent spirit in the child. In West Africa, as in many other parts of the world, there is a strong belief in reincarnation - that humans die to be reborn either as a good or bad (malevolent) spirit. Good spirits live useful and productive lives. The Yoruba term *abiku* and the Igbo term *ogbanje* refers to children who are believed to be malevolent spirits or beings in southern and eastern Nigeria. These children, it is believed, die in infancy only to be reborn into the same family repeatedly. They die a few days, weeks, months or years after birth so as to punish their parents, family or community for their ill treatment during a previous incarnation. It could also be punishment for a parent or a member of the family who has knowingly or inadvertently offended a person with evil powers in the community (a witch), who then cursed the individual or family, causing a couple to have a malevolent child (Nzewi 2001). This deep held belief in reincarnation permeates many traditional cultures worldwide. In describing the Ghanaian culture Kondor (1993) highlighted the practice of consulting a soothsayer when a child is born in order to find out whether the child is a dead ancestor that has been reincarnated, so that the most appropriate name can be selected for the child.
In a study of 225 children classified as Ogbanje Nzewi (2001) found that 80% of the signs and symptoms described by the parents, elders and traditional healers in the three communities studied indicated that the children probably had SCD. The similarities in the clinical description was so compelling that Nzewi argued that the term ogbanje is the Igbo people's way of explaining the disease and the term ogbanje is synonymous with SCD.

Historically it was and still is not uncommon for a woman to lose several children, sometimes in succession, and the cause of death is often not attributable to any of the known childhood illnesses, tropical diseases or other known ailments. These sad events occurring to the same family repeatedly lend support to the community’s witchcraft theory, even where there is a scientific explanation it is assumed that such a misfortune by law of probability could not possibly occur repeatedly by chance to a family.

When a child dies and is suspected to be an abiku, in an attempt to identify such a child when it is reborn, it is common to mark the dead child before burial. This is done by perhaps cutting off the tip of the little finger, or making a small cut somewhere on the body or a burn somewhere on the corpse’s skin. It is believed that such mutilation of the dead body will make it impossible for the evil spirits, living in the spirit world, to recognise the child when it is preparing to be reborn. In this way when he or she is subsequently incarnated the evil spirits will be unable to call him or her back into the world of the dead, and the child will therefore live a normal life there after. A child born after the death of a child deemed to be an Ogbanje are given names which identify them as reincarnated, for example, the Yoruba tribe of Nigeria apportion names such as Durojaiye, [stay to enjoy life], Kokumo [will not die again], Malomo [don't go again], Durosinmi [Stay to bury me – this reflects the African’s desire for a child to outlive their parents and bury their elder parents, rather than parents burying their own child] and Makumo (don't die again).

Edelstein (1983) conducted a study to test the reincarnation theory and to determine whether the names of ailments supposedly attributed to SCD are viable. Edelstein examined the corpses of abiku children and their supposed subsequently reborn sibling children and could not find any evidence to support the notion that the mark placed on the dead child in a previous life was present on the child that was subsequently born to the same couple. He concluded that although some ancient African names appear to describe SCD; these names were also used generically to describe any serious illness. Especially where there are symptoms akin to rheumatic pain, therefore, these names may have little or no connection to SCD. For example, as stated earlier,
the Yoruba tribe called SCD *lakuregbe*, which is also a term used to describe rheumatic disease and its associated pain. The cultural belief in reincarnation remains strong in many developing countries. This belief is also common among many health and allied professionals, including those trained and living in western countries. This demonstrates the power of ‘culture’ and the influence that an individual's culture has on their beliefs, irrespective of their exposure to other cultures and the medical discourse.

One study, conducted by Duster and Beeson (2007), compared cultural and socio-structural variations in disease perspectives and attitude to genetic testing. The attitude of African-American people with sickle cell trait and White-American people with cystic fibrosis with a carrier state and disease were examined. The findings of the study demonstrated that a significant proportion of individuals’ knowledge of the genetic condition in the family did not necessarily influence the decision of many of the family members in terms of subjecting themselves to premarital testing or, where carrier status is known, selecting a ‘safe’ partner.

Following extensive literature search, no literature was found that examined the Caribbean community’s cultural belief and attitude to SCD specifically.
2.4 Genetics

2.4.1 Political aspects of genetics and sickle cell screening

The frequently quoted aim of antenatal genetic screening is to offer women and their partner’s genetic choices. However, it is evident that screening during pregnancy offers no genetic choice since pregnancy is already established and a genetic choice is no longer feasible. I argue therefore that the aim of antenatal genetic screening is to offer options with regard to identification of an affected fetus and subsequent continuation or termination of an affected pregnancy. Some health policy-makers’ perception is that the primary aim of funding a genetic screening programme is to reduce the number of children born with preventable diseases.

The Department of Health Standing Medical Advisory Committee (SMAC) (1993) proposed that the aim of antenatal screening for haemoglobinopathies is to enable those at risk of having a child with a major disease an opportunity to avail them of the offer of PND. The committee subsequently outlined the objective of PND, which is to diagnose an affected fetus and offer parents the option of continuing or terminating an affected pregnancy. A United States Government Committee endorsed this principle, by stating that, ‘our committee stressed the importance of autonomous decision-making by individuals and by their families even if the development of a genetic disease might be the outcome. We believe that in a society such as ours, autonomy far outweighs any public health consideration’ (Andrews et al. 1994 in Marteau 1995:1216).

These sentiments will probably resonate with many policy-makers, health and allied care professionals and members of the general public. However, it is a view that may not be shared by all policy-makers who hold responsibility for allocating resources. In respect of Alpha Feto Protein screening one policy-maker was reported to state: ‘the objective of AFP screening is to reduce the number of infants born with Downs Syndrome and neural tube defects’ (McColl and Gulliford in Marteau 1995).

Policy-maker David Danks, then director of the Murdoch Institute for Research in Birth Defects in Australia, claim that it is ‘self-indulgent’ for parents to knowingly bring a child with a fetal abnormality into the world. Dank’s goes on to suggest that choosing not to terminate an affected pregnancy is tantamount to social negligence, an act of cowardice, which fails to take into
account the best interest of society; a society to which the parents should have a collective moral responsibility (Marteau 1995). In support of this argument Short in Marteau (1995) claimed that following PND where an affected pregnancy is identified it should be ‘eliminated’ and it is a ‘true act of moral cowardice’ where an individual knowingly allows such pregnancies to proceed to term and subsequent birth. If this being the case it will be interesting to observe whether women and couples at risk of having a child with SCD perceive themselves as cowardly if they make choices that are perceived as not benefiting the wider society.

Outlining the process for the delivery of a haemoglobinopathy antenatal diagnostic service Petrou et al. (1990) identified a significant increase in the uptake of PND mainly of Mediterranean and Asian couples at risk of having a child with thalassaemia major. They stated, ‘service monitoring in the Mediterranean has shown for thalassaemia that a comprehensive control programme can lead to near-eradication of the disease’ (Petrou et al. 1990). Emphasis was placed on eradication, and many will argue that that is the major objective and target for the thalassaemia programme, especially in the Mediterranean and Asia, probably because of the disproportionately heavy burden of providing lifelong health and medical care for these individuals. In respect of couples at risk of having a child with SCD the authors stated: ‘We would expect a smaller reduction in the birth-rate since only 50% of counselled [at risk] couples request PND’ (Petrou et al. 1990). The question should be: is eradication the objective of screening the African and Caribbean communities at risk of having a child with SCD or is the aim to control and manage the condition when found? The severity of SCD is unpredictable and ranges from a mild benign to potentially life-threatening condition. This may account for the differences in attitude to prevention or eradication and this may be reflected in the response to PND between those at-risk of having a child with thalassaemia major and those at-risk of having a child with SCD. Use of the term only suggests that the aim of eradication may not be attained in the case of those at-risk of having a child with SCD.

Anionwu and Atkin (2001) discussed some of the tensions inherent in provision of genetic screening and counselling services. They reported that the late Cedric Carter, who played a significant role in the development of clinical genetic services in UK, was in favour of giving people informed choice, and leaving the ultimate decision about an at risk pregnancy to the woman and couple. However he was also quoted as saying ‘the long-term aim of genetic counselling is to see that as few children as possible are born with serious genetically determined or part genetically determined handicap’ (Anionwu and Atkin 2001). In addition in order to
persuade health service purchasers to buy genetic counselling services there is an underlying assumption that the majority of parents will make what is considered the ‘right decision’, which is termination of an affected fetus. This will reduce the short- and long-term medical and social care costs of caring for these children.

Weighing the cost of genetic screening against the long-term cost of caring for a child with a genetic disease has become the basis on which decisions are made about funding a screening programme. Discussions about parental choice become superfluous in light of this. Marteau and Anionwu (1996) demonstrated that in one antenatal screening programme, over a period of one year approximately 18,907 women were tested for a genetic condition that could affect their baby. Of those who were at risk, five opted for PND, of whom four had an affected fetus diagnosed and one opted for termination. One must ask then, whether prenatal screening is financially viable when the majority of women carrying a fetus with a significant genetic disease do not accept termination of an affected pregnancy. Can one justify the exorbitant cost? The justification may be based on moral and ethical arguments if one is to adhere to the principle that the purpose of testing is to offer parents a genuine choice. As highlighted by Marteau et al. (2001) and Marteau and Dormandy (2005), screening aims to offer people choices irrespective of the outcome. They argued that the resulting choice should ‘reflect the values of the decision-maker’. Many policy-makers will argue that offering screening is not viable economically if a reduction in births of affected children is not achieved, and screening programme resources should be redirected to the care of those born with these genetic conditions if couples do not avail themselves of termination of an affected pregnancy. This argument may be deemed justified in view of increasing financial constraints on the National Health Service in the UK and the increasing demand from society for health services to constantly meet their sometimes unrealistic expectations.

In defence of this argument it may further be argued that science has created a situation where ‘survival of the fittest’, which is in tune with nature, has been disrupted by scientific interventions, without which many pregnancies that have a genetic or structural defect would have resulted in intrauterine death, perinatal death or death within the first few years of life due to the complications of the genetic condition. Scientific advances have enabled society to choose other possible reproductive outcomes. Perhaps this is the time to consider whether eugenics is a viable and acceptable proposition!
With the now fully implemented national neonatal screening of all newborns in England for sickle cell (NHS National Antenatal & Neonatal Screening Programme 2006), irrespective of racial or ethnic group, it will be interesting to observe how many parents opt out of screening and whether they felt truly able to make such an informed choice.

Tapper (1999) argued that the terminology (discourse) applied to sickle cell when it was first reported in western medical literature by James Herrick in 1910 has resulted in the condition being labelled a 'disease'. Tapper maintained that if one examines the names given to conditions, which affect the white population, for example, cystic fibrosis and haemophilia, few will be found to have the title 'disease' attached. He suggested that it is this disease discourse that has enabled a dominant group - white western researchers, health carers and policy-makers, to exert power over a subordinate minority group, in this context Blacks living in Africa and the African Diaspora. Tapper (1999) argued that the use of power had a major impact on the development of sickle cell research in North America, Africa and other parts of the world. Research was used not to gain knowledge in order to promote a better understanding and improve care, but to perpetuate the notion that ‘blackness’ is synonymous with being ‘diseased’. Tapper claimed that sickle was used in this historical context to racially demarcate those of Negro from those of non-Negro genetic stock and perpetuate stigmatization of Black communities in whom the sickle gene is of highest prevalence.

Tapper stated:

… at specific moments (in history), sickling was established as an object of analysis and a target of intervention, and its identification and treatment became instruments of power … during the 1920s, 1930s and 1940s medical researchers used sickling to call into question the racial identity of whites afflicted by the phenomenon … geneticists and anthropologists seized on the disorder to establish the American Negro … as a hybrid and therefore inherently diseased individual.

(Tapper 1999: 3)

With this historical stigmatization the majority of the at-risk group, notably Black people, were reluctant to be associated with or be identified with the sickle gene. Blacks were targeted for testing as it was assumed that sickle and other genetic mutations of haemoglobin are peculiar to the Black race and colour was the determining factor. It is now scientifically established that this is not the case, and there are over one thousand genetic mutations of haemoglobin (Huisman et
al. 1996) and approximately 90% of these occur predominantly in the white population. Many of these mutations are rare in Black and other minority ethnic groups (Chami et al. 1995).

According to Tapper (1999) sickle became a means for Whites to exercise power over large populations of 'Blacks'. There are few ways of assessing who is truly white, but many ways of determining who is not white, and perhaps it is assumed that the discovery of the sickle gene is one of the distinct indications of being non-white. In the US, mass screening was advocated without adequate community and public education, consultation or involvement. The consequence of this was increasing discrimination, especially in employment. There was stigmatization of many sections of the Black community and those with the genetic mutation were ostracized. This led to the Black community’s suspicion of government agencies and their agents, including Black health professionals, many of whom were employed to participate in implementing the mandatory national sickle cell screening programme, targeting the Black community only.

The stigmatization of those who carry the sickle gene was perpetuated by attitudes that were evidently immoral and racist. An example of these attitudes was described by Bradby (1996) who claimed that in order to limit the transmission of the sickle cell gene to future generations a respected scientist had proposed ‘tattooing’ the presence of a sickle cell carrier state on the forehead of every young person so as to prevent their coupling and producing affected children. Initially one would dismiss such a proposal by assuming that it was voiced during the era when racial segregation was still active in early twentieth-century North America, and certainly before the emancipation of Black people. However, Bradby reported that the comment was made in the late 1980s, at a time when the Black power movement had already reached a peak, emancipation speeches were being delivered by the likes of Martin Luther King Junior and Malcolm X in the USA, Mahatma Ghandi in India and Kwame Nkurumah in Africa. This was a time when racial tensions were high but racial tolerance and enlightenment was emerging, albeit precariously, even in the UK.

Dyson and Boswell (2006), in a detailed review of deaths of people with sickle cell anaemia in police custody in the USA and UK, demonstrated that marked racist policies and practices led to the death of even those who were not yet convicted of a crime but were detained and awaiting trial. Many of the prisoners who died were victims of police brutality at worst, and at best suffered lack of care and attention. The reporting of these deaths in the media was to create a
setting for the development of Black people’s mistrust of the police and other government agencies, including health officials, in the USA and the UK. Again, such experiences and public awareness of such events compounds the development of stigma and causes further negative attitude towards the sickle cell gene.

With this historical background, it is not surprising that many Black people in the USA and other parts of the world remained suspicious of policy-makers and their employees. This suspicion was also extended to Black health carers who were sometimes labelled ‘sell outs’ and ‘coconuts’, these terms describing their outer blackness concealing a hidden whiteness shared with those in power, notably white policy-makers. The Black community’s suspicion was greatly aroused because the sickle cell screening programme was only targeted at Black people, and many believed screening and offer of PND and termination of an affected fetus was a surreptitious attempt by the government to reduce the Black population.

2.4.2 Research, genetic screening and impact

Science offers genetic choices that have surpassed the human expectations of twenty years ago. Many single gene conditions can be detected through simple genetic testing techniques. This has placed the onus of reproductive decision-making on individuals themselves. However, many feel unprepared and ill-equipped to make such far-reaching life decisions, especially in the context of cultural and social influences and pressure from the family, community and wider society (Press 1998). The freedom to make genetic choices has brought increased anxiety and guilt (Shiloh 1996). With the sequencing of the 'human genome' many more disorders will become possible to diagnose along with 'multi-gene' and 'risk-gene' conditions. In addition developments in the field of clinical genetics have greatly increased people’s expectations of having genetically and biologically ‘normal’ ‘healthy’ children. Zimmern et al. (2001) claimed that genetic testing will increasingly be used to identify a myriad of medical conditions and to initiate prevention.

Lenaghan stated:

The extent to which the public accept, demand or avoid genetic testing or screening services in the future will depend in part upon who will have access to genetic information and how they will use it. A key concern is not just that these
issues will affect future levels of demand but that insurance or employer-related use of
genetic tests could undermine the concept of unpressured consent.

(Lenaghan 1998: xi)

The concerns raised by Lenaghan have created much public debate at government level and in
the British and international media. They remain a major discussion point for the UK
government’s Human Genetics Commission (HGC). Such discussion has culminated in the
publication of a number of HGC reports including: Whose hands on your genes? Inside
information – balancing interest in the use of personal genetic data; Genetics and Insurance
(HGC 2000, 2002, 2004). Several newspaper articles raised concerns about the discriminatory
collection and use of Black men’s DNA for use by the police. Such articles included Your DNA
could be sold – fears that Black men are at-risk from firms seeking DNA for criminality gene
test; Police hold DNA of 37% of Black men and could be sold to private companies for research
(Bascombe 2006) and Police DNA database holds 37% of Black men (Randerson 2006). These
articles were reporting on the disclosure that mouth swabs were being collected routinely and
DNA profiles generated on arrest victims prior to any criminal investigation or conviction. The
fear was voiced that such electronically stored data could be used without the owner’s consent
for future investigations and for sale to companies who wish to use the data for research. It
transpired that Black men were disproportionately represented on the database and had no right
of appeal for their details to be removed, even when acquitted of any crime. This created public
outcry.

Beeson and Duksom (2001) maintain that enthusiasm for genetic testing is not restricted to
experts; there is popular support for testing among young people and those with a high level of
education within society. In 1992, a survey by Louis Harris and Associates for the March of
Dimes Birth Defects Foundation, found that 99% of North Americans said they would have a
genetic test prior to having children. This is in order to find out if their future offspring is likely
to inherit a fatal genetic disease, presumably in order to avoid such an occurrence (Beeson and
Duksom 2001). The implication is that these respondents would be prepared to terminate an
affected fetus. Whether similar attitudes will be observed among Africans and Caribbeans will
need exploration. The same authors highlighted that criticisms levied against PND were not
emanating from religious groups, as one would expect, but from some feminists and those who
advocate the rights of people with disabilities. They argued that negative cultural attitudes
towards people with disabilities, directive genetic counselling by some physicians and a positive
attitude to increasing technology which promises to deliver opportunities for having a perfect child may be forcing women to make painful decisions and perhaps opt for PND and termination of an affected fetus.

Many lay people, and even some professionals, have a poor understanding of genetic inheritance, the concept of being a ‘healthy carrier’ and how genetic probability works. In a pilot study of populations at risk of Tay-Sachs disease Marteau et al. (1992), demonstrated that screening had a subtle unintended effect on those identified as ‘healthy carriers’. 7% of carriers wrongly believed that carrying the abnormal gene may adversely affect their future health, and they were less optimistic about their future health compared to non-carriers and the untested control group. This finding highlights the importance of pre and post-test information and counselling. Richards (1996) argued that lay knowledge of inheritance is poor even among people who have received genetic counselling for a recessively inherited condition.

In my experience of counselling in the field of haemoglobinopathies, many couples who already have a child with SCD find it inconceivable that the next pregnancy is also at risk, and some women and couples are inclined to ignore invitations for counselling in the belief that they already have their ‘one-in-four’ affected children, not fully appreciating that the probability of one-in-four chance is with each and every pregnancy. This has implications for genetic decision-making as it is likely that this misunderstanding of genetic probability accounts for some people making what Marteau (1995) described as ‘uninformed choices’. Richards (1996) observed that many will be able to correctly relay information about the probability of having an affected child but not the chances of the child being a carrier or not. It appears people focus on the disease, since the future health of their offspring is the aspect that is of most concern to them. In support of this observation Emery (2001) noted that implications of a carrier status for an autosomal recessively inherited condition can be a difficult concept for lay people to understand. Knowledge of the genetic condition and the ability to grasp statistical concepts, relating to 'probabilities of risk', is a prerequisite for an understanding of genetic information. Once this concept has been grasped an individual will then need to draw on a repertoire of cognitive and intellectual skills to be able to consider what this means for their personal circumstance, in terms of selection of a partner, procreation and future parenting.

It is not uncommon for people to be tested for haemoglobinopathies without their knowledge or informed consent, for example, as part of a battery of tests performed during pregnancy or prior
to being given general anaesthetic because of the associated risks of general anaesthesia, even for those with the carrier state if they are poorly managed whilst receiving anaesthetic. Marteau and Anionwu (1996) and Marteau and Dormandy (2005) noted that uninformed genetic testing is most commonly applied to minority ethnic pregnant women, especially non-English-speaking women. They argued that institutional racism has resulted in the failure of policy-makers to respond to the needs of minority ethnic communities, especially in respect of providing accessible and appropriate screening and counselling services.

Many health care professionals who regard testing for haemoglobinopathies as one of several routine blood tests offered to pregnant women advocate preconceptual testing arguing that it will allow people to make genetic choices at a time where it is assumed will be less stressful and traumatic, i.e. pre-marital. Some of these well-intentioned professionals fail to appreciate that, unlike testing for communicable diseases, genetic testing has many social ramifications that can impact on the individual and their nuclear and extended family. This is especially so in areas of the world where an arranged marriage is common and where the status of women is precarious, such that a woman’s worth and ability to secure a partner may be compromised by preconceptual knowledge of her haemoglobin status by her future husband or his family. Perhaps pre marital testing and knowledge of one’s haemoglobin status may not be in the best interest of many African women, especially until the social attitude to the condition and the status of women in some African societies change.

Genetic testing without the individual’s informed consent opposes the ethical principles that govern genetic testing and the code of professional conduct of many health professions, including that of the Nursing and Midwifery Council (NMC) which states, ‘As a registered nurse, midwife or health visitor, you must obtain (informed) consent before you give any (test) treatment or care’ (NMC 2002). In addition the individual must be given the necessary information to be able to provide an 'informed consent'. Whether this is achieved in antenatal and neonatal haemoglobinopathy screening is questionable.

The Advisory Committee on Genetic Testing (1997) endorses an acknowledgement that genetic testing has greater ramifications than other clinical tests since it reveals information about other family members. Emery (2001) describes a scenario which illustrates this succinctly. A man was aware of a history of a sex-linked genetically inherited condition in his paternal line. His father was reluctant to be tested but the man himself went for testing, which confirmed that he had the
gene for the condition. He had evidently inherited it from his father and had therefore inadvertently subjected his father to testing, without his consent.

The decision to be tested for a genetic condition should be fully explored with the individual prior to testing and discussion must include the possible health, social, psychological and emotional impact of a positive result not only to themselves but also to their nuclear and extended family. In my experience, whilst advocating premarital and preconception genetic testing few testing centres explore the potential social ramifications with the client.

Some of the dilemmas inherent in increasing access to genetic information pose challenges for society. As highlighted by the British Medical Association (1998), with greater access to new genetic information there are many positive opportunities, but the greater opportunity to choose also brings painful dilemmas which people have never had to deal with in the past and for which they are poorly equipped. Specialist support is required in future if the developments are to be as beneficial as it is hoped they will be. Policy-makers must take into account issues wider than health and health services.

Richards (1996) proposes the need for greater research into family perspectives on genetics and genetic services. I endorse this proposal and add that it is imperative that we begin to examine the impact of genetic knowledge and services on a multiethnic, multicultural and diverse society, rather than assume that all members of a society require or want a service in a format that suits the dominant cultural group of the society. Most of the research identified in an extensive search, examined the impact of genetics on western communities and few considered multicultural perspectives. This current study will contribute to the sparse body of knowledge on cultural and lay perspectives of genetics and I hope further studies will follow.

Cote (1982) claims that the terminology used in counselling and patient information literature has an impact on people’s perception of the condition. For example, a commonly used term in the field of genetic medicine is being ‘at risk’ which suggests harm, danger, doom and possible gloom. Even the term ‘abnormal’ can initiate negative feelings towards not only the pregnancy but towards self for making an ‘abnormal’ child. This was illustrated in the finding of this study where one respondent felt a sense of shame and failure for producing ‘abnormal’ children. There may be other feelings that these terminologies evoke and these may create, guilt, fear and
anxiety, which may instigate a feeling that one ought to terminate what society perceives as ‘undesirable’ i.e. an affected pregnancy, an abnormal child.

### 2.2.3 Perception of risk and genetic decision-making

Black and minority ethnic populations account for 6% of the total UK population. In some London Boroughs, for example the NW London borough of Brent, the lead centre for this current study, they represent 53% approximately (DoH 1998) and this is probably an underestimation in view of the number of unquantifiable illegal immigrants residing in the borough. Unless one witnesses a major change in the acceptance of pre-natal diagnosis and subsequent termination of an affected pregnancy the population with and at risk of SCD is expected to increase significantly (Streetly et al. 1997).

The Department of Health in England proposed the establishment of a national linked haemoglobinopathy antenatal and newborn screening programme (DoH 2000: 109). In autumn 2006 the national sickle cell newborn screening programme was fully implemented: all babies born in England are offered testing for SCD irrespective of the child’s family racial origin or ethnicity. A strategy is also being developed for the implementation of the national antenatal screening programme, which will be fully operational by the end of 2007. Those in the specialist field applauded this government initiative because it marks the beginning of a new era and offers a unique opportunity for service providers to tailor genetic services to the needs of their local multiethnic population. Especially in London where 40% of the population is of minority ethnic origin, and more in some borough wards, for example, Tokyngton Ward in Brent where they account for 75%. However, some professionals welcomed the news with some reservation because the minority ethnic population’s response to genetic testing, counselling and its impact on their social lives has not been evaluated despite almost thirty years of testing for haemoglobinopathies in the UK.

Will those implementing the policy take into account and be sensitive to the values, beliefs and cultural practices of those being offered haemoglobinopathy testing? Are policy-makers being paternalistic in providing a service without ascertaining whether the communities they purport to serve want the screening service, and if so, in what format? Many would argue that the benefits
of neonatal screening is unquestionably justified since it allows for early identification of babies with SCD and for early prophylactic interventions, which can prevent the associated high rates of morbidity, mortality and handicap; antenatal screening is also of significant value since it allows women and couples to make informed decisions about an at-risk pregnancy, irrespective of the decision made.

Two Health Technology Assessments, Davies et al. (2000) and Zeuner et al. (1999), and findings from a number of other publications were presented at a national Sickle Cell & Thalassaemia Conference held in London in May 2000. The conference opened an important debate among health and allied professionals on, the question: ‘Is there any value in screening pregnant women for sickle cell?’ The debate arose because since 1979 a significant proportion of health authorities in London have provided non-selective comprehensive antenatal screening for sickle cell and thalassaemia. However, this has not reduced significantly the number of babies born with SCD, since few women and couples opt for PND and the termination of an affected fetus; on the contrary the number of babies born with the condition is steadily increasing.

In the UK, specialist centres are located in areas where there are a high proportion of minority ethnic populations, this being the group identified as being at greatest risk of SCD. Some centres have provided non-selective antenatal screening dating back to the late 1970s and non-selective neonatal screening since late 1980s. Such centres include the Council boroughs of Brent, Haringey, Hackney, Islington, Lambeth, Manchester, Birmingham and Liverpool. However, none of these programmes have been evaluated formally, especially in terms of the recipient's attitude to and response to the screening programme. I maintain that an evaluation would have been invaluable prior to implementation of the government proposal.

Pregnant women are screened routinely for a myriad of conditions when booking for confinement of pregnancy. Blood tests to determine a woman's blood group, to exclude infections such as syphilis, HIV and other potentially serious infections are considered routine to ensure the health and safety of the mother and child. Most pregnant women accept antenatal tests without questioning and assume that such tests are done in the best interest of themselves and their unborn baby. Many hospitals in London and other major cities in the UK include genetic screening for sickle cell, thalassaemia and related genetic disorders in the battery of blood tests carried out on pregnant women routinely. There is no evidence that these are being done with the women's informed choice and consent. Marteau and Anionwu (1996) argued that because of a
covert and sometimes overt drive to reduce the number of babies born with a disease, greater emphasis is placed on attempts to achieve a high uptake of screening whilst less emphasis is placed on enabling people to make an 'informed choice'.

Observation in clinical practice led me to believe that a significant proportion of women are not aware that they are being tested for haemoglobinopathies and only those who have a positive result when subsequently invited for genetic counselling become aware. This is likely to occur and is most common when screening minority ethnic women, especially those who do not speak English (Marteau and Anionwu 1996). This suggests a lack of cultural sensitivity on the part of service providers and fails to take account of the legal requirement to provide equal treatment for all irrespective of social differences. ‘Cultural competence’ and ‘cultural sensitivity’ have become buzzwords of the National Health Service but few health professionals actually demonstrate the qualities (Gerrish et al. 1996, Camphina-Bacote 1997, Culley and Dyson 2001, Dreher and MacNaughton 2002).

In a study of people’s perception of health risk following testing for Tay-Sachs, a genetic disease found more commonly among Jews than any other ethnic group, Marteau et al. (1992) compared the perception of the health of those with normal results and those with healthy carrier states. They demonstrated that the latter group, despite counselling and being told they have a ‘healthy carrier state’, perceived their health status as being at risk in future. The authors argued that there is a need to measure knowledge and belief when attempting to clarify people’s perception of their current and future health, especially when they have been subjected to genetic testing. Information about being a carrier may not always be perceived as ‘healthy’ especially long term.

Atkin and Ahmed (1998) argued that sufficient information about reproductive options will lead to prevention, and a failure to provide women with adequate information reduces the possibility of preventing the births of babies with SCD. However, this argument ignores the assertion that responsibility for reproductive decision-making brings increased anxiety and guilt, which may deter women and couples from making a decision at all, irrespective of what that choice outcome will be. Perpetuating the medical model of health promotion Atkin et al. (1998) assume that people always make what is considered the 'right' or 'rational' decision in light of sufficient information and evidence.
In respect of testing for genetic conditions, Duster and Beeson (2007) who studied African-American families at high-risk of sickle cell and White-Americans at high-risk of cystic fibrosis found that although respondents claimed to advocate partner testing, few avail themselves of this option, appearing to demonstrate an element of overt but more often unspoken and covert resistance to testing. A failure to make an appointment for testing is a typical example of this resistance. And even where testing had identified a carrier state, few people communicated this information to a prospective partner and the information was not used as a basis for future choices with regard to selecting a partner or childbearing. This is a common experience which was also observed in the UK and will be seen later as a feature identified in this current study.

Richards (1996) stated that although we do not know to what extent knowledge of genetic disorders affect marital choices, it is highly unlikely that individuals will choose not to marry on this account and that it is unlikely that a prospective partner of someone found to be a carrier will choose not to proceed with the marriage when they find out about the genetic condition in a partners family. However the couple may choose not to have children in order to avoid having an affected child. I suspect this may be the case in the attitude of Europeans but highly unlikely among minority ethnic groups especially Africans as we shall see later, the idea of choosing not to have children or knowingly marrying someone who places one at risk of having a child with SCD I argue is highly improbable in view of many African society’s attitude to SCD.

Duster and Beeson again noted ‘in myriad ways respondents make it clear that they view the use of carrier testing as a factor in partner selection as incompatible with what impels them to have a relationship, the expressed experience of love; once the crucial decision of choice of a mate has been made, genetic testing has direct relevance for reproductive planning’ (Duster and Beeson 2007:21). It will be interesting to see whether the finding of this current study supports that observation and whether the African and Caribbean at-risk groups in Phase 3 express similar views.

Hoffmaster (1990) argued that foreknowledge does not necessarily result in an outcome that is considered a rational decision. When making a decision prospective parents tailor the decision by linking it to their own situation. Rather than applying impersonal moral norms, statistics and probabilities parents take into account a number of what they consider important factors, such as their emotional state, financial circumstances and the social context in which the decision is being made. They personalize the decision-making in an attempt to reach what may be a morally
acceptable solution for them personally. Morality in this context relates to a consistent rationally justified system of norms that are applied to the facts of a problem to generate solutions.

Lipman-Hand and Fraser (1979) examined how prospective parents made moral decisions after receiving genetic counselling. They argued, ‘...moral decision-making is essentially a matter of finding an approach that allows one to cope with the nature of the problem’. A moral decision is not a universal concept and what is moral or amoral for one individual, family, culture and society will not necessarily be the same for another. Hence some individuals or groups may, when offered PND with a view to terminating an affected pregnancy, feel it is immoral. Lipman-Hand and Fraser (1979) also claim that at-risk parents tend to reduce probabilities into binary values, the likelihood of something happening or not and then search for a least loss option, i.e. the option where the minimum-maximum loss would be most acceptable to them. The prospective parents play out a scenario of how they would cope in practical terms with the least and the worst-case scenario. Where there is no least-loss option Lippman-Hand and Fraser argued that it is then not psychologically possible for parents to make a decision, they sway between various options but feel unable to reach a decision.

There is some ‘resistance’ to genetic testing even in families where genetic risk has been established. The use of the term resistance in this context refers to a socio-political act. In an attempt to avoid making what is considered the ‘right’ decision a woman or couple may adopt a discourse of not understanding the genetic information given or of the genetic implications of their predicament. Duster and Beeson (2007) observed that twenty of the African-American mothers of children with sickle cell confirmed that they knew their carrier status prior to the birth of an affected child, but they did not attempt to avoid having an affected child. This raises the question ‘why do individuals not utilise the information to make what Marteau (1995) calls an informed choice?’ Perhaps choosing not to use the information is a choice, irrespective of whether the individual acknowledges and admits that the choice was made consciously. Perhaps this is a response to the dissonance caused by the information, and avoiding making a decision helps to alleviate the dissonance.

In a study of 29 low-income African-American women who already had a child with SCD and were at risk of having another in a subsequent pregnancy Hill (1994a) demonstrated that although 79% of the women knew from a previous pregnancy that they were at risk of having another child with SCD, and had been told to contact the genetic health centre as soon as they
were pregnant again so that they can access services and make informed choices as early as possible in the subsequent pregnancy, the majority failed to make contact and waited until they were recalled by the health services. The women reported that they were not aware that they could present early and without being re-invited by the health clinic, despite their being given such instructions. Hill’s analysis concluded that the women positively obfuscated the health and genetic knowledge they had been given in the previous pregnancy. Hill concluded further that the women ‘obfuscated’ knowledge in their attempt to avoid having to make a decision about the current pregnancy. Others attributed their lack of action to their mistrust of the genetic and medical information that they had been given previously and a mistrust of those who gave it to them i.e. health care agents.

Hill proposed that another reason for the women’s obfuscation is the women’s psychological need to have some control over their fertility. The ability to have children, albeit unhealthy children, gave many of the low-income women some power, at least in this one area of their life, that is, the ability to reproduce; an area which is strongly endorsed by the African-American community as an important aspect of womanhood. To relinquish this important aspect may be perceived by the women as diametrically opposed to their socio-cultural values (Smaje 1995, Schott and Henley 1996). It is interesting to note similar attitudes in African communities as highlighted by Maclean (1978), Madu (1994) and Jegede (1998).

Hill did not explore the historical context in which knowledge about sickle cell evolved in the USA, or the way in which social research into the condition developed globally, or the socio-cultural issues that may help explain the actions or inability to act and the reproductive decisions made by this group of women. Tapper's (1999) account of the historical aspect of sickle cell screening and development of services not only in the USA but worldwide, and Anionwu and Atkin’s (2001) account of the history of sickle cell provide an explanation for some of the Black women's mistrust of policy-makers and health care providers. This is in the context of African-Americans awareness of some of the atrocities perpetrated by health researchers for the sake of science, discriminating against African-Americans by conducting unethical research on an unsuspecting community. There was for example, the Tuskegee Syphilis Project (Tapper 1999, Duster and Beeson 2007) in which African-American men were denied treatment by federal researchers in order to examine the long term impact of syphilis. Even as the men went blind and insane treatment was withheld.
Shiloh (1996) recognizes that during decision-making what people say they will do and what they eventually do can be inconsistent. During genetic counselling some women may express a wish for PND, but then fail to attend the appointment for the procedure. There may be differences in attitude, intention, decision and eventual behaviour. Shiloh (1996) reporting on a study of Down’s Syndrome conducted by Evers-Kieboom highlighted that 66% of those identified, through family studies, as being at risk of having a child with genetically determined Down’s Syndrome, said if a genetic test had been available they would have a test to identify whether they had the gene for the disorder. However, when the test became available some time later only 11% of the same group of people agreed to being tested. Shiloh also alluded to gender differences in decision-making and claimed that men, more than women, were more opposed to having an abnormal child. Similar observations were made by Beeson and Golbus-Mitchell (1985), Sorenson and Wertz (1986) and Marteau (1995).

Duster and Beeson (2007) in a study of cultural attitude of African-Americans at high-risk of sickle cell and White-Americans at high-risk of cystic fibrosis noted that men demonstrated greater embarrassment and shame about carrying a genetic mutation than women. Few men relay their carrier status to prospective partners and where their child is born with a recessively inherited genetic disease few men accept their contribution to the child’s disease. But the authors did not clarify whether this observation was the same in both the African-American and White-American families. It is a phenomenon frequently observed in the sickle cell services in the UK, and extends to both the African and Caribbean populations. In contrast, Durosinmi et al. (1995) reported a study of Nigerians’ attitude to sickle cell, in which women were less accepting of having a child with SCD than men. I propose that the social status of women in the Nigerian cultural context and the societal environment probably accounts for this opposing finding.

In discussing haemoglobinopathy and other genetic testing proposals a number of questions need to be posed. Will preconception testing affect the marriage prospects of members of society where arranged marriage is a cultural norm? What about the high proportion of women who conceive outside of marriage? Will individuals, especially minority ethnic women, have the courage to inform prospective partners of their carrier or disease status at a point in the relationship when it will still be possible to make alternative choices? Noting that this is a point in the relationship when their position is untenable, to disclose such sensitive information may be counterproductive to their aim of finding a suitable partner based on other social measures.
Fichtner et al. (1996) examined the influence of perceived and assessed risk on sexually transmitted disease outpatient clients, their acceptance of HIV testing and likelihood of returning for the test result. They found that people’s perception of their risk is the greatest predictor of acceptance of testing. In the population studied 40% of those who perceived themselves to be at-risk opted for HIV testing, whilst only 28% of those who were objectively assessed by health carers and found to be ‘at risk’ opted for HIV testing. In the study population it was reported that although Black men were assessed as being at greatest risk only 35% attended for their post-test result counselling, compared to 61% of White and 49% Hispanics who were assessed to be at lower risk. Black men perceived themselves as low-risk and consequently did not see the importance of attending for test result counselling. The reasons for this variance were not examined but the researchers asserted that the Black population’s mistrust of government agencies may be contributing to their failure to attend. This is similar to Hill’s (1994a) report of mistrust of health agencies.

Dorticos-Balea et al. (1997) conducted a follow-up study of 343 couples in Cuba who already had a child with SCD to find out how they had used the genetic information and counselling that they had been given between two and eight years after initial diagnosis of their genetic status. The couples were at-risk of having another child with sickle cell anaemia (HbSS) or sickle haemoglobin C disease (HbSC). The researchers observed a mistrust of government policy-makers and health agencies, similar to Hill’s (1994a and 1994b) finding among low-income African-American women. Although racism was proposed as one of the possible explanations in Hill’s African-American study this cannot be the case for Dorticos-Balea et al.’s Cuban group where racism is presumably not an issue since they are indigenous. Therefore there are likely to be other factors contributing to the mistrust of government agencies in the Cuban group. Many of these studies failed to examine the socio-cultural issues, which may help explain the attitude of their populations. The Black populations’ response to genetic testing is perhaps, in part, a reflection of their cultural attitude to coupling, marriage, procreation, pregnancy, parenthood, disease and illness. I argue that people’s perception of risk may be linked to their perception of disease burden. Secondly, perhaps a failure to attend for follow-up is also a psychological defence and an avoidance of what could create psychological distress.

Shiloh (1996) suggested that the way in which risk is presented influences decision-making. If emphasis is placed on the likelihood of having a child with a genetic disorder the counsellee is more likely to reject the pregnancy. But, if the risk is presented with emphasis being placed on
the likelihood of the child not having the condition, the pregnancy is more likely to be accepted. If this argument is true it suggests that in explaining the autosomal recessive inheritance of SCD to a couple who both have sickle cell trait, if emphasis is placed on the 75% chance of the child not inheriting the disease and less emphasis is placed on the 25% chance of the child inheriting the disease the woman or couple are more likely to accept the pregnancy. This hypothesis will require further investigation.

In a study of antenatal women Sherr et al. (1996) argued that a positive HIV test did not affect the majority of the women’s decision to conceive children. They argued:

…the way in which information is framed will affect choice, and losses loom larger than gains in decision situations…negatively framed information concerning transmission risks is taken as a stronger indicator for termination than is positively framed information.

(Sherr et al. 1996: 108-109)

This is in keeping with Cote’s (1982) assertion that the interpretation of genetic probability is subjective and depends on the personal view of the disease as formed by the individual, ‘it is the feeling of being at-risk that counts rather than the mathematical figure’ (Cote 1982).

Women who perceive themselves as powerless in a society and have no prospects other than their ability to conceive may perceive their potential ‘losses’ i.e. not having children because of the genetic risk, as unacceptable. This is amply illustrated in the response of the African Antenatal women interviewed in Phase 3 of this current study. This again supports Hill's (1994) observation of African-American women who obfuscated their knowledge in a possible attempt to justify their unspoken decision to risk having a child with SCD. The way in which genetic information is conveyed to women, and by whom will also influence their response to the information. Discussing approaches to counselling, Green and Statham (1996) claim that the content of the counselling session, the aim and approach differed when conducted by obstetricians, geneticists and genetic counsellors. Richards argued that ‘the decision to have a child (with a genetic condition) may be encouraged by statements from the research community about a possibility of future breakthroughs in treatment or even cure’ (Richards 1996).
In a study of antenatal women offered testing for Down’s syndrome Marteau et al. (2001) found that of the 42 women sampled 24 had made an uninformed choice for or against being tested, a choice that was inconsistent with their stated values and judgement about the test. The authors conceded that appropriate knowledge and a positive attitude towards undergoing a test should result in selection of testing whilst a negative attitude towards a test should result in decline of the offer of testing.

In opposition to this argument in an exploration of attitudes and behaviour Kashima et al. (1992) argued that it is a fallacy that these two concepts, ‘attitude’ and ‘behaviour’ work together consistently. They argue that the level of consistency between attitude and behaviour is dependent on whether the individual originated from an interdependent or independent society and culture. In an interdependent society the individual will take into consideration the impact that his action will have on the family, cultural group, community and society and as a result may behave in a way that is inconsistent with his personal belief, attitude and values, preferring to sacrifice consistency for the sake of interpersonal accommodation.

Conversely in an independent society the emphasis is on the individual and it may require legal sanctions to force the individual to consider the group, community or society. In an independent society a person who acts in opposition to their values and beliefs will often experience and demonstrate a certain degree of dissonance whilst one from an interdependent society will feel comfortable with inconsistencies provided he has done what he perceives as the ‘right thing’ for the benefit of the family, group or society. This observation of culture was found in Wrightson and Wardle’s (1997) study of South Asian societies where they argue that the preservation of social harmony often results in individuals responding positively to something that they do not necessarily agree with. It could be argued that the majority of African communities reflect the interdependent societal way of being whilst, due to a strong European and other western influence, the majority of Caribbean communities especially those of third and fourth generation migrants living in the UK demonstrate independent characteristics similar to the host population.
2.2.4 Is non-directive genetic counselling possible?

With recent mapping of the entire human genome the application of genetics to a wide range of medical conditions is unprecedented. The use of genetic counselling has increased dramatically over the last twenty years and it is predictable that it is likely to reach mammoth proportions over the next ten years. Counselling is an interaction, which allows individuals, couples or groups an opportunity to examine and clarify their problems and identify ways of adjusting to them or finding a solution which will ameliorate the problem (Freshwater and Maslin-Prothero 2006). Genetic counselling is an extension of this process, but focuses on enabling an individual, couple or family to understand the nature of the genetic condition identified and the options available for dealing with the information, which include an acceptance of the presence of the condition and, or finding a solution which will secure an eradication of the problem, including options available in terms of childbearing (British Medical Association 1998).

A variety of health and allied professionals fulfill the role of genetic counselling, some of whom are trained specifically for the purpose, primarily genetic counsellors and geneticists, whilst others are generalists offering the service in a variety of care settings. The skill required to undertake genetic counselling is often underestimated. The possession and effective use of such skill can and often does influence clients’ understanding and genetic decision-making, enabling them to gain understanding and make decisions which reflect their values and beliefs, and not merely those of the person offering counselling. This is crucial for allowing the client to deal with the social reverberations that may follow their decision.

The espoused theory in genetic counselling is that practitioners should apply a non-directive approach to the process. It is generally accepted that being non-directive means the counsellor should be unbiased with the content of the information given to the client and in the manner in which the information is imparted. This includes verbal and non-verbal cues. Of utmost significance is that the counsellor leaves decision-making to the counsellee. Some will argue that being ‘non-directive’ is unattainable, every human interaction involving two or more persons, no matter how carefully executed has an impact on all parties involved and the interaction will have some influence on the players’ perception and possibly their behaviour.
Shiloh (1996) argued that being non-directive is not possible since neutrality is unachievable. The way an individual presents the information, such as how serious they portray SCD will affect the counsellee’s perception of the condition. I propose that counselling and being non-directive are contradictory in terms by virtue of the process being a human interaction to which each participant contributes their own attitude, values and perhaps experiences, and no matter how careful the counsellor is to conceal their own opinions, values, attitude and prejudices, certain elements will filter through.

Clarke (1991), a clinical geneticist, challenges colleagues to defend the traditional stance of non-directive counselling. His argument is that being non-directive is not possible and this is supported by Emery and Hayflick (2001); they argued that counselling is an interactive process, it is impossible to maintain neutrality in an interactive encounter. Inevitably one person will influence the other, in terms of the words used, the body language, what is chosen to be said or not said, expectations, preconceived ideas and the state of each party’s mental state during the period of interaction. Emery asserted that since this traditional stance of non-directive counselling is unattainable shared decision-making is a viable proposition.

Shiloh (1996) argued that non-directive genetic counselling may be unacceptable to some women, who expect and demand joint decision-making with the support and involvement of those they consider experts, such as the doctor or genetic counsellor. This does not imply loss of control necessarily, but self-determination to choose what they consider a viable option i.e. shared decision-making. She argued that being non-directive is not desirable in a helping therapeutic relationship and some clients consult health experts to gain information and get their problem solved and given a choice they will prefer to take a more passive role in the decision-making. In view of this the genetic counsellor needs to assess the need to facilitate the client’s decision-making, giving some direction to enable the client to ‘reach a decision wisely rather than reach a wise decision’. The passive role which counsellors currently take will need to change as they engage more and become facilitators in the decision-making process. Hence Shiloh (1996) argued ‘genetic counsellors (need) to acquire expertise in decision-making theory and counselling techniques aimed at helping clients reach a decision’.

Although many service providers, especially genetic counsellors and specialist nurses, claim to be neutral, non-directive and non-judgemental they are often confounded when women exercise their freedom to choose not to attend a genetic counselling appointment or are resistant to the
type of information the counsellor has predetermined that the client needs. In many specialist centres there is a rate of 30% to 50% non-attendance of antenatal women for genetic counselling and although this is very frustrating for service providers it is perhaps a reflection of the women exercising their right not to wish to hear the information being offered.

Richards (1996) noted that women and couples ‘may avoid contact with genetic counsellors because they do not wish to hear the expected advice’ (Richards 1996); a common response to dissonance as described by Eagly and Chaiken (1993). In 2003, the data from Brent Sickle Cell and Thalassaemia Centre’s unpublished report demonstrated that 42% of antenatal women identified with a haemoglobinopathy failed to attend their genetic counselling appointment. However, it was noted that some of these women were counselled in a previous pregnancy and perhaps did not feel a need to have the information repeated, especially those whose partners had tested negative, thereby placing them outside the area of risk. Declining the offer of counselling is a viable option and demonstrates a woman’s or couple’s ability to make what constitutes an alternative informed choice, especially once the care provider has ruled out other causes of non-attendance, such as failure of postal services. Women and their partners should feel comfortable declining the offer of counselling, provided they have made an informed choice. However re-education of the community is required for individuals to cancel unwanted appointments so as to reduce wastage of health service resources.

Robinson et al. (1989) highlighted that the health care professional who provides the genetic counselling influence prospective parents’ decision in respect of PND. In their study 39% of those counselled by genetic nurse counsellors opted for PND whilst 67% of those counselled by general medical practitioners (GPs) opted for PND, demonstrating that perhaps the GPs in the study were being more directive, supporting lay perceptions that ‘the doctor knows best’. It is possible however that the information presented by the doctor was done in a way that enabled parents to make a truly informed decision because they received a more realistic clinical picture of the condition from the GPs. Perhaps the genetic nurse counsellors, presumably these are non-specialist counsellors, having had little or no exposure to the reality of the clinical and potential health implications of the condition may have inadvertently minimized its seriousness. It will be interesting to note whether women and couples in this current study felt any sense of coercion since the majority would have been counselled by a specialist nurse counsellor, and whether this impacted on their decision-making in Phase 3 of the project.
Marteau et al. (1994) supported by Green and Statham (1996) observed that when offering genetic counselling to pregnant women obstetricians were more directive than geneticists, and geneticists more than genetic nurse counsellors, especially when discussing options of PND and termination of an affected fetus. It is reported that obstetricians hold the view that affected pregnancies should be identified and preferably terminated, whilst midwives and genetic nurse counsellors tend to be of the opinion that women and their partners should make the ultimate decision and not be influenced by health practitioners.

Clarke (1991), a clinical geneticist, asserted that those who provide genetic services but are not directly involved in care and treatment are not able to offer firsthand clinical information about the condition or about care and support available for those born with it. Clarke argued that without firsthand knowledge of the clinical aspects of a condition clinical geneticists could not genuinely demonstrate impartiality for termination of an affected fetus. Clarke attributed the success of haemoglobinopathy screening to the involvement of clinicians who treat and manage patients with the condition; they have in depth knowledge of the disease and are better able to provide a true picture of the health and social impact.

Anionwu (1996) proposed that the cultural origin of the counsellor should match that of the client in order to promote a better therapeutic relationship and experience for the client and create an ideal for meeting the client’s cultural needs. This proposition, although commendable, may be perceived as impractical in a multicultural society where the likelihood of being able to culturally match all clients and counsellors will prove unattainable. Maclachlan (1997) stated that because two people are from the same culture does not guarantee cultural similarity. Developing health care systems that accommodate cultural diversity and training health care professionals to provide culturally sensitive care, irrespective of the client’s cultural background, is a more realistic proposition.

Provision of a screening service supported by the availability of selective termination of an affected fetus is itself directive. Offering a test during pregnancy conveys the message that the condition is ‘serious’ enough to warrant offering testing and termination. Whether one has a true choice during pregnancy is debatable. Green and Statham (1996) maintain that following PND and choosing not to terminate an affected pregnancy there are no other options open to a woman except ‘inaction’, and the human psyche does not comfortably support a state of inaction, knowing that they are carrying an ‘affected’ child.
I propose that whilst awaiting the birth of an affected baby some women may demonstrate overt or covert psychological distress. It is possible that during this period women may create negative psychological images of the unborn child in their minds, whether this will subsequently affect maternal and child bonding will require future investigation.

2.2.5 Prenatal Diagnosis – to test or not to test?

A number of papers propose that Black women who are aware that they carry sickle cell trait and are potentially at risk of having a child with SCD are less likely to seek partners that will eliminate their risk of having an affected child, i.e. choose a partner with normal haemoglobin (HbAA). In addition they rarely choose not having children; few opt for PND or termination of an affected fetus. In comparison White and other non-Black women who are at-risk of having a child with other haemoglobinopathies, for example, beta thalassaemia major and other genetic conditions are more likely to choose these options (SMAC report 1993, Petrou et al. 1992, Modell et al. 1997, Greengross et al. 1999, Weatherall 1991). Despite genetic counselling only approximately 25% of Black women at risk of having a child with SCD opt for PND (Anionwu et al. 1988, Modell et al. 1997).

In Petrou et al.’s (1992) review of factors influencing the uptake of PND during 1979 and 1990 they reported that of the 170 couples referred to a London tertiary centre 52 % accepted PND and 82 % of those who attended during the first twelve weeks of pregnancy opted for PND whilst only 49% of those who attended in the second twelve to twenty six weeks opted for PND. 52 % of the total number of women referred opted for PND and 90 % of these had a child with SCD already; 94% of those with an affected pregnancy opted for termination of the pregnancy, and more Africans than Caribbeans accepted the offer of PND. The higher proportion of women opting for PND in the Petrou et al. study is probably due to this being a fetal diagnostic centre, a tertiary unit where a significant proportion of the women would have received primary genetic counselling from a genetic counsellor at one of the specialist sickle cell and thalassaemia centres prior to referral to the tertiary unit, invariably only women who have opted for PND already or are undecided would be referred to the tertiary unit, not those who have declined for a variety of reasons.
Petrou et al. (1992) observed a notable difference in the social class of the clients opting for PND. The better educated, higher social class women and couples were more likely to opt for PND than those less educated or of a lower social class. This is similar to Duster and Beeson’s (2007) finding. Petrou et al. also observed that more Africans than Caribbeans opted for PND. However, it could be argued that this is probably as a result of differences in prevalence of sickle in each ethnic group, Black Caribbeans 3.6/1000 births result in a child with SCD annually, whilst 15.6/1000 births occur in Black Africans (DoH, SMAC 1993). Alkuraya and Kilani (2001) did not observe educational differences in the Saudi Arabian families studied, however, all those sampled were only educated to primary level education, the homogeneity of the population limits the possibility of finding a significant difference in relation to education.

Duster and Beeson (2007) in their research of families with sickle cell and cystic fibrosis found that, in the latter group, having an affected close family member influenced the respondents’ attitude to having PND and termination of an affected pregnancy because to consider such options they perceive will be interpreted that they do not value the life and existence of their existing child or sibling who has the condition. They found that the stronger the bond with the affected individual the more difficult it is to opt for PND or contemplate termination of an affected pregnancy. However, those who are highly educated did not express such difficulties but none of them were in the at-risk predicament. It will be interesting to note whether respondents in the current study express similar sentiments or not and whether there will be differences in the two cultural groups.

The variation in up-take of PND and termination of an affected fetus between those at risk of sickle cell and beta thalassaemia major in the UK suggests that the impact of the sickling condition was considered by at-risk couples to be less of a burden than the burden perceived by those at risk of beta thalassaemia. This perception is probably the result of how information about the conditions was presented, but also more importantly, due to the unpredictability of the clinical severity of SCD compared to the more predictable clinical severity of beta thalassaemia major. Dryden in Green and Statham (1996) noted that the degree of burden caused by the disease influenced parents’ decision-making. The opposite was found in Alkuraya and Kilani’s (2001) study of Islamic Saudi families who were at-risk of having a child with SCD. The latter reported that the burden of disease did not appear to influence the decision to have PND or termination of an affected pregnancy, though the Islamic religion did.
A number of authors postulated that the reason for not opting for PND, or contemplating termination of an affected fetus, include advanced gestational age at initial presentation, marital status (where single women were more likely to opt for PND and termination of an affected fetus than married women) and finally religion (Weatherall 1991, Hill 1994b). Others reasons include perceived future prospects (accomplishment) of an affected child, perceived severity of the disease, an unwillingness to terminate an affected pregnancy (influenced choosing PND), woman or couple’s siblings approval of abortion, existence of a previously affected child, woman’s age, reproductive plans (total number of children wanted), position of affected child in the number of children born already (if first born or subsequent child). Following PND in some cases decisions about termination is also influenced by the gender of the fetus with more affected females than males being terminated (Petrou et al. 1992, Green and Statham 1996, Shiloh 1996). This is perhaps a reflection of cultural attitudes. Many African, Asian and other cultures appear to value sons more than daughters especially a firstborn child, they may be more prepared to overlook the disability if they perceive that gender has compensated adequately for the disability.

In Dorticos-Balea et al.’s (1997) follow-up study of 343 couples in Cuba who already have a child with SCD they examined the couple’s attitude to PND. 9% had a subsequent pregnancy, of these 44% attended spontaneously for PND; 44% waited to be re invited for genetic counselling and offer of PND. This was despite knowing that they were at-risk and having been told in a previous pregnancy that they should present to the medical centre as soon as another pregnancy is established so as to maximize their options in respect of making a decision about PND. However, following re-appointment and counselling 88% of the late presenters opted for PND. The authors claim that the women who waited ‘passively’ to be re identified claimed that they did not know that they could attend spontaneously. The authors argued that the women’s procrastination is more likely to be a case of the women “hiding behind alleged forgetfulness” and that the true reason for failure to attend is the women’s fear and reluctance to make a decision about the pregnancy. This is similar to Hill's (1994a and 1994b) study of low-income African–American women. Hill reported that the women had obfuscated their medical knowledge of sickle cell and their awareness that they could avail themselves of specialist services as early as possible once another pregnancy was established.

In Dorticos-Balea et al.’s (1997) study uptake of PND was found to be significantly higher among educated women, and they tended to present earlier in pregnancy, they also formed a significant proportion of those who attended spontaneously without waiting to be re invited. This
supports Petrou et al.’s (1992) assertion that the better-educated women are more likely to present for PND than the less educated women. Could this finding be due to other social factors, such as stigma and a threat to one’s status in society and the practicality of caring for a child with a health limiting ailment when one has a career to consider? Similarly, women who have had a previous “bad” experience, such as a previously affected pregnancy or couples who already have a severely affected child also opted for PND. Of the total study population 22% of the couples had separated, of these 9% reported that the separation was as a result of the genetic risk. Of the 78% who remained in the at-risk relationship 63% had decided not to have any more children. 27% of this 63% reported that the reason for their decision was based on the fear of having another affected child and 4 % were concerned about the risk of miscarriage posed by having such an invasive procedure as PND. It was unclear how many had made the decision not to have any more children because they had already reached their desired family size.

Dorticos-Balea et al. (1997) also observed that it is difficult for parents who are at-risk of having a child with SCD to make a decision about an already established pregnancy or plan another pregnancy without anxiety. This is because of the difficulty of predicting the severity of SCD. One cannot reliably predict whether in a given individual it will present as a mild, moderate or severe disease, with the potential of it being debilitating and fatal.

The Human Genetics Commission in the UK stated that the ‘majority of those whose fetus is diagnosed with a serious condition decide to terminate the pregnancy’ (HGC 2006). This is not reflected in Duster and Beeson’s (2007) study among those at risk of having a child with SCD or cystic fibrosis, where the majority of those who said they would opt for PND said they would do so in order to prepare for a sick child and not to terminate an affected pregnancy.

In a study by Dryden et al. and reported by Green and Statham (1996) 93% of women opted for PND in the case of chromosomal abnormality which is known and proven to have severe clinical consequences, compared to only 29% of women where the prognosis is unknown or unclear. This is clearly demonstrated in the different decisions made by those at risk of having a child with beta thalassaemia major, where the majority opted for PND and termination of an affected pregnancy compared to those at risk of having a child with SCD where the majority do not appear to opt for termination of an affected pregnancy (Modell et al. 1997), as we shall see later this is amply demonstrated in this current study.
In a public consultation conducted by the Human Genetics Commission (HGC) (2006) it was noted that even women who are considering PND many are doing so in order to prepare for a sick child and not necessarily to terminate an affected pregnancy. Green and Statham (1996) noted that in offering PND to at-risk women obstetricians are seeking an abnormality whilst the women, are seeking reassurance that there is no abnormality. Secondly, obstetricians assume that women are opting for PND in order to have a termination of an affected pregnancy, but the majority of women have the test in order to allay their anxiety and where the result is positive to mentally and practically prepare for an affected child.

In contrast, many health care professionals consider limiting the use of such invasive diagnostic procedures to women who are contemplating termination of an affected pregnancy, professionals argue that such procedures places the fetus at unnecessary risk of miscarriage (1%) and it is a waste of resources if the procedure is being carried out purely to enable women to ‘prepare’ for a potentially sick child (HGC 2006).

Attitude to abortion does not predict attitude to PND. Policy-makers may argue that funding a screening programme for the purpose of giving women reassurance or time to prepare for the birth of a disabled child is a waste of resources and one that society cannot afford. The decision to terminate an affected pregnancy creates a distressing dilemma for women and their partner. The acceptance of PND for the haemoglobinopathies and thalassaemia vary. Those at risk of having a child with alpha or beta thalassaemia major are more likely to accept PND compared to those at-risk of having a child with SCD (Petrou et al. 1992). In Jones et al.’s (1988) study, a cohort of Jamaican women expressed a preference for first trimester antenatal diagnosis and possible termination of an affected pregnancy. However, the authors acknowledge that the use of PND in this cohort of women would not necessarily reduce the number of children born with SCD. The reason for the women opting for PND is not to necessarily terminate a pregnancy but to prepare for the arrival of a ‘sickly child’. This is a similar finding to that in Duster and Beeson’s (2007) study and was expressed by the at-risk couples in Phase 3 of the current study.

Durosinmi et al.’s (1995) study examining acceptance of PND among Nigerians noted that a significant number expressed a likelihood of opting for PND and subsequent termination of an affected pregnancy, and that more women than men were willing to opt for PND with a view to termination of an affected pregnancy. This latter finding contrasts with Marteau et al.’s (1995) assertion that men were less accepting of a disabled child and were more likely to consider PND
and termination of an affected child. It is unclear whether the researchers examined a multicultural, multiethnic group and took into consideration the possible cultural differences that may impact on this gender difference. It is also noted that Durosinmi et al.’s study consisted of only one ethnic group (Nigerian), which raises the question is race the issue or culture? And will Caribbeans demonstrate a similar attitude to the Africans?

The gender difference observed in Durosinmi et al.’s (1995) Nigeria study could be a reflection of the society’s negative social attitude to women who produce sick children. Selecting another woman who is not likely to produce ‘sickly’ children, is a viable alternative and an option open to men in a male dominated society, despite his having sickle cell trait. A woman with sickle cell trait appears a less attractive proposition; especially a woman who has been married and divorced on the grounds of producing ‘sickly’ children. Given the options available to women, prevention is often perceived a better option and in many African societies couples known to have sickle cell trait are vehemently discouraged from marrying each other.

The variation between the male and female attitude could also be due to the African society's attitude to children and the expectation of having children who will not be a potential burden to the family and its meagre resources, in an environment where health and social support services are sparse. There appears to be greater pressure for women in developing countries to have healthy children. Within some African countries the cost of antenatal testing and PND is considered justified for those who can afford it, when compared to the cost of providing health and social care for a child that is perceived as health-limited and as a potential economic, social and emotional burden on the family throughout his or her life. The desire to have a healthy child is probably a reflection of this socio-economic reality. I argue that living with the reality of social and economic constraints is alien and has no impact on those living in more affluent societies and therefore they can afford to consider the human rights of the unborn child, which I suspect many in underdeveloped countries will perceive as one aspect of life that they cannot afford to subscribe to or take very seriously. It is possible that if an equitable, accessible health and social care services were made readily available and affordably in developing countries attitudes to having a child with a disability such as sickle cell may change.

Marteau (1995) argued that the seriousness of the genetic condition is a better predictor for assessing women and couples’ decision to have PND and termination of an affected fetus than the gender of the fetus, age of the woman, ethnicity, class, educational level, or gestational age at
time of presentation. Secondly, the way in which health professionals present information about the condition and how serious it is affects parents' perception of the illness and ultimately influences decisions about the pregnancy. Thirdly, the person conducting the counselling session, whether a generalist health care professional, a specialist nurse or genetic counsellor and whether the counselling was directive or non-directive (Clarke 1991, Green and Statham 1996, Shiloh 1996, Emery 2001) has an influence on acceptance or decline of PND.

Timeliness of a screening programme is vital if it is to be accepted by expectant couples. It is claimed that women will consider PND if testing can be carried out in the first twelve weeks of pregnancy (Petrou et al. 1992, Nuenschwander and Modell et al. 1997, Modell et al. 2000, Thomas, Oni et al. 2005). Services that fail to offer couples PND as early as possible during pregnancy fail to give them a choice at a most conducive time for deciding whether to continue or terminate an affected pregnancy. Some will argue that testing during pregnancy fails to give men and women the opportunity to make informed ‘reproductive choices’ since a pregnancy is already established; preconception screening would provide better options, but one needs to consider the social and cultural acceptability of this especially among minority ethnic populations where arranged marriages and premarital family history investigations are more common.
2.5 Conclusion

A number of authors have argued cogently that there are different levels of culture and that culture is a learned concept, some also argued there is a genetic element to the acquisition of culture and that the interplay between the biological and sociological is important. All societies have a primary culture, which is transmitted to each member of the cultural group through a process of enculturation, and the assimilation of other cultures evolves over time through a process of acculturation. Culture provides the individual with a lens through which to perceive the world and how they should relate to it.

Culture within a group is not static and different external forces can force it to change and adapt. Hence culture is dynamic and the more cultures there are in a society the more complex its cultural practices and consequently the cultural attitude of the people within that society. Actions are influenced by cultural orientation and social and psychological perspectives.

Culture is susceptible to change and a society’s ability to adapt is one of the key features of a modern-day society. The more migration into and out of a cultural environment the more it changes. Societies with minimal interaction with other socio-cultural groups are less likely to experience major changes in their cultural orientation. Culture shapes an individual’s attitude, perception and response to health, disease and illness and this is demonstrated in the way in which an individual, family and cultural group will deal with these issues. A number of factors influence attitude to being at risk of having a child with a serious genetic condition and some of these factors are shaped by cultural orientation, values, beliefs and social experiences.

The concepts underpinning dissonance theory offer an opportunity to assess whether the choices and behaviour of women and couples at risk of having a child with sickle cell anaemia are as a result of cultural orientation solely or also a response to the psychological dissonance that societal expectations and conflicting personal preferences has created.
## 3.1 Human haemoglobin

- 3.1.1 Composition of human blood  
- 3.1.2 Genetic inheritance of normal haemoglobin  
- 3.1.3 Genetic mutations of haemoglobin

## 3.2 Sickle cell disease

- 3.2.1 Structure of sickle haemoglobin  
- 3.2.2 Epidemiology of sickle cell  
- 3.2.3 Genetic inheritance of sickle haemoglobin  
- 3.2.4 Bio-pathophysiology of sickle cell  
- 3.2.5 Clinical implications and complications of sickle cell disease  
- 3.2.6 Treatment and prevention of complications
3.1 Human haemoglobin and sickle cell

3.1.1 Composition of human blood

Human blood is composed of four elements: red blood cells (RBC), which contain haemoglobin a molecule that transports oxygen to and from the lungs and gives blood its red colour; white blood cells, which act as the body’s defence against infection; platelets, which enable blood to clot thus arresting bleeding; plasma, which is the liquid enabling flow of blood particles.

Since SCD affects red blood cells the focus will be on the normal and abnormal red blood cell structure and function.

A normal mature RBC is a biconcave, pliable, flexible disc with a diameter of 7um. Over 3000 RBCs can be placed side by side on a British 1p (diameter = 2cm.) By distorting its shape the RBC is able to manoeuvre through blood capillaries which are narrower than its own diameter. This it does without damage to its structure, and is capable of regaining its original discoid shape once the narrow channels have been traversed. It is responsible for transporting oxygen around the body and under normal conditions it is capable of doing so efficiently. However, a genetic mutation of haemoglobin, such as sickle cell, alters the cell's ability to perform this crucial function.

On average the RBC constitutes 42% of women’s and 45% of men's total blood volume (red cell mass). The remaining volume is made up of plasma (55-57%), white blood cells and platelets (1%). The depression on each flat surface of the RBC gives it a thinner central cortex with a thicker and denser outer ring. This central depression occurs as a result of the RBC losing its nucleus during its development in the bone marrow, from the immature nucleated cell to the mature non nucleated cell, the cell mass caves in on itself to occupy the central space which was originally occupied by the nucleus. This central depression also gives the RBC a wider surface area, promoting the cell’s capacity to transport oxygen and maintain its flexibility. There are approximately 2-300 million molecules of haemoglobin within each RBC.
The primary component of a mature RBC is haemoglobin, which accounts for over a third of the cell mass and volume. Marieb (2001) describes red blood cell as ‘little more than bags of haemoglobin’. The remainder is mostly water. Haemoglobin makes up 95% of the cells dry weight. The biconcave shape of the RBC is maintained by a network of proteins, one of which is spectrin, which attaches to the cytoplasm face of the plasma membrane. This spectrin net is deformable and thus allows the RBC to bend flexibly over itself without damage to its own structure or function. The haemoglobin molecules within the RBC are soluble and remain separate whether oxygenated or deoxygenated (Diagram 1). The RBCs are the main contributors to the blood viscosity. Where there is increase in viscosity blood flows more slowly, conversely if there is decrease in viscosity blood flows more rapidly. This has implications in the biological and pathophysiological changes which occur in the red blood cells of those with SCD.
3.1.2 Genetic inheritance of normal haemoglobin

Haemoglobin is inherited in an autosomal (non-sex linked) Mendelian recessive pattern and different haemoglobin predominates at different stages of human development, from early embryonic haemoglobin, to fetal and subsequently adult haemoglobin (Serjeant and Serjeant 2001, Bain 2001).

There are a number of chains making up the different forms of human haemoglobins. The genes for the synthesis of the alpha (α) and zeta globin chains are located on chromosome 16 whilst the genes for the synthesis of the beta (β) epsilon (ε), delta (δ) and gamma (γ) globin chains are located on chromosome 11. All haemoglobin is tetramic, made up of a pair of globin chains. The normal adult haemoglobin is made up of two alpha (α²) and two beta (β²) chains (Diagram 2 and Table 1).

The adult beta globin chain is implicated in the inheritance of sickle and other common mutations of haemoglobin. The normal adult haemoglobin combination is βA βA commonly written (HbAA), in this instance an individual has inherited normal haemoglobin A from both parents.

Diagram 2: Double helix and adult haemoglobin tetramer

*An original drawing commissioned by L Oni (2007)*
Table 1 - Haemoglobin type at different stages of human development and globin chain present

<table>
<thead>
<tr>
<th>Normal haemoglobin types</th>
<th>Globin chains present</th>
<th>Hb type</th>
<th>% at Birth</th>
<th>% &gt;1 Year of age and adulthood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gower I</td>
<td>(\zeta^2 \varepsilon^2)</td>
<td>Gower I</td>
<td>Embryonic only</td>
<td>-</td>
</tr>
<tr>
<td>Gower II</td>
<td>(\alpha^2 \varepsilon^2)</td>
<td>Gower II</td>
<td>++</td>
<td>-</td>
</tr>
<tr>
<td>Portland</td>
<td>(\zeta^2 \gamma^2)</td>
<td>Portland</td>
<td>Embryonic only</td>
<td>-</td>
</tr>
<tr>
<td>Fetal</td>
<td>(\alpha^2 \gamma^2)</td>
<td>HbF</td>
<td>90 – 95%</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Adult</td>
<td>(\alpha^2 \beta^2)</td>
<td>HbA</td>
<td>5 – 10%</td>
<td>&gt;95%</td>
</tr>
<tr>
<td>Minor Adult (A2)</td>
<td>(\alpha^2 \delta^2)</td>
<td>HbA2</td>
<td>&lt;3.5</td>
<td>&lt;3%</td>
</tr>
</tbody>
</table>

Key to symbols: \(\zeta\) – Zeta \(\varepsilon\) – Epsilon \(\alpha\) – Alpha, \(\beta\) – Beta, \(\gamma\) – Gamma \(\delta\) – Delta

Chromosome 16 – location of Alpha (\(\alpha\)) and Zeta globin genes
Chromosome 11 – location of Beta (\(\beta\)) Epsilon (\(\varepsilon\)), Delta (\(\delta\)) and Gamma (\(\gamma\)) globin genes

3.1.3 Genetic mutations of haemoglobin

Genetic mutations of haemoglobin are the most common genetic defects occurring in humans worldwide. They are categorized into three groups:

- Haemoglobinopathies
- Thalassaemia
- Hereditary persistence of fetal haemoglobin (HPFH)

Haemoglobinopathies affect the quality of the globin chain synthesized (qualitative defects). Thalassaemia affects the quantity of the globin chain synthesized (quantitative defects). The genetic mutation resulting in HPFH is due to a failure of the mechanism that switches off synthesis of large quantities of the gamma chain which contribute to the production of fetal haemoglobin, thereby resulting in continued production of quantities of fetal haemoglobin beyond the normal range of 1 % seen in those above one year of age

For the purpose of this review the focus will be on haemoglobinopathies, since sickle cell is within this category. However, it is acknowledged that it is possible to co-inherit beta
thalassaemia with the sickle haemoglobin and it is also possible to inherit alpha thalassaemia independent of the beta chain inherited, normal or abnormal.

Haemoglobinopathies

The haemoglobinopathies include sickle haemoglobin (βS), haemoglobin C (βC), haemoglobin D_Punjab (βD_Punjab), and haemoglobin E (βE). These are the most common haemoglobinopathies worldwide. Sickle is the most common of the group and often the most serious clinically when inherited in a homozygous or compound heterozygous state.

Where an individual has inherited one normal adult beta globin (βA) gene from one parent and a haemoglobin mutation from the other parent they are regarded as heterozygous, or 'healthy carriers'; for example, the inheritance of one normal beta globin gene from one parent and a sickle gene from the other parent results in sickle cell trait (βA/βS), commonly written (HbAS). Similarly where an individual has inherited one normal beta globin gene from one parent and a haemoglobin C gene from the other they have haemoglobin C trait (βA/βC), commonly written (Hb AC). Other examples include haemoglobin D_Punjab trait (βA/βD_Punjab), commonly written (Hb AD_Punjab) and haemoglobin E trait (βA/βE), commonly written (Hb AE). However, none of these other mutations give rise to the sickling phenomena unless they have been co-inherited with the sickle gene in a compound heterozygous state. Other genetic mutations of the beta globin gene can be co-inherited with haemoglobinopathies notably beta thalassaemia; when co-inherited with a sickle gene gives rise to sickle beta thalassaemia (βS/β^{Thal}), commonly written (HbS/β^{Thal}).
3.2 Sickle cell disease

3.2.1 Structure of sickle haemoglobin

Sickle haemoglobin S occurs as a result of a point mutation on the 6th point of the beta globin chain, where the amino acid Glutamic Acid has been substituted by another amino acid Valine ($\beta^{6}\text{Glu} \rightarrow \text{Val}$).

Where two sickle haemoglobin genes are inherited the individual has sickle cell anaemia (Hb SS), a homozygous state. Where another mutation is inherited with the sickle gene this gives rise to a compound heterozygous state, for example, sickle beta plus thalassaemia (Hb $\beta^{+}\text{Thal}$), or sickle beta zero thalassaemia (HbS $\beta^{0}\text{Thal}$), sickle haemoglobin C disease (HbSC), sickle haemoglobin D Punjab disease (Hb SD$\text{Punjab}$) and sickle haemoglobin E disease (Hb SE). All these examples are the most common combinations observed in the United Kingdom, with sickle cell anaemia (HbSS) being the most common and usually the most severe pathologically and clinically (Davies and Oni 1997).

Sickle, haemoglobin C, D$\text{Punjab}$ and E are only a few examples of over one thousand mutations of haemoglobin identified in humans to date (Huisman et al. 1996, Bain 2001).

3.2.2 Epidemiology of sickle cell

The epicentre for the sickle gene is west and central Africa but it occurs in areas of the world where malaria is or was endemic this include north and eastern Africa, Asia, Middle East and the Mediterranean Islands. Because of migration it is also observed in those from the Caribbean, South America and other parts of the world (Map 1 and Table 2).

The incidence of the sickle cell gene varies across Africa ranging from less than 1 % in the south, 25 % in the west and as high as 45 % in central Africa; conversely in the Caribbean the overall incidence is 10 % among Caribbeans of Black African origin.
Table 2: The most common Incidence of sickle cell trait

<table>
<thead>
<tr>
<th>Hb type</th>
<th>Ethnic origin</th>
<th>Incidence of carrier state</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sickle Cell Trait</td>
<td>Central Africa</td>
<td>1 in 2 – 3 (&gt;45%)</td>
</tr>
<tr>
<td></td>
<td>West African</td>
<td>1 in 4 (25%)</td>
</tr>
<tr>
<td></td>
<td>Black Caribbean</td>
<td>1 in 10 (10%)</td>
</tr>
<tr>
<td></td>
<td>Mediterranean</td>
<td>1 in 3 – 100 (1-30%)</td>
</tr>
<tr>
<td></td>
<td>Pakistan and India</td>
<td>1 in 3 – 100 (1-30%)</td>
</tr>
</tbody>
</table>


SCD and is now the most common genetic disease in England and 1 in 2,380 births result in the birth of a child with the condition (NHS Sickle Cell and Thalassaemia Screening Programme 2002).

Map 1: Incidence of sickle cell trait

Sickle cell disease is the collective name for the group of genetically inherited diseases affecting red blood cell (RBC) haemoglobin where the sickle gene is inherited in a homozygous or compound heterozygous states. Sickle cell anaemia (HbSS) is the most common and often the most severe of the group of sickle cell diseases worldwide. Compound heterozygous states for example, HbSC, HbSD\textsuperscript{Punjab}, HbSB\textsuperscript{Thal} are seen commonly throughout Northern Europe and North America; HbSC, which has the highest prevalence in Ghana where 1 in 6 have the carrier state, is also seen in southern Nigeria sporadically due to its close proximity to Ghana, and
occasionally among white English due to gold trading between Ghanaians and these northern Europeans. Nigeria has the largest concentration of people with SCD in the world and 3 % of all newborns have SCD (Adekile 1992). The majority of these, perhaps as much as 90 %, are born with sickle cell anaemia (HbSS).

The majority of those with SCD are born in under-developed and developing countries especially, west, east, central Africa and Asia. There are approximately 12,000 people with SCD in the UK. Worldwide it is estimated that at least 4.5 % of the world population carry a significant haemoglobin mutation, in a carrier state, whilst 2.0 / 1000 have a major disease state (Modell 1994). This number has increased significantly since 1994. However, it is difficult to obtain accurate demographic data from developing countries and numbers given are projections based on population size and expected prevalence in each ethnic group. Because of improvement in living standards, medical technology, health care and population awareness many of those with SCD who would have died in early childhood, especially in developing countries, now live beyond the fourth decade. The average lifespan in western countries is between 42 and 48 years however there remains a significantly high mortality rate associated with SCD world wide including western countries.

3.2.3 Genetic inheritance of sickle haemoglobin

Because the majority of genetic mutations of haemoglobin, including sickle cell trait (HbAS), when inherited in a heterozygous state are asymptomatic, individuals are often unaware of their haemoglobin status. That is until they are tested for the condition specifically or when they and their partner inadvertently pass on the genetic mutation to their offspring who is diagnosed as having a clinically significant disease state, usually during a routine neonatal screening programme, pre-operatively or whilst undergoing other investigations for an illness.
Diagram 3 illustrates the inheritance probabilities for the offspring of a couple who both have asymptomatic sickle cell trait (Hb AS).

Diagram 3 – Autosomal recessive Mendelian inheritance of the sickle cell gene

In each and every pregnancy the genetic probability for this couple's child:

- Hb A A = 1 in 4 (25%) chance normal haemoglobin
- Hb A S = 2 in 4 (50%) chance sickle cell trait
- Hb S S = 1 in 4 (25%) chance sickle cell anaemia

1 in 60 West African and 1 in 300 Caribbean couples are at risk of having a child with SCD. The majority of the African respondents in this current study are of West African origin. The Caribbean respondents originated from a wide variety of Caribbean islands.

3.2.4 Bio-pathophysiology of sickle cell

Under normal day-to-day living conditions those with sickle cell trait do not experience any clinical symptoms and are regarded as healthy carriers. However, in abnormal physiological situations the red blood cells of those with sickle cell trait can sickle, for example, where there is extreme oxygen deprivation such as may occur during deep sea diving and in very high altitudes.

Those with SCD however experience varying degrees of a painful event called a ‘sickling crisis’. Whilst oxygenated the red blood cells containing a high proportion of HbS maintain the biconcave flexible shape of a normal red blood cell. However, when deoxygenated the haemoglobin molecules within the cell polymerize and aggregate to form a sticky gel within the
red blood cell. These polymers form long stiff rods of haemoglobin \((tactoids)\), which distort the fine membrane of the red blood cell and cause it to become ‘sickle’ shaped, a rigid, inflexible distorted cell, which makes the cell incapable of transporting oxygen efficiently. The shape of a farmer’s sickle typifies the peculiar shape of this abnormal red blood cell (Diagram 4).

**Diagram 4: Sickled red blood cells and abnormal stacking of haemoglobin molecules**

![Diagram 4: Sickled red blood cells and abnormal stacking of haemoglobin molecules](image)

When re-oxygenated the red blood cells will un-sickle and continue to function, albeit inefficiently, but repeated sickling and un-sickling will eventually result in irreversibly sickled red blood cells which are then targeted for destruction by the reticulo endothelial cells of the spleen. This reduces the red blood cell’s life span from the normal 120 days to 5-30 days. This rapid and extensive destruction of the red blood cell results in chronic haemolytic anaemia with an average haemoglobin level of 5-6g/dl (normal value = 11-15g/dl) in those with HbSS but can be elevated up to 10g/dl in those with some mild compound heterozygous states e.g. HbSC. The distorted red blood cells when deoxygenated adhere to the endothelial walls of capillaries and consequently impede blood flow. This is commonly called a *sickle cell vaso occlusive crisis*. Obstruction in blood flow prevents vital oxygen from reaching the affected organ or tissue, causing excruciating and sometimes intractable pain. During these painful episodes individuals may require hospitalization and medical intervention to address the acute episode and prevent potential short- and long-term complications. Any factor that contributes to increased blood viscosity, such as dehydration, increases the likelihood of the red blood cells sickling. The viscosity of the blood makes the cells sluggish in circulation, they clump together and adhere to the lining of the blood vessels, impeding blood flow precipitating sickling of other red blood cells and increasing vaso-occlusion.
SCD gives rise to chronic haemolytic anaemia. The condition is debilitating and contributes to high handicap, mortality and morbidity, especially during childhood, and more so in developing countries of Africa, where early infant death is reported to be as high as 80% in some communities (Konotey-Ahulu 1992, Akinyanju 1989). In Eastern Nigeria it is estimated that 30,000 preschool children have SCD (Juwah 2004) and the majority of these die by their fifth birthday (Serjeant 2005). These deaths are preventable with simple interventions, such as administration of daily prophylactic antibiotics, folic acid and extensive education of parents and families of affected infants and individuals. These strategies have enabled a dramatic reduction in mortality in developed countries and need to be extended to developing countries as a matter of urgency.

The clinical severity of the disease is dependent on a number of factors, the most significant being the proportion of haemoglobin S present in each red blood cell. Where the predominating haemoglobin in the red blood cell is sickle haemoglobin, as occurs in sickle cell anaemia (HbSS), >90%, this gives rise to a potentially serious clinical presentation. In compound heterozygous states where the proportion of HbS is less, for example, in sickle haemoglobin C disease, where there is approximately 45% HbS and 40% HbC, the clinical presentation is often less severe, but can be as debilitating.

### 3.2.5 Clinical implications and complications of sickle cell disease

A number of known factors may precipitate a vaso-occlusive crisis: these include hypoxia, acidosis, dehydration, infection (there is increased susceptibility to infection due to early damage to the spleen and a consequent poor development of the immune system), sudden changes in temperature, physical and emotional stress and prolonged increased physical demand on the body as occurs during pregnancy.

With significant improvements in standards of living, medical care and increasing community knowledge the average life span has increased incrementally in the last four decades. Worldwide the highest death rate occurs in children between the age of 6 months and 5 years. The median age of survival of those with sickle cell anaemia (HbSS) in western countries, in 1994, was reported to be 42 years for men and 48 years for women (Platt et al. 1994) and in 2003 it was on
average 50 years. This rate is significantly reduced in developing and undeveloped countries where death during infancy even in the non-sickle population is high, due to infection, lack of basic amenities, preventable childhood diseases and inaccessible health care. In the sickle patient the high mortality in those with SCD occurs as a consequence of immuno-suppression and the consequent inability to deal with infection, parasitic infestations, and childhood ailments and the clinical implications and complications of SCD itself (Diagram 5) (Konotey-Ahulu 1992, Akinyanju 1989, Serjeant and Serjeant 2001).

It is observed that the number of vaso-occlusive crises necessitating hospitalization increase the rate of mortality. Platt et al. (1991) noted that those who have more than three admissions per year have a significantly increased risk of early death when compared to those admitted less frequently. A serious complication of SCD, particularly in those with HbSS and HbSβ⁰Thal, is cerebral vascular accidents (stroke) (Davies and Oni 2001). 7-10% of children will have a stroke between the ages of 2-9 years, with a mean age of 4 years, a second peak occurs in those above 30 years of age (Ohene-Frempong 1991, 1998). Hoppe et al. (2003) asserted that a 200-fold increased risk of stroke in children with sickle cell anaemia and further suggests that it is the most common cause of stroke in children (Hoppe et al. 2003). Meschia et al. (2005) stated that the cumulative risk for stroke was 11% by age 20 years and 24% by 45 years, whilst a large proportion of children with SCD experience their first stroke before going to elementary school.

The result of a stroke is often handicapping with hemiplegia, loss of speech and sometimes fatal. It is a major cause of death in this patient group. The effect of the stroke can be transient or permanent, cognitive ability is often compromised, there can be reduced mobility, visual disturbance, personality change, fits and sensory loss. A stroke can also occur in adulthood, especially in women during pregnancy, labour and the early postnatal period.

Complications of SCD include splenic sequestration and aplastic crisis - two of the major causes of death in childhood. Other complications are painful involuntary erection of the penis (priapism), which untreated can result in impotence, hip necrosis, which incapacitates and can result in partial or total loss of mobility; sickle chest syndrome, which is one of the most common causes of death in adults (Vichinsky (2007) reported an 11% rate of acute chest syndrome) cardiomegaly, liver failure, susceptibility to infection, retinopathies, chronic leg ulcers, acute haemolytic anaemia and failure of major organs (Diagram 5). An untimely death is
often as a result of a myriad of complications associated with SCD (Embury et al. 1994, Serjeant and Serjeant 2001, Steinberg et al. 2001).

3.2.6 Treatment and prevention of complications

Ameliorating factors which can lessen the severity of SCD include the type of SCD inherited. For example, in sickle haemoglobin C disease and sickle beta plus thalassaemia (HbSβ+Thal) the haemoglobin level may be higher and the disease manifestation less severe; the coinheritance of alpha thalassaemia and continued synthesis of high levels of fetal haemoglobin (HbF) also reduces clinical severity.

The only routine preventive medical management provided for those with SCD in the UK and in other developed countries is prophylactic penicillin twice daily to commence by age three months, for a minimum of five years in the USA (Falleta et al. 1995). In the UK this treatment is often maintained up to 16 years of age or into adulthood if medically warranted (Raghavan and Davies 2002, Riddington-Owusu 2002, UK Forum 2006). Other preventive measures include prophylactic vaccinations of Prevenar and Pneumovax to prevent pneumococcal infection, regular monitoring of steady state, such as annual brain scans (Transcranial Doppler) to detect early signs of transient ischaemic attacks (TIA) which may cause mild to moderate neurocognitive deficits that may go unnoticed but can be an early indicator of impending risk of a major stroke with the risk of leaving the child permanently impaired physically and cognitively or causing death. Where there are signs of TIA children are placed on long-term transfusions (every four to six weeks) in an effort to avert the occurrence of a stroke or to prevent further strokes.

The UK Forum guidelines (2006) also recommend contacting the child’s parents routinely if a child fails to attend even one outpatient clinic appointment. SCD is very unpredictable and potentially fatal: a mild flu or common cold can suddenly develop into an acute chest syndrome leading to something more sinister and catastrophic, such as death. During episodes of acute illness an individual may require hospitalization.
Diagram 5

Clinical implications and complications of sickle cell disease

Cerebral vascular accident (stroke)

- Gnanopathy (Gnasher teeth)
- Gnanopathy (Gnasher teeth)
- Auditory impairment
- Diploe expansion
- Retinopathy
- Cardiomegaly
- Pulmonary (e.g. Chest syndrome)
- Splenomegaly (Sequestration)
- Delayed puberty
- Reduced fertility
- Skeleto-pathology
  (Aplastic crisis)
  (Osteonecrosis)
  (Leg ulcers)

- Physical disability
- Obstetric complications

- Hepatomegaly
  (Cholelithiasis, jaundice)
- Growth impairment
  (Endocrine dysfunction)
- Renal pathology
  (e.g. Haematuria, enuresis, papillary necrosis)
- Micro-vascular occlusions
  (e.g. Mesenteric)
- Hand foot syndrome
  (Dactylitis)
- Priapism
  (involuntary erection of penis)
- Renal pathology
  (e.g. Haematuria, enuresis, papillary necrosis)
- Micro-vascular occlusions
  (e.g. Mesenteric)
- Hand foot syndrome
  (Dactylitis)
- Priapism
  (involuntary erection of penis)

Psychosocial implications
- Immuno-suppression
- Chronic haemolytic anaemia

96
The aim of management is to identify and address any precipitating factors, alleviate the associated pain, usually with potent analgesia such as an opiate and the treatment of medical complications. Other medical interventions may include the use of oxygen therapy, intravenous fluids to correct dehydration, bed rest and reassurance. In cases of complications treatments may warrant short- or long-term use of blood transfusions and other medical interventions, depending on the complication and presenting symptoms. For example, following a cerebral vascular accident blood transfusion is given long-term to prevent the high incidence of a recurring stroke (Ohene-Frempong 1998, Ohene-Frempong 2001).

The clinical severity of SCD is unpredictable. Two siblings with SCD and with the same haemoglobin type may present with a totally different clinical picture. While one is severely affected and requires frequent hospital admissions, the other may be admitted very infrequently or not at all with the crisis being managed effectively at home. The unpredictability of SCD makes genetic counselling of at-risk women and couples difficult as they attempt to make decisions about PND and possible termination of an affected fetus.

There is no simple cure for SCD and treatment is based on dealing with the presenting symptoms and complications when they manifest. The only available cure is bone marrow transplantation but finding an exact HLA* matched donor is extremely difficult and the success rate after several painful pre and post-operative treatment is poor. Likelihood of severe complications is high and a 10% death rate is reported (Davies and Oni 1997).

* Human Leukocyte Antigen (HLA) - glycoprotein molecules, found on the surface of cells, which the immune system uses to recognize ‘self’ from ‘non-self’ cells and initiate the trigger of an immune response to anything that it recognizes as ‘non-self’
# - CHAPTER 4 –

**Philosophical approach, adoption of cognitive dissonance theory and methodology**

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1</td>
<td>Philosophical approach</td>
<td>98</td>
</tr>
<tr>
<td>4.2</td>
<td>Adoption of cognitive dissonance theory</td>
<td>101</td>
</tr>
<tr>
<td>4.3</td>
<td>Methodology</td>
<td></td>
</tr>
<tr>
<td>4.3.1</td>
<td>Triangulation of data collection</td>
<td>103</td>
</tr>
<tr>
<td>4.3.2</td>
<td>Ethical approval</td>
<td>105</td>
</tr>
<tr>
<td>4.3.3</td>
<td>Instrument design</td>
<td>105</td>
</tr>
<tr>
<td>4.3.4</td>
<td>Pilot study</td>
<td>110</td>
</tr>
<tr>
<td>4.3.5</td>
<td>Recruitment &amp; distribution of questionnaires</td>
<td></td>
</tr>
<tr>
<td>4.3.5.1</td>
<td>Sample size</td>
<td>110</td>
</tr>
<tr>
<td>4.3.5.2</td>
<td>Recruitment process</td>
<td>113</td>
</tr>
<tr>
<td>4.3.5.3</td>
<td>Inclusion criteria</td>
<td>114</td>
</tr>
<tr>
<td>4.3.5.4</td>
<td>Exclusion criteria</td>
<td>115</td>
</tr>
<tr>
<td>4.4</td>
<td>Organization of questionnaire and interview schedule (measurement tools)</td>
<td>116</td>
</tr>
<tr>
<td>4.4.1</td>
<td>Section 1 – Knowledge of sickle cell</td>
<td>116</td>
</tr>
<tr>
<td>4.4.2</td>
<td>Section 2 – Attitude to sickle cell</td>
<td>116</td>
</tr>
<tr>
<td>4.4.3</td>
<td>Section 3 – Demography</td>
<td>118</td>
</tr>
<tr>
<td>4.4.4</td>
<td>Section 4 – Multi-dimension Health Locus of Control</td>
<td>118</td>
</tr>
<tr>
<td>4.4.5</td>
<td>Section 5 – Ethnicity &amp; cultural orientation</td>
<td>119</td>
</tr>
<tr>
<td>4.4.6</td>
<td>At risk women – Phase 3 questionnaire</td>
<td>120</td>
</tr>
<tr>
<td>4.4.7</td>
<td>At risk women – Phase 3 interview schedule</td>
<td>120</td>
</tr>
<tr>
<td>4.5</td>
<td>Study Population</td>
<td></td>
</tr>
<tr>
<td>4.5.1</td>
<td>Study Population inclusions</td>
<td>121</td>
</tr>
<tr>
<td>4.5.2</td>
<td>Phase 1 - Respondents excluded</td>
<td>122</td>
</tr>
<tr>
<td>4.5.3</td>
<td>Phase 2 - Respondents excluded</td>
<td>122</td>
</tr>
<tr>
<td>4.5.4</td>
<td>Phase 3 - Respondents excluded</td>
<td>122</td>
</tr>
<tr>
<td>4.6</td>
<td>Process of Data analysis</td>
<td></td>
</tr>
<tr>
<td>4.6.1</td>
<td>Addressing the research question</td>
<td>123</td>
</tr>
<tr>
<td>4.6.2</td>
<td>Management of parametric and non-parametric data</td>
<td></td>
</tr>
<tr>
<td>4.6.2.1</td>
<td>Regression analysis</td>
<td>126</td>
</tr>
<tr>
<td>4.6.3</td>
<td>Qualitative data management</td>
<td>127</td>
</tr>
<tr>
<td>4.6.4</td>
<td>Presentation of participants’ voices</td>
<td>130</td>
</tr>
</tbody>
</table>
4.1 Philosophical approach

A hermeneutic phenomenological approach is the philosophical perspective used for underpinning this study and is particularly relevant for Phase 3 where the primary aim is to examine the experience of women and their partners’ who are at-risk of having a child with SCD and to present this in their own words.

In support of a hermeneutic epistemology, Dowling offered a useful comparative description of two of the three philosophical approaches identifiable in the phenomenological school and proposed:

(descriptive) Phenomenology has its focus on a person’s lived experience and obtained commonalities and shared meanings, whereas (interpretive phenomenology) hermeneutics assumes that humans experience the world through language, and that this language provides both understanding and knowledge.

(Dowling 2003: 31)

Interpretive phenomenology, also commonly known as hermeneutics, advocates an acknowledgement of the researcher’s influence on the research process and population. Interviewing, like counselling, is a social interaction and no matter how carefully executed so as to eliminate researcher influence it is inevitable that both players will influence each other. This study being previously uncharted territory has adopted the principles of the Dutch school of phenomenology which is a combination of the descriptive and interpretive philosophical approach. It will attempt to interpret the meanings which participants give to their experience of being at risk of having a child with SCD and a qualitative approach appears suitable in order to elucidate participants’ response to this confusing phase of their lives.

An interpretivist researcher aims to interpret the data using concepts that emerge from the data itself as well as concepts derived from literature to determine whether there are any differences or similarities to previously studied populations and in this instance to help explain whether culture also plays a part in explaining the findings. An interpretivist researcher aims to produce work that is not constrained by positivist inflexible designs and methodologies. Although there may be some ambiguity in interpretivism this in itself allows for observing, analysing and using data that may emerge unexpectedly. This was amply demonstrated in the current study, where
age of migration and other unexpected findings emerged as important factors influencing peoples’ attitude to sickle cell. The aim of the interpretivist is to add what may be discovered in their exploration to what is already known or available on the subject rather than attempt to prove or refute a given theory or hypothesis. Following a path of discovery is the realm of interpretivist inquiry and I propose that the adoption of this approach was therefore appropriate for this study.

Foucault, a French social theorist, historian and philosopher argued that there is a relationship between discourses of knowledge and power and questioned the validity of a value-free objective methodology of scientific investigation. Borrowing from Foucault's post-modernist theory of 'discourse' and 'power' Tapper (1999) argued that the sickle cell discourse evolved in the west during an era of discrimination, racism, and Euro-centric ideology. This has led to a highly politicized sickle cell discourse in which power is exerted by the powerful minority, predominantly White health and social care professionals and researchers, over disempowered carriers of the sickle gene, predominantly Blacks in Africa and those in the African Diaspora. The post-modernist theory of Foucault was used by Tapper to describe the political arena in which sickle cell research and services evolved, as discussed in the literature review.

The post-modernist philosophers acknowledge the role of the researcher in the process of research and argue that research is not value-free and the researcher exerts some influence on the environment and the subjects being studied, therefore it is important to examine the impact which the researcher has on the research material, subjects and environment (Creswell 1998). The researcher determines many aspects of the research, including which questions to ask, how to ask it and which lens to utilize when interpreting the findings.

Unlike descriptive phenomenology, which is strongly associated with a positivist paradigm where the demand is to aim for objectivity by ‘bracketing’ and suspending one’s experiences, beliefs, biases about a phenomena prior to data collection, hermeneutic phenomenology advocates an acknowledgement of the researcher’s influence on the research population and process without which the researcher is likely to fail to analyse, reflect on and attribute meanings to what may constitute important elements of the research process or the data collected. A researcher conducting face-to-face interviews, no matter how carefully executed will invariably have an effect on the interviewee since the encounter is a social interaction. This is the supporting argument for adopting a hermeneutic approach for this study. Being Black I share a
racial group with all the respondents and a cultural orientation with the African group; I also share gender with the female respondents, therefore I acknowledge that it is possible to inadvertently influence some of the participants’ reaction to the questions being asked in the Phase 3 interviews. For example, one may ask, how did the traditional African men feel about being questioned by an untraditional, educated, self-assured academic African woman?

Kaplan (1972) argued that without making comparisons between different cultures there can be no theory in anthropology. Because we cannot do laboratory type experiments on ‘culture’, comparisons of one culture with another is the only way in which we can begin to understand similarities and differences, then we can formulate a theory of cultural research. When studying a particular culture the ethnographer cannot help applying knowledge gained from experiencing or reading about other cultures. A comparison of one culture with another helps test general ideas about culture, our perceptions and formulated theories of culture.

Madu proposed:

The only objectivity there is, is the confirmation of a fore-meaning which any person who is trying to understand (something) is exposed to…all interpretation begins with pre-conceptions that we replace by more suitable ones…prejudices are an ontological fact…understanding should be considered a mode of being as opposed to the popular concept of mode of knowledge.

(Madu 1994:19)

One’s prejudice, pre-structured opinions, pre-conceptions comes into the interpretation of what is observed; what we know, see or believe in advance of the thing we are trying to interpret.

It is an absurdity to suggest that one is able to record all the facts in a phenomenon observed. As humans we filter the facts through a screen of interest, predisposition and prior experience. Different observers will report different aspects of an observation depending on their area of interest: thus a nurse, a psychologist, a biologist, a sociologist and a preacher observing the same phenomena are likely to provide differing interpretations because they approach the observation with different aims, objectives and screen of interest.
4.2 Adoption of cognitive dissonance theory

During the early stages of the project a number of theories were examined in order to identify one most suited to the exploration of ‘attitude to sickle cell and socio-cultural factors influencing decisions about a pregnancy at-risk of producing a child with sickle cell disease’. Some of the theories examined included attitude theory, attribution theory, reasoned action theory, self perception theory and learning theory however none of these proved useful theoretical models. Following an in depth exploration of cognitive dissonance theory it appeared to be the most promising for interpreting the emerging data that would help explain some of the participant’s contradictory views of the world, as observed in the Phase 3 interviews.

The initial hypothesis formed in clinical practice is that women and couples who are at-risk of having a child with SCD experience a great deal of anguish whilst attempting to make a decision about whether to have prenatal diagnosis (PND) and what to do if an affected pregnancy is diagnosed. But what was most striking is that it appeared that the choices made often conflict with the clients expressed attitude to SCD. Whilst many women and partners do not wish to have a child with SCD the majority do not opt for PND or even when this option is selected only a small proportion opt for termination of an affected fetus. It is possible that although a social factor, culture, was considered the most viable focus for the study at the outset following Phase 3 data collection it became evident that an exploration of this dimension was not sufficient in explaining the emerging data which suggested that perhaps there is strong psychological dimension which if explored will help explain the discrepancy between values and behaviour, hence the application of cognitive dissonance theory to the qualitative data post hoc.

African and Caribbean societies place great value in parenthood. Yet within some of these communities, especially African communities, there appears to be an intolerance of disability. However the prospect of having a disabled child did not appear to influence the decision to have children or take steps to avoid having a child with a disability. This raises a number of pertinent questions: what compels individuals to make certain choices where there may be several conflicting cognitions. For example, the tension between ‘it is important to have children’, yet ‘it is not acceptable to have a disabled child’; ‘birth of disabled children should be avoided’ and a conflict in religious values which says ‘it is wrong to kill, even an unborn fetus’; a society that
believes that ‘one should marry for love’ and the conflicting view in some cultures that ‘two people with sickle cell trait should not marry each other’.

These cognitive tensions are a reality for many sections of the African and Caribbean community, but how do they deal with them? What factors are at play to enable individuals to deal with these conflicting cognitions and the tensions they cause? What strategies are adopted to reduce the cognitive tensions, especially when making a decision about marriage (coupling), having children, an at-risk pregnancy and an affected pregnancy? Cognitive dissonance theory was applied to the interview data in order to explore these pertinent questions.
4.3 Methodology

4.3.1 Triangulation of data collection (Quantitative / qualitative)

In this study I used a triangulation of research methods by adopting both a quantitative and qualitative approach in order to explore what is a previously uncharted research territory: a comparison of the cultural attitude to sickle cell among African and Caribbean people living in the United Kingdom. The use of the quantitative approach in Phases 1 and 2 of the study aimed to generate data on factors identified through literature review and prior clinical experience, enabling a comparison with other similar research findings whilst the Phase 3 qualitative data will help illuminate and enable discovery of previously unidentified socio-cultural issues that may be peculiar to the study population or reflect the attitudes of African and Caribbean people in the wider population in the UK. I suggest that this approach is appropriate where one is seeking to obtain naturally-arising meaning from the subjects themselves (Berg 2001, Denzin and Lincoln 2000, Silverman 2001).

Although much criticism has been levied against qualitative research for not being scientific Berg (2001) has asserted that such an approach compared to quantitative methods is more fruitful in providing greater depth of understanding, especially in a previously untested subject or population, and the data obtained is just as valid since it measures the subjects essence, the meaning attributable to it.

In support of triangulation Berg (2001) asserts that ‘certain experiences cannot be meaningfully expressed in numbers’ and by applying more than one methodology the researcher will be better able to obtain a richer more illuminating data. However Foss and Ellefsen (2002) warns that in using triangulation of methods one must acknowledge that they originate from different epistemological traditions and avoid the danger of ranking the methods, recognizing instead that one approach is just as valid as the other, both have equal merit and the combination of both methods has the potential to provide richer data.

Although quantitative approaches allows one to take distinctive measures and make comparisons between groups it gives only half of the story since it does not provide the why of what is observed and cannot convey the meaning of the player’s actions or views about an issue. Hence Cotter and Smith’s (1998) argument that adopting a multiple research approach (an eclectic
methodology) for nursing research helps test known theories, as they apply to nursing and helps elucidate relevant data from non-traditional sources and theoretical approaches, especially in a subject area that has not been studied in the past. In view of this a triangulation of quantitative and qualitative methods appeared justified and appropriate for the current study.

The data collection will not rely entirely on what has been written before on the subject, so that bias is not introduced into the interpretation of the data obtained, especially in Phase 3.

A number of convincing concepts derived from literature were used to formulate the quantitative questionnaire and develop a semi-structured interview guide for Phase 3, so as to prevent collection of irrelevant material, but women and their partner’s were encouraged and given an opportunity to deviate from the semi-structured questions in order to enable pertinent and unexpected issues to emerge.

Creswell supports the idea that a qualitative approach is appropriate where, ‘…the topic needs to be explored…(if) variables cannot be easily identified, theories are not available to explain behaviours of participants or the population of study and theories need to be developed’ (Creswell 1998). In addition this approach places emphasis on the researcher being an active learner who is there to tell the 'story' from the participant's point of view. Thirdly, it is appropriate where the audience is likely to be more receptive to this approach compared to structured quantitative methods. It was noted that Phases 2 and 3 of the project were conducted at a time when women / couples were emotionally vulnerable, the subject is highly sensitive and this may adversely affect their decision to participate in the study.

Only women / couples who are aware that they are at risk of having a child with SCD are included in Phase 3, this is a time when they are cogitating about whether to test the fetus in the womb through PND or not, or they have just made a decision to test and are awaiting the appointment. Some of the women had already declined an offer of PND, others were awaiting the result of a PND and a few had already received the result of the PND and the fetus is unaffected whilst in one case the result showed that the baby has sickle cell anaemia and the woman was contemplating whether to terminate the affected pregnancy or not.

These varied circumstances made the interviews emotionally stressful and sometimes painful for the participants, and on one occasion for the researcher too, but all participants agreed to
continue with the interview, which added richness to the data. Shavers-Hornaday et al. (1997) argued that ‘merely obtaining the appropriate signature on a consent form does not absolve the investigator of his or her obligation to the participant. A signed consent form, while affording legal protection, does not provide moral immunity’. It was acknowledged that this period required extreme sensitivity, and the researcher, who is a qualified counsellor, was able to adopt and apply humanistic counselling approaches (Rogers 2003, Nelson-Jones 2002) to the interview situation. This helped to relieve the participants’ anxieties and distress on the two occasions that it occurred.

4.3.2 Ethical approval

Ethical approval was obtained from the London Multi-centre Research Ethics Committee (MREC), and the University of Surrey Advisory Committee on Ethics. The following Local Research Ethics Committees (LREC) and or Research and Development (R and D) Ethics Committees also gave approval – Brent Medical Ethics Committee, Croydon Local R and D, Guys Research Ethics Committee, Camden & Islington Community Health Services Local Research Ethics Committee; the joint ethics committee of King’s College London (university), Guy’s & St Thomas’ Hospital NHS Trust, King’s College Hospital NHS Trust, The Lewisham Hospital NHS. Approval was also obtained from East London and The City Local Research Ethics Committee; Harrow Research Ethics Committee; and the University College London Hospital NHS Trust R and D.

A signed consent was sought and obtained from all participants in all three phases. Where consent was not provided the respondent was contacted and re-sent a form, and where this attempt failed the respondent was excluded from the study so as to meet the criteria for gaining ethical approval.

4.3.3 Instrument design

Michie and Marteau (1996) proposed that when designing a research instrument which aims to measure attitude to genetics and counselling it is important to include open-ended questions and numerical rating scales, to allow for more accurate and richer data to emerge, otherwise one may lose important subjective information. In view of these arguments a questionnaire was devised
specifically for the study containing questions that were predominantly numerical rating scales, and also giving opportunities for participants to comment or elaborate on their response. Open-ended questions were incorporated into the face-to-face interviews in Phase 3.

The questionnaire was submitted to three experts in the field: a specialist clinician managing patients with SCD, a psychologist with a special interest in genetics, a specialist clinical psychologist dealing with patients with SCD; comments were also received from my three project supervisors and a pilot study was conducted (See section 4.2.4).

The instrument aimed to measure four dimensions:

- Knowledge of sickle cell (section 1: Questions 1-21)
- Attitude to sickle cell and genetics (section 2: Questions 22-39)
- Health locus of control (psychological) (section 3: Question 1-18)
- Ethnicity and Cultural orientation (section 4: Question 1-37)

The knowledge of sickle cell questions were devised based on information obtained from patient and general public health promotion materials, written and electronic, that are readily available and accessible to the general public. A basic knowledge of sickle cell can be obtained from these sources and members of the general public who have had any exposure to sickle information, including counselling, would be able to answer the questions devised.

The locus of control concept originated with Rotter’s (1966) social learning theory where an individual is assessed on the degree to which they believe that they have control over their lives or whether external forces have some or greater control. These two dimensions were perceived and named ‘external’ and ‘internal’ locus of control. External refers to the belief that forces or factors outside of an individual determine outcome and the individual has little or no power over these, conversely internal refers to the outcome being dependent on the beliefs, decisions and actions generated from within the individual. The developers of this approach suggest that the locus of control scale measures characteristics or tendencies and the outcome of these can be generalized to a wider population.

The locus of control concept was further developed and extended by Levenson (1973a and 1973b) who described three variables internal control, the effectiveness of powerful others and the role of chance in determining locus of control, this culminated in the Levenson Locus of
Control Scale. Using Levenson’s scale Wallston et al. (1976) and Wallston et al. (1978) and Wallston (1992) developed the Multi-dimension Health Locus of Control (MHLC) scale, which as reported by Black (2003) has been used in over one thousand studies, for a variety of health conditions and populations worldwide. Concept and construct validity, content validity, instrument reliability and validity have been demonstrated in a number of studies and many of these studies have been replicated (Lefcourt 1983). Stephen et al. (1983) claim that those with an internal locus of control have greater control over their health and respond better to life situations that demand resilience and fortitude and there is mounting evidence that internality seems related to positive health behaviour and outcome.

The concept and instrument has been further developed and adapted for use in different ethnic groups and has been used by a number of researchers among minority ethnic communities (Wrightson and Wardle 1997).

Shiloh (2000), in a discussion of decision-making in the context of genetic risk suggests and supports the use of the Health Locus of Control as a psychological construct in this new field of research, suggesting that it will help elucidate important information about people’s response to genetics and genetic risk and will help promote objectivity in the interpretation of the findings. In view of this the MHLC questionnaire was incorporated into this study to obtain quantitative data on psychological dimensions of health and illness and to examine whether health locus of control had any influence on African and Caribbean people’s attitude to health and to sickle cell specifically.

In criticism of locus of control scales, however, Kline (2000) argued that MHLC scales are of a low psychometric value, are probably too ambitious in their attempt to measure attitudes since they can only measure a small number of specific questions therefore it will be difficult to assess and defend them as contributing any psychological insight to the body of knowledge already available in the field of psychology.

Despite this criticism, there is a wealth of evidence that demonstrates the validity and reliability of the MHLC in measuring internal, external and powerful others locus of control. Therefore it is used in this study because it serves the purpose of providing basic data that will enable a comparison of the two ethnic groups. A complicated, highly sensitive psychometric tool was not deemed necessary for this study because the main objective is not to measure an in-depth
psychological response but to gain a basic measure of how people perceive their health and whether they or others have greater control of it; whether differences in terms of MHLC have any impact on the individual’s attitude to sickle cell.

A more sophisticated psychometric measurement tool would be appropriate for a more psychology-focused study seeking data for the purpose of an intricate psychological assessment. In the case of this current study such a sensitive tool would yield unnecessary detailed data and in any case it would be difficult to administer, particularly in Phases 1 and 2, which were postal surveys.

The Tsai cultural orientation scale (Tsai, et al. 2000) has been selected with the aim of measuring to what extent an individual demonstrates being 'African' or being 'Caribbean'? A number of instruments were examined and many of these did not appear suitable, and would not have been effective for conducting a study which used a postal survey.

In discussing cultural orientation several authors suggest that age of migration is significant when measuring cultural attitude, those who have spent their most formative years in another culture will reflect the attitude of that culture of origin more strongly than those who migrated at a later age, who will demonstrate a dual culture and a greater degree of assimilation of the host (new) culture (Tsai et al. 2000, Atkinson 2004). In view of this the current study aims to compare those who were born/migrated to the UK <15 years of age with those who migrated >15 years of age. The age demarcation was selected because this is the end of the secondary-level education in Africa, Caribbean and a year later in the UK and was therefore considered an age that one would expect an individual to be cognitively, psychologically and culturally mature in terms of identification with a specific cultural group.

The ethnicity measurement instrument that was selected was designed by a North American psychologist, Professor Tsai, and has been applied extensively to the examination of the cultural orientation of Chinese, African-American, Asian and other cultural groups (Tsai et al. 2000).
Tsai et al. (2000) argued that identification with an ethnic group and cultural orientation can be measured in six domains:

- Language
- Social affiliation
- Activity (cultural)
- Ethnic pride
- Ethnic food
- Ethnic exposure

Scoring in these six domains gives insight into the level of cultural orientation: the higher the score the stronger the cultural orientation.

It is possible to measure level of cultural orientation to a primary culture i.e. country of enculturation, and, where an individual has migrated to another culture, to simultaneously measure the level of acculturation to the host culture. This is described in Tsai et al.’s (2000) study of 353 Chinese American young adults recruited from a group of college and university students in San Francisco. The research team compared those born in the USA with those who migrated before the age of twelve and a third group who migrated after the age of twelve. Statistically significant differences were observed in the three groups in respect of the relationship between level of ‘being Chinese’ and level of ‘being American’ in the six cultural domains. Those born or migrated to the USA before the age of twelve demonstrated ‘being American’ more than those who migrated after the age of twelve. This supports Atkinson’s (2004) assertion that age of migration influences ethnic orientation and acculturation to the host culture. It is possible to add that it also influences cultural viewpoint and attitude.

This instrument was chosen for the present study because of its reported validity and reliability and since it purports to measure some of the factors that were identified through literature reviews as significant factors that influence cultural identity and attitude, for example, language. Other literature supporting the claim that these factors influence cultural identity include Kaplan and Manners (1972), Jenks (1993), Krauss and Chiu (1998), Salzman (2001) and Atkinson (2004).
Unlike Tsai and her team who measured level of ‘being Chinese’ and ‘being American’ simultaneously using the same sample population, I utilized the instrument to measure level of cultural orientation in one culture only, either ‘being African’ or ‘being Caribbean’, and subsequently compared these two cultural groups to determine whether the African participants demonstrated being African more than the Caribbean participants demonstrated being Caribbean or vice versa. I was particularly interested in level of orientation to culture of origin, hence the exclusion of those who had a dual culture - for example, those who had one African and one Caribbean parent and those of mixed Black and White origin.

4.3.4 Pilot study

The questionnaire was distributed to a purposefully selected group of five African men, five African women, five Caribbean men and five Caribbean women (N=20) of varying educational backgrounds, religion, marital status and age range. The pilot study also asked participants to comment on the design, use of language, terminology, cultural sensitivity, content and ease of completion of the questionnaire. Responses were received from four African women, two African men three Caribbean women, one Caribbean male and one mixed race African/Caribbean female. Comments from these were used to revise the questionnaire, for example, questions that appear ambiguous, repetitive, contradictory or culturally insensitive were rephrased or omitted prior to completion of a final version. Secondly, the layout, font and design of the questionnaire was changed and made into a professionally printed booklet to make it more pleasing aesthetically.

4.3.5 Recruitment and distribution of questionnaires

4.3.5.1 Sample size

The project was divided into three phases. Phase 1 aimed to obtain baseline data of knowledge of sickle cell, attitude, health locus of control and ethnic orientation of general public African and Caribbean men and women in general. This data was compared with the data obtained from pregnant women in Phase 2. This comparison revealed to what degree the pregnant women were
similar or different to the general population and whether pregnancy and being at-risk of having a child with SCD influenced attitude in comparison to the general non-pregnant population.

A major aim of the study is to determine whether there are differences in knowledge of sickle cell between Africans and Caribbeans. Practical clinical experience had led me to think that knowledge of sickle cell is greater among Caribbeans than Africans.

With a 5% significance level and 90% power, it was calculated that approximately 63 subjects would be required from each comparison group to enable the researcher to detect a statistically significant difference in knowledge and attitude between any two or more groups. To be able to determine whether gender influenced attitude it was deemed necessary to recruit approximately 63 subjects in each gender and ethnic group for Phase 1 of the study i.e. 63 African women, 63 African men, 63 Caribbean women and 63 Caribbean men. Similarly in Phase 2 to be able to detect statistical significance at the 5% level it was estimated that 63 subjects were required from each ethnic group i.e. 63 African Antenatal women and 63 Caribbean Antenatal women. Sadly this was not achieved in terms of Caribbean Males and Caribbean Antenatal women.

In order to address the issue of error in multiple testing caused by the large number of variables collected in this study only statistically significant findings at the 1% (p<0.01) level or below are reported.

Number of women potentially at-risk of having a child with SCD in the UK each year is approximately 300. About 90% of these reside in London and a significant proportion of these women book for confinement of pregnancy at any one of the centres participating in the project. The aim was to recruit ten African and ten Caribbean pregnant women and their partners who are at-risk of having a child with sickle cell anaemia to participate in the Phase 3 interview.

Phase 1 - Convenience sample of 423 African and 410 Caribbean men and women from the general population were asked to participate in the project. A total of 156 African and 154 Caribbean returned the questionnaire; of these 142 African and 145 Caribbean met the study criteria and were included in the study.

Specific Aim: to identify whether there are statistically significant differences in the knowledge and attitude of African and Caribbean, men and women.
Phase 2 - Convenience sample of 224 African Antenatal women and 124 Caribbean Antenatal women identified with laboratory-confirmed sickle cell trait (HbAS) were asked to participate. A total of 78 African Antenatal and 42 Caribbean Antenatal returned the questionnaire; of these 75 African Antenatal and 41 Caribbean Antenatal met the study criteria and were included in the study.

Specific Aim: to identify whether there are statistically significant differences in the knowledge and attitude of African and Caribbean, men and women.

Specific Aim: to identify whether there are statistically significant differences in the knowledge and attitude of pregnant African and Caribbean women and to identify those at-risk and eligible for inclusion in Phase 3 of the project

Phase 3 - Convenience sample of 14 African Antenatal women, 9 Caribbean Antenatal women and their partners (6 African Male Partners and 1 Caribbean Male Partner) with sickle cell trait (HbAS) who are at-risk of having a child with sickle cell anaemia (Hb SS) agreed to participate in the interview and completed an additional questionnaire (see Appendix 2).

Specific Aim: to engage women and couples in the research process and identify socio-cultural factors that influence attitude to sickle cell and decisions made about a current at-risk pregnancy, to give a voice to women and their partners to enable them to tell their ‘own’ story.

In view of targeting the general public for Phase 1 of this study the use of a postal survey appears to be the most conducive method for obtaining the necessary data. Secondly the low number of women and their partners that were accessible for Phases 2 and 3 made the selection of an alternative sampling method unrealistic. This was confirmed with the difficulty experienced in recruiting for Phase 3, where the original intention was to obtain details of all eligible women and partners in Phase 2 identified over a six month period and from these to purposefully select 10 African and 10 Caribbean pregnant women and their partners, taking into account socio-demographic aspects. However, it became increasingly difficult to obtain the number required hence the need to use a convenience sample. Fowler et al. (2002) suggested that ‘the main problem with quota (convenience) sampling is that accessible individuals may not be representative of the study population’, however any other form of sampling for this study would limit the opportunity to obtain the number required for a robust study.
4.3.5.2 Recruitment process

**Phase 1** - Participants were recruited via community voluntary organizations; statutory organizations, such as the sexual health clinic in one hospital; advertising in a newspaper aimed at the Black community, attendance at events attended by minority ethnic communities e.g. the Martin Luther King Annual Memorial Lecture, where an announcement was made and an advert placed in the event programme; distribution of leaflets in higher education institutions and advertisements on Websites targeted at Black communities in the UK. Professional colleagues, friends and family members also assisted in distributing questionnaires. This method of convenience sampling influenced the calibre of respondents recruited to the study and may have inadvertently biased the sample. The impact of this recruitment style is discussed later.

**Phases 2 and 3** - A letter of invitation was distributed to pregnant African and Caribbean women who had a laboratory-confirmed sickle cell trait result. The women were recruited through six specialist sickle cell and thalassaemia centres serving a total of eight antenatal clinic hospitals. The invitation letter was sent to the women a few days after their genetic counselling appointment letter was sent with the intention that the research letter should arrive at least two days after the genetic counselling appointment letter. The reason for adopting this posting method is an attempt to prevent any confusion between the women’s genetic counselling appointment and the request for participation in the study.

When the women attended the genetic counselling appointment which was approximately seven to ten days after the invitation letter was sent they were given face-to-face information about the project by the researcher or by the onsite collaborating clinicians. Those who agreed to participate were asked to complete the questionnaire on site or given a pack to take away and return in a prepaid envelope with a signed consent form. Those who failed to attend the genetic counselling appointment were contacted on the telephone by the onsite participating clinician to obtain their consent for the researcher to contact them about the project specifically this process was adopted in order to maintain patient confidentiality. Those who did not furnish a telephone number when booking confinement of pregnancy were deemed ‘not contactable’ and excluded from the project.
In addition at-risk African and Caribbean pregnant women and their partners were invited to participate via two fetal diagnostic units; these were recruited through face-to-face contact with onsite clinicians and they were later sent letters of invitation. Although 64 women (56 African and 8 Caribbean) appear to meet the inclusion criteria by virtue of being at risk of having a child with sickle cell anaemia, all of these were not approached due to the participating clinician not having direct contact with all those who were eligible to take part and in some instances the personal circumstances of the women at the time of consultation made it inappropriate for the clinician to discuss the project.

Written consent was obtained from all those who agreed to participate. Where necessary an interpreter was provided but was required on one occasion only in interviewing an African Antenatal respondent. A translator or reader was offered for those who have literacy or reading difficulties. This offer was accepted on one occasion by a Caribbean Antenatal respondent whilst completing the questionnaire.

It is acknowledged that Black people, especially men, are extremely difficult to recruit to research studies. Following discussion with the project supervisors, community groups, the Black press and other media it was considered appropriate to offer an incentive so as to maximize participation, thus those who participated in Phases 1 and 2 of the project were entered into a free prize draw and were eligible to win a DVD player/recorder.

Those participating in Phases 2 and 3 were offered reimbursement of local public travel expenses but this was not utilized as the majority of respondents were seen in the clinic and those interviewed were visited at home by the researcher and one was interviewed at the local sickle cell and thalassaemia centre.

### 4.3.5.3 Inclusion criteria

Participants in the three phases are those both of whose parents are either of African origin or Caribbean origin, and they are of natural childbearing age, which has been determined as below 45 years, and respondents must be currently residing in the UK. Respondents in Phase 2 must be pregnant, booked for confinement at one of the eight participating centres with a laboratory-
confirmed diagnosis of sickle cell trait. In addition, Phase 3 must be women identified as being at risk of having a child with sickle cell anaemia (HbSS) only.

4.3.5.4 Exclusion criteria

Those below the legal age of consent, 18 years, and those above natural childbearing age of 45 years were excluded. The former group were excluded in order to minimize the difficulty of seeking parental consent and to limit the possible impact of cognitive immaturity. Those over the age of 45 were also excluded on the basis that other factors, such as difficulty with conceiving and other age-related obstetric factors may influence participants’ attitude to the risk of having a child with sickle cell anaemia. Individuals where both of their parents are not of African or of Caribbean origin including those with mixed African and Caribbean parentage were also excluded, since they will have had dual cultural exposure and this may influence data outcome.

Those with evidence of a cognitive, physical or mental disability, which may affect their ability to make an informed decision about taking part in the project or the ability to complete tasks required in the project were also excluded. In Phases 2 and 3 those with any other haemoglobinopathy, including those with disease states and in Phase 3 women whose partners have other genetic mutations of haemoglobin that may pose a risk of having a child with other forms of SCD were excluded.

Attempts were made to collect as much missing data as possible, participants who failed to complete the questionnaires fully were contacted on the telephone number, which they supplied in the questionnaire, missing data were obtained verbally and in a few cases the questionnaire was returned for completion. Of those who were re-sent the questionnaire only one failed to return it because the participant had moved in the interim. Attempts to contact three participants failed, the number of missing data in their questionnaires warranted their exclusion from the final data analysis.
4.4 Organization of questionnaire and interview schedule (measurement tools)

4.4.1 Section 1 – Knowledge of sickle cell: Question 1-21

See Appendix 1 for copy of questionnaire.

Questions 1 – 21 were developed for the study specifically to assess general knowledge of sickle cell. They cover educational aspects commonly found in public health promotion materials and used for basic education and genetic counselling of lay groups. Lay members of the African and Caribbean community who have been exposed to basic information about sickle cell are expected to be able to answer all these questions correctly. Concept and content validity was tested during the pilot study. Participants in the pilot study indicated that the questions were appropriate and could be answered by those who have had some exposure to the information through basic educational programmes, public awareness campaigns and genetic counselling. Participants who indicated that they had no prior knowledge of sickle cell were still encouraged to participate because this would reflect the general population and reduce selection bias. These individuals were permitted not to complete the general knowledge and attitude to sickle cell questions in section 1 and 2 of the questionnaire, and they were not included in the data analysis of those sections. However, they completed section 3: demographic data; section 4: multi-dimension health locus of control data; and section 5: ethnicity data.

In the final data analysis of section 1 questions 7, 11 and 19 were omitted due to their being considered ambiguous or tautological.

4.4.2 Section 2 - Attitude to sickle cell: Questions 22–37

These were recoded numbers 1-16 for ease of data analysis. In an attempt to deter participants from merely ticking boxes without going through a true thinking process some of the statements were reversed, giving a negative attitude to the statement was given a high score whilst a positive attitude to the statement was given a low score. Questions 22, 24, 26 and 28 were negatively
phrased in order to challenge respondents and ensure their selection reflected their attitude to the statement. During the analysis it appeared that this strategy may have had an undesired outcome, especially for respondents whose first language is not English and those who may have difficulty relating to this method of questioning. Factor analysis indicated that some of the participants may have misinterpreted these reverse statements. For example, in Q22, “I believe that sickle cell disease is not a serious condition”, it appeared that some participants may have interpreted this as “I believe that sickle cell is a serious condition”, because of the inconsistency of their response to other questions, where one anticipated a similar attitudinal response. However, it is difficult to ascertain to what degree this confusion may have occurred and this appears to be one of the limitations of the study. Where there appeared to be discrepancies in response to the questions a number of respondents were contacted by telephone to clarify their response.

For the purpose of data analysis the negatively phrased questions were subsequently reversed so as to maintain consistency in output where a high score demonstrates a positive attitude to the statement whilst a low score demonstrated a negative attitude to the statement.

All the questions in this section were condensed into five attitude summary variables to measure the relevant concepts that were used for designing the questionnaire as identified through literature reviews, informal discussion with support groups and parent’s of children with SCD. The attitude summary variables are:

- Perception of severity of disease - Question: 1, 2, 6, 8, 13
- Attitude to prevention of affected births - Question: 3, 9, 16
- Genetic decision-making - Question: 4, 10, 12
  (Self versus Others)
- Level of burden of sickle cell disease - Question: 5, 14
- Reproductive drive (desire to have a child) - Question: 15

Other elements measured were:

- Knowing someone with sickle cell disease personally - Question: 17
- Whether the person lived with you or not? - Question: 18
These two questions were devised in an attempt to ascertain whether having had personal experience of living with someone with SCD influenced attitude to the illness and pre-conceptual decision-making with regard to selecting a partner and having children.

Questions 7, 11 and 19 were omitted from the final analysis as these were deemed ambiguous or they measured aspects that were being measured by other questions.

4.4.3 Section 3 – Demography: Questions 40-64

This section collected general demographic data, which included ethnicity, age, marital status, gender, educational level, employment, religion and level of religious activity if any, whether born / migrated to the UK <15 years of age or migrated >15 years of age, whether tested for sickle cell and who influenced decision to be tested (self or others e.g. pregnancy, newborn and pre-surgery requirement), result of the blood test, how result was obtained, and if face-to-face whether counselling was received and if so from whom, and whether the counselling was useful and reassuring, and, if respondents knew their test result before having children whether they chose their partner based on their own test result. They were also asked if their partner had been tested and the result of his or her blood test. If the individual had not been tested they were asked to say why they had not been tested so as to determine whether they made an informed choice about being tested or not or they had never considered the issue.

4.4.4 Section 4 – Multi-dimension Health Locus of Control (MHLC): Questions 1–18

The MHLC attempts to measure an individual’s health locus of control in three domains:

- Internal (I) - measured by Q 1, 6, 8, 12, 13 and 17
- Chance (C)  - measured by Q 2, 4, 9, 11, 15 and 16
- Powerful Others (P)  - measured by Q 3, 5, 7, 10, 14 and 18

The maximum score in each domain is 36.
4.4.5 Section 5 – Ethnicity and cultural orientation: Questions 1-37

As discussed earlier, Tsai et al. (2000) suggest that ethnicity has six measurable domains: language, social affiliation, social activity, cultural pride, use of food associated with one’s culture and exposure to culturally specific social situations. These dimensions were used by the researchers to construct a tool to measure an individual’s level of acculturation to their culture of origin and, when migrated, level of enculturation and assimilation of the host culture.

In Section 5 of the questionnaire questions 5 and 26-36 were recoded for data analysis to maintain consistency whereby a high score represented a positive response to the statement whilst a low score represented a negative response to the statement.

In addition the 36 questions in this section were condensed into six categories for the analysis of the dimensions that constitute ethnic orientation as described by Tsai et al. (2000). These were:

- Ethnicity and language - Q8, 15, 26-32, 34, 35, 36 (maximum possible score 60)
- Ethnicity and social affiliation - Q10, 12, 13, 14, 22, 23, 24 (maximum possible score 35)
- Ethnic activity (participation) - Q16, 17, 33 (maximum possible score 15)
- Ethnic pride - Q 4, 5, 6, 7, 11, 18 (maximum possible score 30)
- Ethnic food - Q19, 20 (maximum possible score 10)
- Ethnic exposure - Q1, 2, 3, 21 (maximum possible score 20)

Possible maximum overall score is 170, demonstrating the maximum degree of acculturation or enculturation to the culture that is being measured. The lower the score the less oriented an individual is to that culture.
4.4.6 At-risk women - Phase 3 questionnaire

A questionnaire was developed for Phase 3 (See Appendix 2) which attempted to examine factors that were not included in the Phase 2 questionnaire. This brief questionnaire was administered at the time of the face-to-face interviews and aimed to assess whether the women had other issues that may have an impact on their attitude to sickle cell and decision-making. The intention was not to apply a statistical data analysis to the instrument but to extract qualitative data which may help elucidate some of the findings in the Phase 3 interviews.

This included whether they had any difficulty conceiving, treatment for infertility before current conception, previous miscarriage or terminations of pregnancy and reasons (this was to ascertain whether an individual has terminated a previously affected pregnancy), number of children already in the family and, if tested, their Hb type, number of affected births (SCD), whether they knew they were at-risk of having a child with SCD prior to the current pregnancy, whether they were planning to have the current pregnancy tested (PND) and consider termination if it is affected, whether they were planning to have more children and what was influencing this decision, and, finally, whether they sought the support of non-professionals in their decision-making.

4.4.7 At-risk women - Phase 3 Interview Schedule

An interview schedule Appendix 3 was developed based on the factors identified through literature search and following an initial analysis of themes emerging from the quantitative data, particularly the textual comments made by participants in the Phase 1 and Phase 2 questionnaires. This schedule was used as a guide to stimulate discussion, focus the interview and enable relevant issues to emerge from the interview however interviewees were able to deviate from the scheduled questions if during the course of the interview the issues they raise appear relevant to the research question or offer a new dimension to the subject.
4.5 Study population

4.5.1 Study population – Inclusions

The study population comprises of the following:

**Box 1 – Study population**

<table>
<thead>
<tr>
<th>Group</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Female</td>
<td>67</td>
</tr>
<tr>
<td>Caribbean Female</td>
<td>86</td>
</tr>
<tr>
<td>African Male</td>
<td>75</td>
</tr>
<tr>
<td>Caribbean Male</td>
<td>59</td>
</tr>
<tr>
<td>African Antenatal</td>
<td>75</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>41</td>
</tr>
</tbody>
</table>

All respondents completed the questionnaire except 1 African Antenatal who participated in Phase 3 only because the questionnaire was missing in the post. As indicated above despite all attempts to recruit a minimum of 63 respondents in each ethnic group and gender this was not achieved in the Caribbean Male and Caribbean Antenatal. However, it was still possible to conduct a robust statistical analysis with the number obtained.

**Box 2 – Phase 3 interview population**

<table>
<thead>
<tr>
<th>Group</th>
<th>Pregnant Women</th>
<th>African Male Partners</th>
<th>Caribbean Male Partners</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Antenatal</td>
<td>14</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>9</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Of the total number of at risk-women and partners interviewed it should be noted that a proportion were recruited from two tertiary Centres (5 African Antenatal, 4 Caribbean Antenatal, and 2 African Male Partners); these individuals have selected to have and in some cases have already had prenatal diagnosis.

The Phase 3 African and Caribbean Male Partner’s quantitative data was included in the Phase 1 general public data analysis because these were an insufficient number to analyse separately.
4.5.2 Phase 1 – Respondents excluded

Fourteen African and nine Caribbean participants were omitted because they did not meet the inclusion criteria. These included individuals who were < 18 years and > 45 years of age, those of mixed ethnic origin, non-UK resident, those with SCD and insufficient completion of the questionnaire.

Twelve respondents reported that they had no previous knowledge of sickle cell and were therefore unable to complete sections 1 and 2 of the questionnaire, however they completed Section 3 – demographic data, Section 4 – Multi-dimension Health Locus of Control (MHLC) and Section 5 – Ethnicity, and this is reflected in the analysis; number of respondents included for analysis of knowledge and attitude was less than the total population (n=275), whilst the total population was used for the analysis of MHLC and ethnic orientation (n=287).

4.5.3 Phase 2 - Respondents excluded

Four pregnant antenatal women were excluded from the project because they did not meet the inclusion criteria they were of mixed ethnic origin or had failed to complete the questionnaire sufficiently.

It was noted that one African Antenatal woman reported that she had no previous knowledge of sickle cell and was therefore unable to complete Section 1 and 2 of the questionnaire, therefore she was excluded in the analysis of attitude (n =115), however she completed Section 3 – demographic data, Section 4 – Multi-dimension Health Locus of Control (MHLC) and Section 5 – Ethnicity and in the analysis of MHLC and ethnicity (n=116).

4.5.4 Phase 3 - Respondents excluded

All the pregnant women and partners who agreed to being interviewed met the inclusion criteria, but following the interviews one African Antenatal woman was excluded because the tape was inaudible.
4.6 Process of data analysis

4.6.1 Addressing the research question

i. Is the attitude to sickle cell influenced by cultural outlook and other social experiences?

ii. Are decision-making and pregnancy outcome influenced by culture and other psychosocial factors when a woman or couple is at risk of having a child with sickle cell anaemia?

The quantitative data obtained in Phases 1 and 2 demonstrated that question (i) has been answered effectively, utilizing the tool developed specifically for the project. Initially the data appear to suggest that the original hypothesis, that there will be statistically significant difference in knowledge and attitude base on ethnicity, was not strongly substantiated in that there were only a few statistically significant differences observed between African and Caribbean respondents. However, on further inspection there was unexpected statistical significant differences based on whether an individual was born/migrated to the UK <15 years of age or migrated >15 years of age. This supports the assertion that culture does play a part in influencing attitude to sickle cell.

4.6.2 Management of parametric and non-parametric data

The quantitative data was entered into SPSS and a normal bell-shaped distribution curve was observed.

Analysis was conducted using parametric and non parametric techniques this included: two-tailed t–test, one- and two-way Analysis of Variance (ANOVA) and Multivariate Analysis of Variance (MANOVA), Mann-Whitney U test and Chi-square. These were applied to a number of dependent and independent variables to determine whether there were any statistically significant differences between two or more groups or variables. Analysis was conducted on the groupings listed in Box 3 whilst the variables analysed are listed in Box 4.
Box 3 – Composition of groups analyzed

<table>
<thead>
<tr>
<th>Group comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnic All Group - Africans (African Males/African Females) v. Caribbeans (Caribbean Males/Caribbean Females)</td>
</tr>
<tr>
<td>Gender Group - Females (African Female / Caribbean Female) v. Males (African Male/ Caribbean Male)</td>
</tr>
<tr>
<td>Females - African Female v. Caribbean Female</td>
</tr>
<tr>
<td>Males - African Male v. Caribbean Male</td>
</tr>
<tr>
<td>Ethnic Gender Group 1 - African Female v. African Male</td>
</tr>
<tr>
<td>Ethnic Gender Group 2 - Caribbean Female v. Caribbean Male</td>
</tr>
<tr>
<td>Ethnic Group Pregnant - African Antenatal v. Caribbean Antenatal</td>
</tr>
<tr>
<td>Ethnic Group Pregnant / Non Pregnant - (African Antenatal / Caribbean Antenatal) v. (African Female / Caribbean Female)</td>
</tr>
</tbody>
</table>

Box 4 – Variables analyzed

<table>
<thead>
<tr>
<th>Group comparison variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary Attitude Variables two-tailed t-test:</td>
</tr>
<tr>
<td>• Perception of severity of disease</td>
</tr>
<tr>
<td>• Attitude to prevention of affected births</td>
</tr>
<tr>
<td>• Genetic decision locus of control (Self v. others)</td>
</tr>
<tr>
<td>• Level of burden (of sickle cell disease)</td>
</tr>
<tr>
<td>• Reproductive drive (importance of having children)</td>
</tr>
<tr>
<td>Multi-dimension Health Locus of Control (MHLC) two-tailed t-test:</td>
</tr>
<tr>
<td>• Chance</td>
</tr>
<tr>
<td>• Internal</td>
</tr>
<tr>
<td>• Powerful Others</td>
</tr>
</tbody>
</table>
Table: Group comparison variables

<table>
<thead>
<tr>
<th>Variables analyzed</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnic orientation (Enculturation) two-tailed t-test</td>
<td>Language, Social affiliation, Activities engagement, Pride, Exposure, Food</td>
</tr>
</tbody>
</table>

Analysis of Variance (ANOVA) and Multivariate Analysis of Variance (MANOVA) was conducted to look for one and two-way interaction between the following:
- Ethnicity
- Gender
- Born/came to UK < 15 years or >15 years of age
- Marital status
- Educated to above degree level
- Lived or not lived with someone with sickle cell disease
- Blood test result - normal and carrier
- Mode of notification of blood test result - postal or face-to-face counselling

Chi-Square analysis was applied to the following:
- Born/ migrated to the UK < 15 years of age / migrated > 15 years
- Practising a religious faith / not practising a religious faith
- If Christian, Orthodox Christian / non-Orthodox Christian
- Educated to < degree level / educated to > degree level
- Knowing someone with SCD / not knowing someone with SCD
- If knowing someone with SCD lived with/ not lived with individual
- Tested for the sickle cell gene / not tested
- Selection of partner based on own test result
- Mode of receiving result (post/face-to-face notification or counselling)
- Employed / unemployed
- Married - cohabiting / single- separated - divorced

In conducting the multivariate analysis of variance (MANOVA) two factors included in the original analysis were:
- Blood test result - normal and carrier
- Mode of notification of blood test result - postal or face-to-face counselling
These were subsequently excluded because a substantial number of respondents, 199 of the total 287, indicated that they had not been tested and this made it difficult to conduct a robust analysis with these two factors included. In order to determine whether to include or exclude these two factors, analysis was conducted with and without the two factors. The data output was examined and their subsequent exclusion was justified by the richer data obtained without them, therefore the reported data excludes these two factors.

A two-tailed t-test and one-way ANOVA was also conducted examining religion by comparing the four main religions, Orthodox Christian, Charismatic Christian, Moslem and Rastafarian, and Orthodox and Charismatic Christians separately to determine whether religious affiliation and depth of religious activity had any statistically significant impact on the summary attitude variables, multi-dimension health locus of control variables and the summary ethnicity variables.

A thematic analysis was conducted on the open-ended question responses and comments written by the respondents in the questionnaires. The findings are presented and discussed.

In order to address the issue of error in multiple testing caused by the large number of variables collected in this study only statistically significant findings at the 1% (< p=0.01) level or below are reported.

### 4.6.2.1 Regression Analysis

A backward stepwise multiple linear regression was performed on the following outcome variables:

- Attitude to severity of disease
- Attitude to prevention
- Genetic Locus of control
- Perceived Level of burden
- Reproductive drive
with the following variables as potential predictor variables:

- Gender
- Ethnicity
- Age
- Marital status
- Religion
- Employment status
- Educational level
- Born in UK/ Migrated < 15 years of age vs Migrated >15 years of age
- Knowledge of sickle cell disease (test score)

### 4.6.3 Qualitative data management

The Phase 3 qualitative data was transcribed and entered into QSR N6 which is a non-numerical and instructional data indexing, searching and theorizing software, a redesign of the brother software NUDIST. Miles and Huberman (1994) suggest that a researcher commences by compiling a list of general themes obtained from literature review and add additional themes as one progress through the research and especially as one begins to read the transcripts. The data was read and reread, multidimensional scaling was used to cluster and sort the data into themes. Interrelationships were identified to determine how these relate to the research question (Mason 1996). Silverman (2000) advised building into the research design various devises to ensure the accuracy of ones interpretation of qualitative data, measures such as intercoder agreement and use of computer-assisted qualitative data programmes, both of these techniques were adopted in this study and proved of benefit. The data was subjected to thematic analysis and all coding was conducted by the researcher and a research assistant independently before inferences were made about each section of the transcribed data. Comparisons were made of the coding and where there were discrepancies in the allocation of coding a third coder was asked to allocate coding independently and the final code was agreed between the researcher and the third coder.

Miles and Huberman (1994) proposed three approaches to qualitative data analysis:
interpretative, social anthropological and collaborative social research. Denzin and Lincoln
(2000) argued that text obtained from transcribed interviews is social facts, which are produced, shared and used in a socially organized way. This suggests that the interviewee and the researcher in the social interaction and the context of the research both contribute something to the data. The interviewee interpret what it is he or she feels the researcher wants to know and responds accordingly; the researcher uses his or her social lens to interpret what they feel the interviewee is saying or mean by what is said. And although attempts are made to accurately interpret the interview data it is possible for misinterpretation to occur from both sides. Denzin and Lincoln (2000) also support Silverman’s (1998) claim that subjecting interview material to content analysis would be reductionist and counter productive because one is likely to lose the essence and the meanings which can be meaningfully attributed to each section of text.

In order to maintain the essence of what the subjects say an interpretative approach has been adopted in analysing the data; the transcripts were further examined in order to identify the patterns of meanings that were being expressed by each interviewee, individually in the first instance and then by the group collectively. Although the data was organized into themes an attempt was made to capture the essence of what each interviewee was saying and latterly the cultural group. A narrative analysis approach was then applied whereby the text was read and reread several times to determine the meaning of each sentence or phrase until I felt that all possible interpretations were exhausted.
Box 5 – Qualitative data coding strategy

<table>
<thead>
<tr>
<th>Process</th>
<th>Activity</th>
<th>Coder</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Reading of all interview transcripts</td>
<td>Researcher</td>
</tr>
<tr>
<td>2</td>
<td>Identification of thirty-two broad themes obtained from literature review and interview transcripts</td>
<td>Researcher</td>
</tr>
<tr>
<td>3</td>
<td>Reduction of themes to form fifteen first line codes which were entered into N6 (see appendix 6)</td>
<td>Researcher, Second coder</td>
</tr>
<tr>
<td>4</td>
<td>Rereading of all transcripts, allocation of first line codes and identification of other relevant codes from transcripts</td>
<td>Researcher, Second coder</td>
</tr>
<tr>
<td>5</td>
<td>Restructuring of first line codes amalgamation of similar codes to form twelve second line codes see appendix 6</td>
<td>Researcher</td>
</tr>
<tr>
<td>6</td>
<td>Refinement of first line codes Discussion and agreement on code allocation</td>
<td>Researcher, Second coder</td>
</tr>
<tr>
<td>7</td>
<td>Any discrepancy in allocation of codes re examined discussed and where agreement was not reached requested independent coding by a third coder</td>
<td>Researcher, Second coder, Third coder</td>
</tr>
<tr>
<td>8</td>
<td>Agreement on allocation of final codes</td>
<td>Researcher, Third coder</td>
</tr>
<tr>
<td>9</td>
<td>Further reduction to six third line codes see appendix 6 which were used for the presentation of the qualitative data</td>
<td>Researcher</td>
</tr>
</tbody>
</table>

Pollock (1991) observed that at the initial stage of data analysis the labels given to the broad themes will at times be longwinded, ungainly and fanciful; this was observed in my allocation of the initial broad themes however as I became immersed in the data I was able to reclassify these in order to obtain themes that were more meaningful and manageable. Throughout the process I maintained one essential element and that is, the labels that were used fitted consistently with the phenomena being described in the data, where this was not the case there was repeated revision of the themes until this was achieved.

Following extensive analysis and restructuring the six themes which emerged as relevant in addressing the research question were: attitude to procreation and childbearing, knowledge and perception of sickle cell disease, factors influencing decisions about an at-risk pregnancy, prenatal diagnosis (acceptance or rejection), influence of religion on decision making and possible impact of having a child with sickle cell anaemia see appendix 6.

In selecting the quotes I utilized the principles of interpretive narrative analysis, valuing each respondent’s words, regarding them as legitimate expressions of their attitude and life experiences. Any or all of the participant’s text were deemed relevant for inclusion since I
treated all the data as stories and narratives through which people described their experiences of their world. I identified quotes that reflected the most common experience of the participants and the issues identified in the literature review especially those that provided insight into the subject matter and not necessarily those that support or negate my hypothesis.

Ryan and Bernard argued that in conducting qualitative data analysis:

Samples (selected for analysis) may be based on extreme or deviant cases, cases that illustrate maximum variety on variables, cases that are somehow typical of a phenomenon, or cases that confirm or disconfirm a hypothesis... A single case may be sufficient to display something of substantive importance.  

(Ryan and Bernard 2000: 780)

In order to address the research question and present relevant data quotes from interviews which I felt would contribute meaningfully to the subject were presented. In a few instances whilst addressing issues relating to culture and socio cultural attitudes to sickle cell disease an attempt was made to present a variety of participant’s views provided they contributed meaningfully to the research question however one or two respondents provided poignant responses.

I looked for evidence of social conflict or cultural contradictions, the methods people used for dealing with cultural expectations and social relationships at the micro and macro level within cultural group and society.

4.6.4 Presentation of Participants’ voices

As a researcher I am conscious of the dilemmas inherent in ones attempt to retain the philosophy of a feminist researcher which aims to promote the empowerment and liberation of women by presenting the women’s stories and voices in a way which is in keeping with honesty, truth and a shared empathetic understanding of women’s experiences in a male dominated society. Spalter-Roth and Hartman (1999) suggest that feminist researchers need to resist the temptation of merely producing data which fails to influence or improve the lives of those they have researched hence they should produce policy relevant research which can be used by policy
makers, feminist researchers and the women affected by the policies. I suggest that the same can be said of researchers who conduct research on black and minority ethnic people who have a genetic condition that is almost peculiar to their specific group and who may have little or no opportunity for their voices to be heard about what it feels like to live with the condition or the experience of the condition and its impact in their community. These voices need an opportunity to be heard by those who produce policies and by the wider society who have not been exposed to the reality of being at-risk of having a child with this debilitating and unpredictable condition.

I acknowledge that I share certain characteristics with the research population. I share being black with all the participants; whilst I share being a woman, African and a Christian with some of the participants. This as described by Ann Oakley (1981) depicts the ‘insider’ aspect of being a researcher. As highlighted by Parr (1998) this could pose a double-edged sword which can enable or limit the participants’ ability to share their experiences with the researcher. As an ‘outsider’ to the study population I am an academic, researcher and policy maker and need to recognize that I am also influenced by an already existing body of knowledge in these professional worlds and to a certain extent need to adhere to rules and the regulations and the expectations of these roles. Hence the ‘insider’ and ‘outsider’ roles could conflict unless efforts are made to identify and limit areas of potential conflict. I experienced the benefits as well as the negative impact of being an insider, this I discuss further in the reflection in section 9.2.

During the course of the interviews I made efforts to represent the participants’ voices by allowing them to deviate from the interview schedules when the situation arose, hence there was some movement in the research approach shifting from a positivist, structured and organized approach adopted in Phase 1 and Phase 2 to a more ethnographic approach in the data collection and analysis of Phase; ensuring that the data analysis was firmly rooted in the data and the influence of the research participants in the research process was acknowledged and allowed to emerge. It is important to recognize that an interview is an interactive process and both the interviewer and the interviewee influence the research process and the data that emerges.

Standing argued that,

If a piece of writing or research is not accessible because of the language it is written in, to those who take part in the research, what is its purpose? Who is the research for?

(Standing 1998: 187)
In view of this challenging question I have attempted to write the thesis in a format and language that will meet academic requirements yet be accessible not only to policy makers and other researchers but to the participants themselves by making it available on the Brent Sickle Cell / Thalassaemia Centre website in due course.

It should be noted that as a result of missing data some cases were omitted for specific analyses. As a consequence the total sample in each analysis may vary.
5.1 Demography
5.1.1 Ethnicity and gender 133
5.1.2 Ethnicity, gender and age group 134
5.1.3 Ethnicity, gender and marital status 134
5.1.4 Ethnicity, gender and educational level 135
5.1.5 Ethnicity, gender and employment 137
5.1.6 Ethnicity, gender and religion 138
5.1.7 Ethnicity, gender and knows someone with sickle cell disease 140
5.1.8 Ethnicity, gender and tested for sickle cell 140

5.2 Migration
5.2.1 Patterns of migration 142
5.2.2 Migration and religion 142
5.2.3 Migration and living with someone with sickle cell disease 142
5.2.4 Migration and other variables 142

5.3 Inferential Analysis
5.3.1 Ethnicity – African and Caribbean
5.3.1.1 Ethnicity and enculturation 143
5.3.1.2 Ethnicity and general knowledge of sickle cell 144
5.3.1.3 Ethnicity and attitude to sickle cell and reproductive drive 145
5.3.2 Gender – Male and female
5.3.2.1 Gender and attitude to sickle cell and reproductive drive 150
5.3.2.2 Gender and Multi-dimension Health Locus of Control (MHLC) 151
5.3.2.3 Gender and other variables 151
5.3.3 Migration
5.3.3.1 Migration and enculturation 151
5.3.3.2 Migration and religion 152
5.3.3.3 Migration and general knowledge of sickle cell 152
5.3.3.4 Migration and attitude to sickle cell and reproductive drive 153
5.3.3.5 Migration and Multi-dimension Health Locus of Control (MHLC)  
5.3.3.6 Migration and other variables  

5.3.4 **African Female / Caribbean Female**  
5.3.4.1 African Female / Caribbean Female – and enculturation  
5.3.4.2 African Female / Caribbean Female – attitude to sickle cell  
5.3.4.3 African Female / Caribbean Female – other variables  

5.3.5 **African Female / African Male**  
5.3.5.1 African Female / African Male – enculturation  
5.3.5.2 African Female / African Male – attitude to sickle cell and reproductive drive  
5.3.5.3 African Female / African Male – Multi-dimension Health Locus of Control  
5.3.5.4 African Female / African Male – other variables  

5.3.6 **Caribbean Female / Caribbean Male**  
5.3.7 **African Male / Caribbean Male**  
5.3.7.1 African Male / Caribbean Male – and general knowledge of sickle cell  
5.3.7.2 African Male / Caribbean Male – Attitude to sickle cell & reproductive drive  
5.3.7.3 African Male / Caribbean Male – other variables  

5.3.8 Analysis of other variables  
5.3.9 Regression analysis  
5.3.10 Analysis of qualitative response in questionnaire  

5.4 **Phase 1 Discussion**  
5.4.1 Enculturation  
5.4.2 Educational level  
5.4.3 Impact of religion  
5.4.4 General knowledge of sickle cell  
5.4.5 Attitude to sickle cell disease  
5.4.5.1 Severity of disease  
5.4.5.2 Level of burden  
5.4.5.3 Reproductive drive  
5.4.5.4 Multi-dimension Health Locus of Control  
5.4.5.5 Test result and selection of partner  
5.4.5.6 Qualitative data in questionnaire  
5.4.5.7 Other concepts and variables  
5.4.6 Conclusion
5.1 Phase 1 Demography

5.1.1 Ethnicity and gender

It should be noted that as a result of missing data some cases were omitted for specific analyses. As a consequence the total sample in each analysis may vary.

Questionnaires were distributed to approximately 423 African and 410 Caribbean men and women from the general population. 156 completed questionnaires were received from Africans (36%) and 154 from Caribbeans (37%). Of these 14 African and 9 Caribbean participants were omitted because the individuals did not meet the inclusion criteria, for example, individuals who were < 18 years and >45 years of age and those of mixed ethnic origin. Analysis was conducted on 142 African and 145 Caribbean (67 African Female (23%), 86 Caribbean Female (30%), 75 African Male (26%), 59 Caribbean Male (21%), total number of respondents n=287 (Pie chart 1).

Pie Chart 1 – Phase 1 Ethnicity and gender

The four groups were analysed using a range of dependent and independent variables as outlined in Chapter 6. Females and Males were subsequently analysed based on gender and ethnicity: African Female / Caribbean Female, African Male / Caribbean Male, African Female / African Male and Caribbean Female / Caribbean Male.
5.1.2 Ethnicity, gender and age group

The age distribution of the respondents is illustrated in Table 3 and Graph 1.

Table 3 – Ethnicity, gender and age group

<table>
<thead>
<tr>
<th>Gender/Ethnic group</th>
<th>18-24</th>
<th>25-30</th>
<th>31-40</th>
<th>41-45</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female African</td>
<td>21</td>
<td>15</td>
<td>22</td>
<td>9</td>
<td>67</td>
</tr>
<tr>
<td>Female Caribbean</td>
<td>25</td>
<td>16</td>
<td>31</td>
<td>14</td>
<td>86</td>
</tr>
<tr>
<td>Male African</td>
<td>11</td>
<td>20</td>
<td>34</td>
<td>10</td>
<td>75</td>
</tr>
<tr>
<td>Male Caribbean</td>
<td>14</td>
<td>9</td>
<td>34</td>
<td>2</td>
<td>59</td>
</tr>
<tr>
<td>Total</td>
<td>71</td>
<td>60</td>
<td>121</td>
<td>35</td>
<td>287</td>
</tr>
</tbody>
</table>

Graph 1 – Ethnicity, gender and age group

5.1.3 Ethnicity, gender and marital status

For the purpose of data analysis those who are married, co-habiting or living with their partner were amalgamated and re-classified as married, since these are all similar social situations in terms of living arrangements and social-psychological interaction and possible social response to having a child with a medical condition. Those who are single, separated or divorced were re-classified as single for the same reason.
65% of the African Female are single and 35% are married; 62% of the Caribbean Female are single and 38% are married; 48% of the African Male single and 52% are married; 65% Caribbean Male single and 35% are married (Graph 2). However, it should be noted that in these populations being single is not necessarily synonymous with living alone without a significant other person periodically because serial coupling is common, particularly among the Caribbean group (Schott and Henley 1996) and the state of being single may not be long-term but relate to the time that the questionnaire was being completed.

5.1.4 Ethnicity, gender and educational level

There was a statistical significance between African and Caribbean respondents educational level, Mann Whitney U (p=0.000) (z = -5.184) (Table 4, Graph 3). A greater proportion of African respondents had qualifications greater than GCE/ Higher National Diploma (HND) and some had undergraduate and post-graduate qualifications. Of those who had no educational qualifications Caribbean Females accounted for the largest group whilst African Males accounted for the largest group with a first degree or above.
<table>
<thead>
<tr>
<th>Gender / Ethnic Group</th>
<th>None</th>
<th>CSE</th>
<th>GCE to HND</th>
<th>&gt;Degree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Female</td>
<td>10</td>
<td>3</td>
<td>26</td>
<td>28</td>
<td>67</td>
</tr>
<tr>
<td>Caribbean Female</td>
<td>28</td>
<td>18</td>
<td>26</td>
<td>14</td>
<td>86</td>
</tr>
<tr>
<td>African Male</td>
<td>6</td>
<td>8</td>
<td>23</td>
<td>16</td>
<td>59</td>
</tr>
<tr>
<td>Caribbean Male</td>
<td>16</td>
<td>4</td>
<td>16</td>
<td></td>
<td>59</td>
</tr>
<tr>
<td>Total</td>
<td>60</td>
<td>33</td>
<td>103</td>
<td>91</td>
<td>287</td>
</tr>
</tbody>
</table>

Applying the Mann-Whitney U- Wilcoxon there was a statistically significant difference in the educational level of African Female and Caribbean Female respondents (p=0.000): 15% of the African Females had no educational qualifications (<General Certificate of Secondary Education or its equivalent) whilst 33% of the Caribbean Female respondents had no educational qualifications. 42% of the African Female respondents were educated to above first degree level whilst 16% of the Caribbean Female respondents were educated to above first degree level.

6% of the African Male respondents had no educational qualifications (<Certificate of Secondary Education or its equivalent) whilst 16% of the Caribbean Male respondents had no educational qualifications. 33% of the African Male respondents were educated to above first degree level whilst 16% of the Caribbean Male respondents were educated to above first degree level.
5.1.5 Ethnicity, gender and employment

The majority of the respondents indicated that they were employed (Graph 4). A significant proportion of full-time students also indicated that they had part-time employment. However they regarded themselves as full-time students and were therefore classified as students. It is postulated that employment status may influence attitude to having a child with sickle cell disease in terms of perception of financial burden.

Graph 4 – Ethnicity, gender and employment

Of the African Female respondents 46 (69%) were employed, 2 (3%) unemployed, 3 (4%) were homemakers, 12 were (18%) students and 4 (6%) did not answer the question. Of the Female Caribbean respondents 61 (71%) were employed, 6 (7%) unemployed, 2 (2%) were homemakers and 17 (20%) were students. Of the Male African respondents 57 (76%) were employed, 3 (4%) unemployed, 1 (1%) was a homemaker and 14 (19%) were students. Of the Male Caribbean respondents 40 (68%) were employed, 10 (17%) unemployed, 0 (0%) were homemakers and 9 (15%) were students.
5.1.6 Ethnicity, gender and religion

Chi-square analysis indicated a statistically significant difference in religious practises between the African and Caribbean respondents (p=0.0000). Table 5 and Graph 5 demonstrate that more African respondents practised a religion than Caribbean respondents. The data also demonstrated that Africans engaged in more religious activities and visited a place of worship more often than the Caribbean respondents.

Table 5 – Ethnicity, gender and religious faith

<table>
<thead>
<tr>
<th>Gender / Ethnic group</th>
<th>Yes</th>
<th>Sometimes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Female</td>
<td>53 (80%)</td>
<td>7 (10%)</td>
<td>7 (10%)</td>
<td>67</td>
</tr>
<tr>
<td>Caribbean Female</td>
<td>41 (48%)</td>
<td>20 (23%)</td>
<td>25 (29%)</td>
<td>86</td>
</tr>
<tr>
<td>African Male</td>
<td>61 (81%)</td>
<td>11 (15%)</td>
<td>3 (4%)</td>
<td>75</td>
</tr>
<tr>
<td>Caribbean Male</td>
<td>28 (48%)</td>
<td>13 (22%)</td>
<td>11 (30%)</td>
<td>59</td>
</tr>
<tr>
<td>Total</td>
<td>183</td>
<td>51</td>
<td>46</td>
<td>287</td>
</tr>
</tbody>
</table>

Graph 5 – Ethnicity, gender and religion

Table 6 provides an overview of the religious denomination of each group, demonstrating a similar pattern among African Female, African Male, Caribbean Female, whilst a few of the Caribbean
Females practised a charismatic Christian religion even fewer Caribbean Males practised a Charismatic Christian religion and only the African Males indicated that they practised a Moslem religion. It is possible to suggest that the African respondents are more likely to practise a charismatic Christian religion because of the rapid expansion of traditional African churches in London, many of whom speak their native language.

One Caribbean Female and one African Male did not indicate whether they practise a religion. However they indicated their religious denomination hence n=236 in Table 6, whilst those who said ‘yes’ or ‘sometimes’ practise a religion in Table 5 n= 234. Of 60 Africans who have a first degree or above 56 practised a religion, the majority being differing denominations of Christianity. Of 29 Caribbeans with a first degree or above 20 practised a religion.

**Table 6 – Ethnicity, gender and religious denomination**

<table>
<thead>
<tr>
<th>Gender / Ethnic group</th>
<th>Orthodox Christian</th>
<th>Charismatic Christian</th>
<th>Rastafarian</th>
<th>Moslem</th>
<th>Other Religion</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Female</td>
<td>46</td>
<td>14</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>60</td>
</tr>
<tr>
<td>Caribbean Female</td>
<td>51</td>
<td>9</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>62</td>
</tr>
<tr>
<td>African Male</td>
<td>50</td>
<td>12</td>
<td>0</td>
<td>11</td>
<td>0</td>
<td>73</td>
</tr>
<tr>
<td>Caribbean Male</td>
<td>35</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>41</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>182</strong></td>
<td><strong>37</strong></td>
<td><strong>3</strong></td>
<td><strong>11</strong></td>
<td><strong>3</strong></td>
<td><strong>236</strong></td>
</tr>
</tbody>
</table>

Chi square analysis was applied to religion and a statistically significant difference was observed in the practise of religion among African Male and Caribbean Male respondents (p=0.0002) (Table 5). Similar findings were observed among African Female and Caribbean Female respondents (Chi Square analysis p=0.00037). These findings demonstrate that overall more of the African than Caribbean respondents practise a religion.
5.1.7 Ethnicity, gender and knowing someone with sickle cell disease

To determine whether personal experience of sickle cell disease influenced attitude and selection of partners respondents were asked to indicate whether they knew someone with sickle cell disease and whether they lived with the person or not.

Those who responded positively to the question ‘Do you know anyone with sickle cell disease?’ were asked to indicate if the person is/was a member of their family or not and whether the person lived or did not live with them. A significant proportion of both the African and Caribbean respondents knew someone with SCD (Table 7). However, a greater proportion of the African respondents lived with someone with SCD and therefore would have had personal experience of the disease manifestation, and the possible health and social impact.

5.1.8 Ethnicity, gender and tested for sickle cell

In an attempt to find out about genetic choices respondents were asked to state whether they had been tested for sickle cell or not, what their haemoglobin genotype is and whether their own test result influenced their decisions when selecting a life partner and having children. Of 287 respondents 155 reported that they were tested for SCD, of these 123 knew their blood test result 29 Africans and 20 Caribbeans had a positive test result (i.e. sickle cell trait, Hb C trait or beta thalassaemia trait). The number of those with a positive test result in each ethnic group was not sufficient to conduct a statistical analysis.

To determine whether knowing ones haemoglobin (Hb) genotype influenced selection of a partner prior to starting a family, respondents were asked, ‘If you knew your test result before starting a family did you choose your partner based on your own test result?’
Table 7 – Know someone with sickle cell disease/ tested for sickle cell / chose or not choose partner preconception

<table>
<thead>
<tr>
<th>Ethnicity/ Gender (n=)</th>
<th>Know someone with SCD (% of respondents)</th>
<th>Lived with someone with SCD (% of respondents)</th>
<th>Tested for SCD and other genotypes (AS, AC, Aβ)</th>
<th>Chose partner based on own result</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Female (n=66)</td>
<td>47 (71%)</td>
<td>14 (30%)</td>
<td>39 (16)</td>
<td>0</td>
</tr>
<tr>
<td>Caribbean Female (n=83)</td>
<td>65 (78%)</td>
<td>6 (9%)</td>
<td>49 (13)</td>
<td>1</td>
</tr>
<tr>
<td>African Male (n=71)</td>
<td>51 (72%)</td>
<td>17 (33%)</td>
<td>46 (15)</td>
<td>7</td>
</tr>
<tr>
<td>Caribbean Male (n=55)</td>
<td>34 (62%)</td>
<td>8 (23%)</td>
<td>21 (7)</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>197</td>
<td>45</td>
<td>155 (51)</td>
<td>9</td>
</tr>
</tbody>
</table>

Some of the respondents indicated that they did not know their test result before starting a family and some were single and not in a stable relationship and indicated that this question was not relevant for them. Of those who responded to the question, 16 African Females with a carrier state (HbAS, HbAC or Hb AβThal) none of them chose their partner based on their Hb genotype. Of the 13 Caribbean Females with a carrier state none had chosen their partner based on their genotype. However of those with normal haemoglobin (HbAA) 1 Caribbean Female had chosen her partner purposefully despite knowing that she has a normal haemoglobin (she did not indicate the reason); 1 Caribbean Male selected his partner pre-conception.

Table 7 indicates that 7 of the 15 African Males tested chose their partners based on their own Hb genotype and of the 7 who chose their partners 3 have cell trait. Of the 3 with sickle cell trait 1 respondent did not know his genotype until his partner was pregnant and he was found on routine testing to also have sickle cell trait. One of the African Male respondents with sickle cell trait indicated that he inadvertently selected a partner who also has sickle cell trait. 4 African Males who have normal haemoglobin (HbAA) also purposefully chose their partners irrespective of their own normal Hb genotype this is discussed further in Section 7.4.9 and 8.3.2. Of the 7 Caribbean Males with a carrier state 1 chose his partner based on his Hb genotype and he also had normal haemoglobin (HbAA). He did not indicate the reason for purposefully selecting his partner despite not being at risk of having a child with SCD.
5.2 Migration

5.2.1 Pattern of migration

The migratory pattern of the group was not originally targeted for analysis, however as the data emerged it appeared that this was perhaps a significant factor which may be contributing to attitude to sickle cell. Literature suggests that the society in which an individual spent their most formative years influenced their attitude to social and health issues, and the data in this study demonstrated that there were some statistically significant differences observed among those born in the UK/ migrated <15 years of age and those who migrated >15 years of age.

149 respondents were born in the UK/ migrated <15 years of age (African Female 26, Caribbean Female 66, African Male 18, Caribbean Male 39), and 138 respondents migrated to the UK >15 years of age (African Female 41, Caribbean Female 20, African Male 57, Caribbean Male 20).

5.2.2 Migration and religion

Of those who were born in UK/ migrated <15 years of age 77 practised a religious faith most of the time, 36 practised it sometimes, whilst 36 did not practise any religion.
Of those who migrated >15 years of age 106 practised a religious faith most of the time, 15 practised it sometimes and 17 did not practise any religion.

5.2.3 Migration and living with someone with SCD

Of those who knew someone with sickle cell disease (n=197) in the born in UK / migrated < 15 years of age 13 lived with someone with SCD and of the migrated >15 years of age 32 lived with someone with SCD.

5.2.4 Migration and other variables

There was no statistical significance comparing those born in UK / migrated < 15 years of age and those migrated >15 years of age in all other variables examined.
5.3 Inferential analysis

5.3.1 - Ethnicity (African and Caribbean)

5.3.1.1 Ethnicity and enculturation

In order to determine degree of cultural orientation to African or Caribbean culture the Tsai et al. (2000) ethnic orientation model was adopted. A number of authors argued that cultural orientation influences attitude to disease and illness (Sowell 1994, Petrie et al. 1998, Henley and Schott 1999, Tsai et al. 2000). Migration and enculturation within another cultural environment also influence attitude. In view of this the study attempted to take into account cultural orientation by examining ethnicity and cultural orientation.

In analysing the degree to which African n=142 and Caribbean n= 145 respondents identified with their ethnic (cultural) group a two-tailed t-test was conducted on the output from the ethnicity questions in section 5 of the questionnaire. There were no statistically significant differences in terms of ethnicity and level of enculturation, demonstrating that the two groups have the same degree of enculturation to their culture of origin, i.e. Africans to their African culture and Caribbeans to their Caribbean culture. In view of this the data is not discussed. The homogeneity of the two groups make comparative analysis possible since both have a similar degree of enculturation thereby eliminating one potential extraneous variable that could have affected interpretation of the other findings.

It is surprising that there was no statistical difference in respect of language between the African and Caribbean respondents since one would have expected that the majority of the Africans would have a distinct African language whilst the Caribbean respondents speak mostly English. In response to the question about language the lack of difference is demonstrated in Table 8 below:

Table 8 - Ethnicity and language

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Much</th>
<th>Very much</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African</td>
<td>18</td>
<td>31</td>
<td>12</td>
<td>32</td>
<td>49</td>
<td>142</td>
</tr>
<tr>
<td>Caribbean</td>
<td>28</td>
<td>40</td>
<td>32</td>
<td>17</td>
<td>28</td>
<td>145</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>71</td>
<td>44</td>
<td>49</td>
<td>77</td>
<td>287</td>
</tr>
</tbody>
</table>
5.3.1.2 Ethnicity and general knowledge of sickle cell

Anecdotal observation in clinical practise led to the formation of the opinion that Caribbeans have greater awareness and knowledge of sickle cell than Africans. It was therefore argued that differences in awareness and knowledge will contribute to the shaping of attitude to sickle cell, and that where there is greater knowledge of the health and social impact of sickle cell disease (SCD) there will be heightened anxiety and reluctance to have a child with SCD. In view of this, one of the objectives of the study is to identify whether there is a statistically significant difference in knowledge and attitude between African and Caribbean male and female general public and subsequently between pregnant and non-pregnant women. This is to see whether being pregnant influenced knowledge score and attitude and whether this difference is reflected in the attitude of the Phase 3 at-risk women/ couples and their at-risk decision making and outcome.

Twenty-one questions were included in Section 1 of the questionnaire (see Appendix 1), which aimed to measure general knowledge of sickle cell disease. Two-tailed t–test was conducted comparing a number of participant groups and variables, as outlined in Box 4.

There was a statistically significant difference in knowledge score between the two ethnic groups p=0.005 Africans (mean=14.3097) (SD=1.732), Caribbeans (mean=13.6770) (SD=1.933) demonstrating better knowledge of sickle cell among the Africans compared to the Caribbean respondents. Similarly, there was a significant difference between African Males (mean=14.4145) (SD=1.1715) and Caribbean Males (mean=13.3273) (SD=1.944), p=0.001, again demonstrating that the African Male respondents have greater knowledge of SCD than the Caribbean Males. This is contrary to the opinion formed in clinical practise that Caribbeans have greater knowledge and awareness due to greater exposure to health promotion and other educational resources in the UK. However, the result may be a reflection of the recruitment process and the population who responded to the survey: the African respondents had better educational background than the Caribbean respondents. Perhaps language and illiteracy would have been greater among the less well educated Africans than the less well educated Caribbean.

Chi square analysis was applied to each of the individual general knowledge questions to determine whether there were differences in knowledge of sickle cell facts. The number of those who responded to each question was not always consistent however a number of differences were observed.
In response to the statement ‘Sickle cell occurs less commonly in educated people’ of 136 Africans who completed this question 13 ticked True whilst 2 of the 136 Caribbeans ticked true, which is the incorrect answer. Those who ticked true were contacted in order to gain clarification for their responses. It transpired that 7 of the Africans who ticked true felt that educated people have the capacity to make appropriate marital choices and thus avoid having children with the sickle gene especially sickle cell anaemia, 2 other Africans and 1 Caribbean respondent thought that SCD was communicable and those who are educated have the higher social status to live well and avoid catching it. The other respondents were not contactable.

In response to the statement ‘Sickle cell can affect white people’ 46 Africans ticked False whilst 69 Caribbeans ticked False, which is the incorrect answer. In response to the statement ‘People with sickle cell die by the age of 21 years’ 31 Africans ticked ‘True’ whilst 14 Caribbean ticked ‘True’, which is the incorrect answer.

When comparing those who had been tested (n=155) and those who had not been tested (n=132) there was an expected highly significant difference in knowledge score (p=0.000), those who have been tested demonstrated greater knowledge, (mean score=16.3089) (SD=2.450), compared to untested (mean score =14.3799) (SD=4.879) respondents.

5.3.1.3 Ethnicity and attitude to sickle cell and reproductive drive


In exploring the influence of ethnicity to attitude a two-tailed t-test was conducted and applied to each of the four attitude summary variables. A statistically significant difference was observed in attitude to level of burden and reproductive drive (Table 9). In Section 2 of the questionnaire some visual differences were observed in the four groups in relation to the individual statements (Graph 7, 8, 9 and 10).
Table 9 – Ethnicity, attitude to sickle cell and reproductive drive

<table>
<thead>
<tr>
<th>Summary Variable</th>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity of Disease</td>
<td>African</td>
<td>137</td>
<td>3.0715</td>
<td>.809</td>
<td>0.170</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caribbean</td>
<td>138</td>
<td>2.8667</td>
<td>.588</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitude to Prevention</td>
<td>African</td>
<td>137</td>
<td>3.1296</td>
<td>.933</td>
<td>0.130</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caribbean</td>
<td>138</td>
<td>2.9819</td>
<td>.672</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic Locus of control (self v others)</td>
<td>African</td>
<td>137</td>
<td>3.8881</td>
<td>.674</td>
<td>0.410</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caribbean</td>
<td>138</td>
<td>3.8188</td>
<td>.718</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of Burden (Sickle)</td>
<td>African</td>
<td>137</td>
<td>3.8978</td>
<td>.657</td>
<td>0.000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caribbean</td>
<td>138</td>
<td>3.5169</td>
<td>.514</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reproductive Drive</td>
<td>African</td>
<td>137</td>
<td>3.4891</td>
<td>1.092</td>
<td>0.000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caribbean</td>
<td>138</td>
<td>3.0290</td>
<td>1.060</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NB: Not all respondents completed this section of the questionnaire (n=275)

**Level of burden**

The data demonstrated that there is a statistically significant difference between Africans and Caribbeans in respect of the perception that having a child with SCD would be a burden for the family; Africans perceive sickle cell disease a greater burden than Caribbeans. This is also illustrated in Graph 6 where in response to the statement ‘If a couple both have sickle cell trait I think they should not have children together’ African Males were the largest group that ticked ‘strongly agree’ whilst Caribbean Females were the largest group that ticked ‘strongly disagree’.

**Graph 6 – If a couple both have sickle cell trait I think they should not have children together**
Similarly in response to the statement ‘I feel that having a child with sickle cell disease can be a blessing in a family’, although there was no statistically significant difference between the two groups Graph 7 illustrates that more of the Africans ticked ‘strongly disagree’, further supporting the perceived burden of sickle cell disease among the African respondents especially the African Male respondents, whilst more of the women in both groups ticked ‘neither agree or disagree’.

**Graph 7 – Having a child with sickle cell disease can be a blessing in a family**

In further exploration of perceived level of burden in having a child with sickle cell disease Graph 8 illustrates that in response to the statement, ‘I believe that having a child with sickle cell disease can cause financial hardship for the family’, more Africans than Caribbeans ticked ‘strongly agree’ demonstrating that more of the African respondents, especially the African Male who make up the largest number of those who ticked ‘strongly agree’, perceive that having a child with sickle cell disease could pose financial hardship for the family. And although the Caribbean Female respondents did not ‘strongly disagree’ with the statement they made up the largest group who ticked ‘disagree’ and ‘neither agree/disagree’ with the statement.
Reproductive drive

In comparing African and Caribbean respondents’ perception of the importance of having children, a statistical difference was observed among African and Caribbean respondents. The summary attitude variable measuring attitude to procreation and importance of having children demonstrated a statistical significance ($p=0.000$) Table 9 African (mean=3.49) (SD=1.092) and Caribbean (mean=3.03) (SD=1.060), demonstrating that the African respondents place greater importance on having children compared to the Caribbean respondents. Graph 9 provides a pictorial illustration. Although both groups feel it is important to have children (agree) more of the African respondents ticked ‘strongly agree’, whilst more of the Caribbeans ticked ‘disagree’.
Graph 9 - It is important for ALL healthy men and women to have children

In response to the statement, ‘I think people should tell their partners their blood test result before having children’, both African and Caribbean respondents support the statement. However Graph 10 illustrates that more of the African respondents ‘strongly agree’ with the statement than the Caribbeans, suggesting that the Africans are more likely to support pre-conceptual knowledge of a partner’s genotype.

Graph 10 - People should tell their partners their blood test result before having children
A t-test was conducted to determine whether there is any statistical significant difference between Africans and Caribbeans in the Internal, Chance and Powerful Others health locus of control. There was no statistical difference demonstrated.

A two way analysis of variance (ANOVA) was conducted examining whether there is an interaction between ethnicity, having lived or not lived with someone with SCD and the Internal, Chance or Powerful Others Locus of control variables and no interaction was demonstrated. This was repeated for religion, educational level, marital status and employment and no interaction was observed.

5.3.2 Gender (Male and Female)

Analysis was conducted to examine whether gender had a significant impact on any of the variables examined and in influencing attitude to sickle cell. African Females and Caribbean Females (n=153) were compared to all African Males and Caribbean Males (n=134).

5.3.2.1 Gender and attitude to sickle cell and reproductive drive

A two-tailed t-test demonstrated that there was no statistical significance in four of the attitude summary variables in respect of gender but there was a significance in Severity of Disease (p=0.006) Female (mean= 2.8604) (SD=.6777) and Male (mean=3.0968) (SD=.7339) demonstrating that Males perceive that sickle cell disease is more of a burden than Females.

And in attitude to importance of having children (p= 0.007), more of the Male (mean=3.4500) (SD=1.1570) respondents consider it important for all healthy men and women to have children than Female (mean=3.0900) (SD=1.0220) respondents.
5.3.2.2 Gender and Multi-dimension Health Locus of Control (MHLC)

In examining MHLC a statistical significance was observed in the dimension of Powerful Others (p=0.001) Women (mean= 17.8889) (SD=5.6014) and Men (mean=19.9179) (SD=.7339) demonstrating that more Men perceive that Powerful Others have greater control over their staying healthy, rather than themselves (Internal) or uncontrollable events (Chance).

5.3.2.3 Gender and other variables

There was no statistical significance in all the other variables examined.

5.3.3 Migration

5.3.3.1 Migration and enculturation

A two-tailed t-test demonstrated a number of statistical significant differences in three of the ethnicity domains, Language, Social Activity, and Exposure Table 10.

Table 10 – Migration and Enculturation

<table>
<thead>
<tr>
<th>Summary Variable</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>t-test p-</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>149</td>
<td>2.8201</td>
<td>.713</td>
<td>0.000</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>138</td>
<td>3.1942</td>
<td>.754</td>
<td></td>
</tr>
<tr>
<td>Social Affiliation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>149</td>
<td>3.4171</td>
<td>.605</td>
<td>0.143</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>138</td>
<td>3.5217</td>
<td>.603</td>
<td></td>
</tr>
<tr>
<td>Social Activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>149</td>
<td>3.3289</td>
<td>.842</td>
<td>0.000</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>138</td>
<td>3.7029</td>
<td>.821</td>
<td></td>
</tr>
<tr>
<td>Pride</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>149</td>
<td>3.9228</td>
<td>.567</td>
<td>0.349</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>138</td>
<td>3.9843</td>
<td>.541</td>
<td></td>
</tr>
<tr>
<td>Exposure</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>149</td>
<td>3.7987</td>
<td>.788</td>
<td>0.006</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>138</td>
<td>4.0417</td>
<td>.698</td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>149</td>
<td>3.7651</td>
<td>.883</td>
<td>0.206</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>138</td>
<td>3.6341</td>
<td>.868</td>
<td></td>
</tr>
</tbody>
</table>

NB: All respondents completed the ethnicity section of the questionnaire (n = 287)

Age of migration is an important factor which plays a part in influencing ethnic identification and continued association with ethnic cultural group. It was anticipated that there would be elements of difference in these two groups in respect of the ethnic domains. The data showed that those who
migrated >15 years of age were more likely to speak their native tongue (Language), maintain contact with people from their country of origin and participate in culturally oriented, enhancing activities (Social Activity and Exposure).

5.3.3.2 Migration and religion

It was not surprising that there was a statistical difference in the religious practise of those born/migrated <15 years of age and those migrated >15 years of age (Pearson chi-square (p=0.000). A greater proportion of those > 15 years (88%) consistently or sometimes practise a religion whilst 75% of those born/migrated <15 years of age practised a religion.

Although there is a difference between them it is worth noting that few do not practise religion at all, of those born/migrated <15 years of age out of a total of 149 respondents 36 respondents did not practise a religion, whilst of the 138 migrated >15 years of age 17 did not practise a religion (18%), therefore it should be noted that in fact a significantly high proportion of both groups practise a religion (82%).

5.3.3.3 Migration and general knowledge of sickle cell

There was no statistical significance in the summative general knowledge of sickle cell. However, Chi Square analysis was applied to the individual questions in Section 1 of the questionnaire. In response to the statement *‘Sickle cell occurs less commonly in educated people’* there was a statistically significant difference (p=0.010) between the 142 respondents who were Born / Came to UK < 15 years of age. 3 respondents ticked ‘True’ compared to the 130 who Migrated >15 years of age 12 respondents ticked ‘True’, which is an incorrect answer. This demonstrates that some of those who spent their most formative years in their country of origin perceive that educated people are less likely to have a child with sickle cell disease.
5.3.3.4 Migration and attitude to sickle cell and reproductive drive

Although there was no statistically significant difference in knowledge score comparing those born / migrated to the UK <15 years of age (<15) and those migrated >15 years of age (>15) using two-tailed t-test there was a statistical difference in four of the five summary attitude variables Table11.

And in response to statement 6 of Section 1 of the questionnaire, ‘Sickle cell occurs less commonly in educated people’ respondents of those who migrated >15 years 13 ticked ‘True’ whilst 2 of those born / migrated < 15 years of age ticked ‘True’. It was also noted that of the total 15 who ticked ‘True’ 13 were of African origin.

<table>
<thead>
<tr>
<th>Summary Variable</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>t-test</th>
<th>p-</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity of Disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>143</td>
<td>2.8406</td>
<td>.578</td>
<td>0.002</td>
<td></td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>132</td>
<td>3.1076</td>
<td>.814</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitude to Prevention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>143</td>
<td>2.9406</td>
<td>.703</td>
<td>0.015</td>
<td></td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>132</td>
<td>3.1799</td>
<td>.907</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic Locus of control</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(self v others)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>143</td>
<td>3.8741</td>
<td>.668</td>
<td>0.607</td>
<td></td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>132</td>
<td>3.8308</td>
<td>.728</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of Burden (Sickle)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>143</td>
<td>3.5315</td>
<td>.499</td>
<td>0.000</td>
<td></td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>132</td>
<td>3.8965</td>
<td>.679</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reproductive Drive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 15 years</td>
<td>143</td>
<td>2.9580</td>
<td>1.013</td>
<td>0.000</td>
<td></td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>132</td>
<td>3.5833</td>
<td>1.099</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NB: Not all respondents completed this section of the questionnaire (n=275)

Severity of disease
A greater proportion of those who migrated >15 years of age perceive that SCD is a severe disease.

Level of burden
A greater proportion of those who migrated >15 years of perceive that having a child with SCD exerts a burden on the family.

Reproductive drive
A greater proportion of those who migrated >15 years of age perceive that it is very important to have children and these respondents support the statement “It is very important for healthy men and women to have children”.

153
5.3.3.5 Migration and Multi-dimension Health Locus of Control (MHLC)

On examination of locus of control a two-tailed t-test demonstrated that there was no statistical significance in Internal and Powerful locus of control dimensions but a significance was demonstrated in the Chance locus of control dimension (p=0.007), the <15 group (mean=17.7584) (SD=5.666) and the > 15 group (mean=16.0217) (SD=5.041). This indicates that a greater proportion of those born in the UK / migrated <15 years of age perceive that being healthy is a matter of chance and more so than something which is within their control (Internal) or the control of other significant people (Powerful Others).

5.3.3.6 Migration and other variables

There was no statistical significance in all other variables examined in respect of migration.

5.3.4 African Female / Caribbean Female

A number of statistical analyses were conducted to determine whether there were any statistical difference between African Females and Caribbean Females.

Only areas where statistical differences were observed are presented.

5.3.4.1 African Female / Caribbean Female and enculturation

A two-tailed t-test was applied to the five summary ethnicity variables, which demonstrated that there was a statistical difference in one domain only, Language (p=0.000): African Female (mean=2.6841) (SD= .682) and Caribbean Female (mean= 3.1138) (SD= .703), indicating that the Caribbean Females were more culturally oriented to their cultural language than the Africans. This is a surprising finding as one would have anticipated a stronger language orientation among the Africans since they tend to have a distinct language other than English whilst the majority of those of Caribbean descent speak only English. However, many people of Caribbean origin speak ‘Pidgin’ English, which is common not only in the West Indies but among people of Caribbean descent in the Diaspora. Many people of Caribbean origin who are born and raised in the UK argue
that they speak Patua, a dialect of the Caribbean which few of them actually do speak, this may account for this finding.

Perhaps the instrument is not sensitive enough for measuring the language domain especially when applied to the British born Caribbean respondents in this study.

5.3.4.2 African Female / Caribbean Female and attitude to sickle cell

In analysing the five attitude summary variables a two-tailed t-test demonstrated that there was no statistical significance in four of the attitude summary variables: severity of disease, attitude to prevention, genetic locus of control and reproductive drive. There was, however, a statistical significance in attitude to level of burden (p=0.000) - African Female (mean=3.8434) (SD=.608) Caribbean Female (mean= 3.4538) (SD=.525) demonstrating that the African Females perceive sickle cell disease a greater burden than the Caribbean Female respondents.

There was no statistical significance in the respondents’ attitude to the individual questions in Section 2, questions 1 – 16 of the questionnaire.

5.3.4.3 African Female / Caribbean Female and other variables

There was no statistical difference in the other variables examined comparing African Female / Caribbean Female.

5.3.5 African Female / African Male

5.3.5.1 African Female / African Male and enculturation

A two-tailed t-test was applied to the six ethnicity variables. Of these only one was statistically significant: language (p=0.003) African Female (mean=2.6841) (SD=.682) African Male (mean=3.0700) (SD=.828) indicating that African Male respondents identified more with their cultural origin’s language more than the African Female respondents. However, as had been stated previously the reliability of this instrument for this study population appears questionable.
5.3.5.2 African Female / African Male and Attitude to sickle cell and reproductive drive

Applying a two-tailed t-test demonstrated that there was no statistical significance in four of the five summary attitude variables but there was a statistical significance in Reproductive Drive (p=0.001) African Female (mean 3.1667) (SD=1.032), African Male (mean=3.7887) (SD= 1.068) demonstrating that more of the African Male respondents support the notion that it is important to have children than the African Female respondents, which is surprising in view of the social ramifications of childlessness on the African Female.

5.3.5.3 African Female / African Male - Multi-dimension Health Locus of Control

A two-tailed t-test demonstrated that of the three dimensions (Internal, Chance, Powerful others) there was a statistical significance in the dimensions of Powerful Others (p=0.006) African Female (mean=17.000) (SD= 6.010) and African Male (mean=19.6133) (SD= 5.242) demonstrating that the African Male respondents perceive that other people have greater control over their health compared to the African Female who felt this less.

5.3.5.4 African Female / African Male and other variables

Interestingly, in Graph 6 in response to the statement ‘If a couple both have sickle cell trait I think they should not have children together’ both African Female and African Male agreed with this statement but the African Males were the largest group that ‘strongly agreed’ with the statement more so than the African Females.

There was no statistical difference in the other variables examined comparing African Female / African Male.
5.3.6 Caribbean Female / Caribbean Male

There was no statistical difference in all variables examined comparing Caribbean Female and Caribbean Male respondents. The homogeneity of this group was surprising especially as one would have anticipated some gender differences in respect of attitude to sickle cell disease. Although there were no statistical differences a few graphical observations were noted. For example, in response to the statement ‘if a couple both have sickle cell trait they should not have children together’ about 5% of the Caribbean Female ticked ‘Agree’ whilst above 23% of the Caribbean Male ticked ‘Agree’ (Graph 6). Similarly in response to the statement ‘I feel that having a child with sickle cell disease can be a blessing in a family’ there was a marginal visual difference, fewer Caribbean Males ticked ‘Strongly Agree’ than Caribbean Female (Graph 7).

5.3.7 African Male / Caribbean Male

A two-tailed t-test was applied to the summary variables and a number of statistically significant findings were observed.

5.3.7.1 African Male / Caribbean Male and general knowledge of sickle cell

A two-tailed t-test demonstrated a statistically significant difference between African Male and Caribbean Male respondents (p=0.001): African Male (mean=14.4145) (SD= 1.1715) and Caribbean Male (mean= 13.3273) (SD= 1.944). This shows that Male African respondents have greater overall general knowledge of sickle cell than the Caribbean Male respondents.

Interestingly, in response to the to the statement ‘Sickle cell occurs less commonly in educated people’, in section 1 of the questionnaire (Appendix 1), of the 70 African Male respondents who completed this section 9 ticked ‘True’ whilst of the 54 Caribbean Male respondents who responded none ticked ‘True’, which is the incorrect answer.
5.3.7.2 African Male / Caribbean Male and attitude to sickle cell and reproductive drive

A two-tailed t-test was applied to the summary attitude variables and there was statistical significance in two of the variables: Level of Burden and Reproductive Drive Table 12.

Table 12 – African Male/ Caribbean Male – Attitude to sickle cell and reproductive drive

<table>
<thead>
<tr>
<th>Summary Variable</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>t-test</th>
<th>p-</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity of Disease</td>
<td>71</td>
<td>3.1718</td>
<td>.804</td>
<td>0.194</td>
<td></td>
</tr>
<tr>
<td></td>
<td>55</td>
<td>3.0000</td>
<td>.625</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitude to Prevention</td>
<td>71</td>
<td>3.2148</td>
<td>.940</td>
<td>0.226</td>
<td></td>
</tr>
<tr>
<td></td>
<td>55</td>
<td>3.0364</td>
<td>.619</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic Locus of Control (self v others)</td>
<td>71</td>
<td>3.8545</td>
<td>.714</td>
<td>0.157</td>
<td></td>
</tr>
<tr>
<td></td>
<td>55</td>
<td>3.6727</td>
<td>.707</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of Burden (Sickle)</td>
<td>71</td>
<td>3.9484</td>
<td>.701</td>
<td>0.003</td>
<td></td>
</tr>
<tr>
<td></td>
<td>55</td>
<td>3.6121</td>
<td>.488</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reproductive Drive</td>
<td>71</td>
<td>3.7887</td>
<td>1.068</td>
<td>0.000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>55</td>
<td>3.0182</td>
<td>1.130</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NB: Not all respondents completed this section of the questionnaire (n=126)

Level of Burden
The data showed that compared to the Caribbean Males more of the African Male respondents perceive that having a child with sickle cell disease creates a potential burden for the family.

Reproductive drive
This was highly statistically significant and demonstrates that compared to the Caribbean Males more of the African Males feel it is important to have children. This reflects findings in the Ethnicity comparisons in Section 5.3.1.3, and the African Males probably account for the statistical significance in that category.

5.3.7.3 African Male / Caribbean Male and other variables

There was no statistical difference in the other variables examined comparing African Male / Caribbean Male.
5.3.8 Analysis of other variables

A two-way analysis of variance (ANOVA) was applied to a number of other variables which included:

- Ethnicity
- Gender
- Born migrated to the UK <15 or >15 years of age
- Marital status
- Educated to below or above first university degree
- Know someone with SCD
- If know someone with SCD – did they live with the person or not
- Tested for SCD and know blood test result
- Mode of notification of blood test result i.e. face to face counselling or letter in the post

On completion of the initial analysis the last two variables (tested or not tested and mode of notification) were excluded for reasons indicated in Section 4.6.2. Twelve respondents did not meet the criteria for an analysis using all the other variables. The twelve respondents were those who indicated that they did not have any previous knowledge of sickle cell and therefore were unable to complete Section 1 (general knowledge of SCD) and Section 2 (attitude to SCD) of the questionnaire. These individuals however completed Sections 3 (demographic), 4 (MHLC) and 5 (ethnicity).

Analysis was conducted using each of the five attitude summary variables: perception of severity of disease, attitude to prevention, locus of control [genetic decision-making], level of burden and reproductive drive; the three Multi-dimension Health Locus of Control (MHLC) variables - Internal, Chance and Powerful Others).

A two-way between groups analysis of variance (ANOVA) was conducted to explore the impact of the two variables ‘gender’ and ‘ethnicity’ in each of the seven summary attitude variables and there was no statistically significant interaction between the two variables.

There was an interaction between ethnicity and marital status p=0.009, there was no interaction between any of the other variables listed above.
It was proposed that having personal experience of living with someone with sickle cell disease would influence attitude to sickle cell disease. A series of two-tailed t-tests were conducted comparing Africans and Caribbeans, examining a number of dependent and independent variables including the summary attitude variables, the MHLC and ethnicity summary variables. Of those who knew someone with SCD African n=98 (69%) and Caribbean n=85 (58%) the majority did not live with them; 21 African respondents and 15 Caribbean respondents lived with someone with SCD. On analysing the data there was no statistically significant difference observed in those who lived with someone with SCD and those who did not.

A two-way ANOVA was conducted to determine whether there was an interaction between ethnicity and practising a religious faith and whether this influenced knowledge or attitude to SCD. Respondents who practise the Christian religion were subdivided into two subgroups ‘orthodox Christians’ (Anglican, Methodist, Baptist and Roman Catholic), and ‘charismatic Christians’ (such as Seventh Day Adventists, Pentecostal, Cherubim and Seraphim, Celestial; the latter two are religions practised among Yoruba speaking Nigerians), the attitude of these subgroups were analysed. No statistical significance was observed in respect of religion and attitude to SCD, using the four attitude summary variables. There was no interaction between religion and MHLC or ethnicity.

It was not possible to apply any statistical analysis to any of the other religious denominations because there was insufficient numbers (Table 10).

A further analysis was conducted on educational level, (comparing Africans and Caribbeans educated to below first university degree and those educated to above first university degree level), marital status and employment. All these were applied to the attitude summary variables, MHLC variables, ethnicity variables and each of the individual attitude variables in Section 2 of the questionnaire. No statistical significance or interaction was observed in any of these.
5.3.9 Regression Analysis

Statistical significance was not observed in three of the attitude summary variables: attitude to severity, attitude to prevention, genetic locus of control and in the knowledge of sickle cell disease scores therefore data for these are not presented. Significance was observed in perceived level of burden and reproductive drive as follows:

**Perceived level of burden:** final model ($R^2 = 0.128$) was

\[
\text{Predicted score} = 3.754 - 0.276 \times \text{Ethnicity} \quad [p<=0.0005] \quad (1 = \text{African}) \\
+ 0.248 \times \text{Migration} \quad [p=0.002] \quad (1 = \text{born in UK/migrated <15 years of age}) \\
(2 = \text{migrated >15 years of age})
\]

(All other potential predictor variables were no longer statistically significant)

**Reproductive drive:** final model ($R^2 = 0.131$) was

\[
\text{Predicted score} = 4.399 - 0.313 \times \text{Ethnicity} \quad [p=0.026] \quad (1 = \text{African}) \\
+ 0.484 \times \text{Migration} \quad [p=0.001] \quad (1 = \text{born in UK/migrated <15 years of age}) \\
(2 = \text{migrated >15 years of age}) \\
- 0.342 \times \text{Employment} \quad [p=0.015] \quad (0 = \text{Not in paid employment}) \\
(1 = \text{In paid employment}) \\
- 0.082 \times \text{Knowledge of SCD score} \quad [p=0.018] \quad (0 - 18)
\]

(All other potential predictor variables were no longer statistically significant)

These final regression models were not entirely useful in so much as the maximum $R^2$ was only 0.131 indicating that, at most 13.1% of variation in the outcome variable was being explained by the model. All that has been achieved is to re-establish the statistical significance of predictor variables that were previously established in the bi-variate tests performed.

It should be noted that in all instances forward stepwise regression led to the same final model.
5.3.10 Analysis of qualitative response in questionnaire

A number of respondents made comments in response to open-ended questions and requests for further comments in the questionnaire. These were transcribed and analysed, a number of concepts emerged which were coded into thematic groups. The questions that attracted written comments were:

- **Question 56**: If you have not been tested for sickle cell please say why you have not been tested.
- **Question 63**: And explain why you chose or did not choose your partner based on your own blood test result.
- **Question 64**: General comments

Of the 287 respondents those who provided written comments were 15 African Females, 7 Caribbean Females, 17 African Males and 7 Caribbean Males. The themes and concepts which appear worthy of discussion are listed in Table 13.

### Table 13 – Qualitative data obtained from questionnaire

<table>
<thead>
<tr>
<th>Theme</th>
<th>African</th>
<th>Caribbean</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is no history of sickle cell in my / my partner’s family</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>People with sickle cell should not marry each other</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Living with someone with SCD was an unpleasant experience</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>My children and / or I am healthy we cannot have sickle cell</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>I have had blood tests in the past no one told me I have sickle cell</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I / my partner was told the wrong result ‘back home’ (in Africa)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>My partner is white so it is not a problem</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Religion – God is in control of my / my family’s destiny</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>There are lots of myths and stigma associated with sickle cell</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>HIV is better publicized in Africa than sickle cell</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

It is very common for people to assume that if there is no previous history of sickle cell in their family then it is not present and fail to appreciate that a genetically recessive inherited condition can be present as a healthy carrier state in the family for many generations and it is only when an affected child is born that it becomes known.

The opinion that those with sickle cell trait should not marry each other is a common belief among Africans and supports the findings mentioned in Section 5.3.1.3.
5.4 Phase 1 Discussion

The underlying hypothesis of this study is that there would be statistically significant differences in African and Caribbean respondents’ knowledge and attitude to sickle cell and that this would have an impact on the choices that ‘at risk’ pregnant women and their partners make when faced with the risk of having a child with sickle cell anaemia (SCA).

The questions that this study attempted to answer are:

i. Is the attitude to sickle cell influenced by cultural outlook and other social experiences?

ii. Are decision-making and pregnancy outcome influenced by culture and other psychosocial factors when a woman or couple is at-risk of having a child with sickle cell anaemia (SCA)?

The data demonstrated that there are some differences in the attitude of African and Caribbean respondents, knowledge and attitude. However it appears that membership of a cultural group was not the major factor that influenced perception of disease, illness and attitude; the place where an individual had their primary cultural orientation (enculturation), their experiences and the subjective meanings they give to those experiences of health and illness, and the health care system in the country of enculturation plays a more significant part in shaping attitude to sickle cell disease, and this consequently affects attitude to being at risk of having a child with SCA.

The statistically significant and non-significant issues that emerged from the data analysis will be presented under a number of subheadings: enculturation, educational level, impact of religion, general knowledge of sickle cell and attitude to sickle cell disease, this final category will be further sub-divided to examine – severity of disease, level of burden and reproductive. Data on the Multi-dimension Health Locus of Control (MHLC) and other statistically significant and relevant aspects of non-significant concepts and variables will also be presented.

Cognitive dissonance theory will be applied to determine whether this was a factor influencing the respondents, attitude, choices and subsequent behaviour.
5.4.1 Enculturation

The data demonstrated that overall there was no statistical difference in African and Caribbean respondents’ identification with their culture of origin (Section 5.3.1.1). African Female and African Male respondents identified themselves as culturally African whilst Caribbean Female and Caribbean Male identified themselves as culturally Caribbean.

The findings of this study supports other authors (Durham 1991, Berry and Kim in Maclachlan 1997) assertion that those who spent their most formative years in their country of origin are more likely to maintain essential elements of that culture, for example speak the native language. And they are more likely to maintain contact with people from their country of origin, be exposed to and participate in social activities which promote sustained identification with their cultural origin.

These later age migrants will continue to share conceptual realities with people from their original culture due to their continuing interaction with them. It is likely that the majority of these individuals will also demonstrate an ‘integrated’ cultural identity, which is typified by maintaining elements of their culture of origin whilst demonstrating an assimilation of some of the host culture. The need to gain acceptance in the host culture will promote the development of cultural integration without which there is likely to be social conflict and dissonance.

In this study a strong cultural identification was anticipated among African respondents since 69% of them migrated to the UK >15 years of age and therefore spent their formative years in their country of origin, in contrast in the Caribbean group only 27% migrated >15 years of age. However, a strong cultural identification was observed in both groups despite the Caribbean group’s enculturation in Britain and their longstanding association with a multicultural society. A future study could attempt to examine cultural identification and the factors that have enabled maintenance of strong cultural identification with the original culture, for example, an examination of the second- and third-generation of Caribbean and African migrants and why they have maintained this identity despite enculturation in multicultural Britain.

Tsai et al. (2000) and Atkinson (2004) claim that those who are enculturated in a host culture are more likely to assimilate the host culture and identify with it more so than later migrants. This current study did not demonstrate this. It appeared that even those who were enculturated in Britain
still identified strongly with their culture of origin regardless of whether they were born in Britain or migrated at a younger or older age.

It is possible to suggest that this finding gives credence to Durham’s (1991) claim that there is a genetic element to the acquisition of culture and perhaps this is the factor influencing the African and Caribbean respondent’s cultural identification with their culture of origin and that humans have the capacity to demonstrate certain characteristics and modes of behaving that symbolize their cultural group and social orientation even without having lived in their country of origin. However, if this argument is valid why did Tsai et al.’s (2000) later age Chinese migrants not reflect a similar pattern of genetic adherence to their culture of origin? Secondly, the African and Caribbean respondents in the current study are still deeply immersed in their cultural groups by virtue of the high numbers of these communities in London, which in some boroughs is >45% (DoH 1998). If they were placed as individuals in an environment where there is no exposure to their culture of origin I argue the cultural orientation would be lost, as occurred among Blacks following enslavement from Africa to the Caribbean and North America.

5.4.2 Educational level

The statistical significance observed between the African and Caribbean respondents is likely to be the result of differences in the migratory pattern of the two cultural groups historically. Following the Second World War Britain saw the beginning of a significant rise in the migration of people from the British colonies into the UK. A greater proportion of Africans who travelled to the UK in the mid-twentieth century were professionals and scholars, many on government scholarships. They came for education, skills training and professional development with the intention of returning ‘back home’ to utilise their new found knowledge and skills. Although many scholars also migrated from the Caribbean a significant proportion of Caribbeans who migrated were economic migrants seeking employment and a prospect of better opportunities in what they considered the ‘mother’ country (Akinsanya 1988, GLC 1986, Phillips and Phillips 1998).

Many of this latter group were unskilled and untrained and were promised training opportunities if and when they came to the UK. They were recruited in order to assist with the redevelopment of post war Britain. For many the training opportunities that were promised prior to their arrival in the
UK did not materialize, and they found themselves unable to achieve their ambitions relegated to doing menial jobs. For example, those who came to do nursing and had adequate secondary education qualifications that would allow them to undertake State Registered Nurse (SRN) training were coerced into undertaking the lower State Enrolled Nurse (SEN) training, a course that was usually accessed by those with insufficient secondary education for the SRN training. Sadly SEN had limited promotion or career prospects compared to the SRN-qualified nurse. Many of those trained as SEN became disillusioned and found themselves unable to transfer to SRN since this would entail a further two years training, which many of their employers were unwilling to sponsor or recommend them for, many were in a catch twenty-two situation, unable to progress professionally yet unable to retrain.

Another possible reason for the difference observed in educational level is perhaps the recruitment process. Participants were recruited often by word of mouth through those who had already participated, others were from local community groups and some were recruited during public conferences and lectures. Evidently, those who attend conferences and lectures will demonstrate a higher educational background and if these individuals assist in recruiting others it is likely they will recruit from those they associate with, which could influence the sample obtained.

5.4.3 Impact of religion

Religion plays a pivotal role in influencing the social attitude and practises of many African and Caribbean people, a belief that a superior spiritual being has greater power over the life and experiences of individuals continue to be perpetuated. This supernatural element permeates the thinking of the majority of the respondents especially those newly migrated. Although religion has a major influence in the lives of males and females of both cultural groups, double the numbers of Africans practise a religion (See Table 5.)

Thakur (1981) argued that religion is in the sphere of faith and cannot be explained by rationality or intellectual reasoning. Evidence for this is found in this study (Section 5.1.6) where despite having a first degree or above the majority of the respondents who had a first degree or above (Africans 93%, Caribbean 68%) practise a religion. This unexpectedly high level of religion among highly educated respondents gives credence to Thakur’s assertion that religion is beyond rationality and it further highlights the deep roots of culture among the African and Caribbean respondents.
This data gives credence to the observation of other authors (Kondor 1993, Madu 1994 and Beit-Hallahmi and Argyle 1997, Jegede 1998, Read 2001) who argued that it is not uncommon for well educated individuals in many African communities to consider the supernatural aspect of illness and integrate orthodox western medicine with religious activities such as fasting and prayer, and many will seek the support of religious leaders to gain the Lord’s favour and consequent healing. Jegede (1998) stated ‘Churches have rites of healing which in some cases are central to the ritual of the churches’ and attracting new converts. Atkinson’s (2004) ‘enculturation’ theory is further supported by the findings of the current study. It is likely that religion of any form is the foundation of culture for many of these minority ethnic respondents and the enculturation of religion would have been firmly instilled since early childhood in the nuclear and extended family and subsequently in the larger cultural community.

Many of the European educated and westernized respondents will find it difficult to subscribe to the notion that a belief in a benevolent God is a myth and evolution theory is the reality and explanation for human existence. Since the majority of the respondents are Christians and advocate the ‘God’ theory the popular Darwinian concepts of man’s existence will not fit comfortably with their cultural beliefs and values. Dissonance then occurs between the cultural belief in God and scientific explanations.

For many of these African and Caribbean respondents in order to function within an environment that does not necessarily subscribe to the notion of God being omnipotent and yet practise their culturally defined belief in God one would have to find a resolution for the dissonance that has been created between ‘cultural belief’ and ‘educational belief’. To deviate from the original strong cultural norm would create dissonance and as argued by Festinger and Carlsmith (1959) and Eagly and Chaiken (1993) the individual or group would have to go through a cognitive process that will help them find a resolution for the dissonance which these two opposing elements has created.

I suggest this resolution is achieved by individuals and groups getting reinforcement for the original belief and avoiding situations that may increase the dissonance which the scientific explanation is creating, for example, meeting with similar minded individuals by attending church, reading the bible, praying, avoiding confrontation or discussions with non-believers, avoiding situations that will heighten the dissonance such as listening to a debate that discusses the two cognitive positions. Such behavioural strategies demonstrate what Abelson (1959) describe as ‘bolstering’. In order to reduce the dissonance between a belief in God and scientific knowledge or
arguments that may have swayed the individual's belief in God by adding a justification element, such as, ‘I would hate to discover later that there is a God after all. Especially if I am dead, making it too late to change my mind or make reparations’ or ‘My parents believe in God and they would be disappointed if I did not’.

It was not surprising to find a statistical difference between those born/ migrated <15 and those migrated >15 years of age (Section 5.2.1). However, despite this apparent difference it is noted that overall 82% of the total population practise a religion which further demonstrates the power of culture in maintaining cultural values and practises and gives credence to Sowell’s argument that ‘cultures are not erased by crossing a political border, or even an ocean, nor do they necessarily disappear in later generations which adopt the language, dress and outward life style of a (another) country’ (Sowell 1994:4).

Read (2001) asserts that a significant aspect of peoples’ culture is the complexity of their belief in supernatural powers that control them and their universe. Marteau and Senior (1997) proposed that there is considerable variation in the cultural attribution of disease and illness; non-western cultures have a tendency to include interpersonal relationships and supernatural beliefs in their view of illness causation. The current study affirms these assertions and the impact of religion is amply demonstrated in the finding that the African and Caribbean respondents regard religion as an important factor in their attitude to disease and illness and this is further supported by findings in the Phase 3 interview.

5.4.4 General knowledge of sickle cell

The data demonstrated that 78% of the African respondents migrated >15 years of age compared to 28% of the Caribbean respondents. The majority of the African respondents are first-generation migrants, whilst the majority of the Caribbean respondents are second- and third-generation migrants, hence the original hypothesis that a greater proportion of Caribbeans would have greater exposure to health information because there is a well-established and long-standing sickle cell awareness programme in the UK. As a result of such exposure it was anticipated that Caribbeans, the majority of whom have lived in the UK during their formative years, would have greater knowledge of sickle cell than Africans. However, the reverse was observed in the data (Section 5.3.1.2).
The Africans’ greater knowledge of sickle cell could be attributed to the higher incidence of sickle cell among Africans. 79% of the Africans and 58% of the Caribbeans living in the UK live in London (CRE 1999). The majority of those who completed the questionnaire live in London. 25% and 10% of Black Caribbean have sickle cell trait and 1 in 60 children born to West Africans and 1 in 300 born to Caribbean couples have sickle cell disease. In view of this Africans are more likely to live with someone with SCD and therefore observe the health and social impact not only for the individual but for the individual’s family, especially in an environment where good health services are inaccessible to the masses.

The need to maintain secrecy about sickle cell in many African communities may account for the obfuscation of knowledge. An individual may have been tested but misinformed about the result. In many African countries the objective of testing is to identify those with a ‘disease’, identification of a ‘carrier’ is often perceived as irrelevant and individuals are merely told that they are ‘normal’, which in this case means they do not have sickle cell disease. However, it does not exclude a carrier state and individuals are not told about the potential genetic implications of a carrier state to future offspring.

The data in this study confirms that although more of the Caribbeans actually knew someone with SCD, confirming that perhaps there is less secrecy in the Caribbean community and individuals are more likely to share such information with family and friends, however fewer of them lived with the individual (Table 7) and would therefore have little or no experience of the disease and therefore are less likely to acquire in-depth knowledge of the condition. Evidently personal experience promotes greater knowledge and awareness.

Secondly, sickle cell anaemia (HbSS), is the most serious type of SCD and predominates among Africans whilst a myriad of other less clinically serious forms are observed among Caribbean populations e.g. sickle haemoglobin C disease (HbSC) and sickle beta thalassaemia (HbSβthal). Therefore, the African respondents are more likely to have observed the more severe clinical syndrome and witnessed the health and social impact of SCD. This experience of SCD would shape perception of the seriousness of SCD, create fear of the illness and perpetuate a desire not to be associated with the condition.

The data indicates that in the assessment of knowledge of SCD perhaps cultural group is not the important issue but level of exposure to the subject and the educational background of individuals;
the marginally higher educational level of the African respondents (Table 4, Graph 3) probably influences opportunities and a desire to access health information, including information about sickle cell.

It is possible that in the clinical setting when asked about their previous knowledge of sickle cell Africans are reluctant to admit their awareness and are more likely to obfuscate knowledge in an attempt to avoid the stigma associated with knowing about the condition or being perceived, rightly or wrongly, as having the sickle cell gene. As noted by Jegede (1998) in a study of perceptions of disease and illness in the West African community, illness is stigmatizing particularly illness that is hereditary, and individuals and their extended kin can be ostracized by mainstream society, hence the secrecy. This finding could also be a demonstration of denial and a reluctance to deal with the dissonance that admitting to having such knowledge creates, especially where an individual has been tested and is aware of his or her carrier state or has not been tested and does not wish to be confronted with the need to be tested. By reducing the importance of one of the dissonant elements i.e. knowledge of the information and potential to being at risk of having the gene, feigning ignorance or misunderstanding of the genetic information or its importance helps to prevent the ‘cognition’ from becoming fully established and having to deal with the reality of it.

Despite the African respondents’ better knowledge of SCD it was surprising that six times more Africans than Caribbeans perceive that educated people are less likely to have sickle cell disease (Section 5.3.1.2). This further highlights the social context of sickle cell even among well educated Africans, many of whom felt that educated people have the capacity to make appropriate marital choices, i.e. a couple who both have sickle cell trait should not marry each other, and in order to enforce this educated individuals should have enough knowledge to subject themselves to testing prior to marriage and procreation in order to avoid having children with SCD.

Those who had been tested for haemoglobinopathies predictably had greater general knowledge of sickle cell than those who had not been tested, demonstrating the effectiveness of testing policies in the UK, where it is advocated that those who attend for genetic testing must be offered pre-test information and counselling (HGC 2001).
5.4.5 Attitude to sickle cell disease

5.4.5.1 Severity of disease

The respondents who perceive sickle cell disease as a severe condition were also likely to perceive that having a child with the condition poses a potential burden for the family. These two summary variables appear related and the contributory factors relevant to one appear relevant to the other.

The data demonstrated that overall Males perceive sickle cell disease as being a more ‘severe disease’ than Female respondents (Section 5.3.2.1) and those migrated >15 years of age more than those born/migrated <15 years of age (Table 11).

The difference observed in gender is in support of a number of authors’ findings and the assertion that males were more opposed to having a child with an abnormality than females (Beeson et al. 1985, Sorensen et al. 1986, Marteau 1995 and Shiloh 1996). Conversely, in a study of Nigerian males’ and females' attitude to SCD Durosinmi et al. (1995) observed that female respondents were less accepting of the risk of having a child with SCD.

Why is there this difference between the attitude observed in the current and some of the former studies and that of Durosinmi et al. (1995)? I suggest the influencing factor is cultural location. Beeson et al. (1985), Sorensen et al. (1986), Marteau (1995) and Shiloh’s (1996) studies were conducted in the west among multicultural, multiethnic communities. The current study, although conducted with Black African and Black Caribbean populations, was also conducted in the west, whilst Durosinmi et al.’s (1995) study was conducted in Africa in a population who share a social reality, a socio-cultural context, values and beliefs. The Nigerian population in Durosinmi’s study would have a perception of the severity of SCD based on the observations of the condition in Africa, where the majority of those affected have sickle cell anaemia (HbSS), the most severe and often debilitating form of SCD. They will also be conversant with the health care system in Nigeria, which is often inaccessible, unaffordable and in many circumstances unavailable except for those living in major cities and who have the means to pay the exorbitant cost for medical consultations, treatment and prescribed medications. Even where health care is accessible, in less reputable medical units treatment is precarious because you can never be sure of the quality of care and medications purchased from local pharmacists, the selling of fake drugs is difficult to police.
The clinical picture and the image of an individual experiencing the intractable pain of sickle cell crisis can and often leaves an indelible memory of suffering; a pain which in many circumstances in the African context cannot be effectively alleviated because of lack of affordable medicines, medicines such as opiates which are readily available in the UK.

The Male respondents’ perception of the severity of SCD (Section 5.3.2.1) can also be examined in the context of the potential burden of SCD and the future plans for the family. The prospect of caring for a child with a debilitating chronic condition when they go ‘back home’ is a factor taken into consideration and the anxiety that this will provoke probably influences the Males’ attitudes to the severity of SCD. The reality of the disease burden looms larger in the ‘back home’ context than it does whilst individuals are still living in the UK, and the potential challenges and burden of caring for a child with such an unpredictable, debilitating, chronic and potentially life threatening condition is likely to fill many more males than females with fear and trepidation.

The social status of women in Durosinmi et al.’s (1995) study is also likely to be a contributory factor which may account for the Females’ attitude. For a woman to bear children with a debilitating, chronic, potentially life-threatening illness stigmatises the nuclear and extended family, jeopardises the family’s social status, threatens their economic position and poses a social burden that is borne primarily by the women. In my clinical experience despite attempts to explain Mendelian inheritance and the fact that a child with SCD has inherited the gene from both parents many African and a few Caribbean men refuse to accept the role they play in their child’s inheritance of the condition.

The accusations levied against a woman for bearing an unhealthy child is a situation that the majority of African women would prefer to avoid. Hence in Durosinmi et al.’s (1995) study a larger proportion of females than males said they would opt for prenatal diagnosis (if it was readily available and affordable) with a view to termination of an affected pregnancy. The stigma existing in many African societies mans that couples known to have sickle cell trait are vehemently discouraged from marrying each other, and this is supported by findings in this current study where a number of respondents, especially African Males believe that an at-risk couple should not marry (Graph 6). It is therefore not surprising that in the UK a greater proportion of African women opt for prenatal diagnosis and termination of an affected pregnancy than Caribbeans (Petrou et al. 1992), however, some of the African women are referrals from Africa where compared to the Caribbean there are fewer fetal diagnostic units.
In the UK Africans and Caribbeans who migrated >15 years of age will observe differences in health care provision in the UK compared to provision in Africa and the Caribbean. Females, who are often the main health care givers, would have observed and recognized that health and allied services are available to provide adequately for a child with sickle cell disease and choosing to have a child with this genetic condition is less of a burden in the UK than Africa or the Caribbean. Secondly, Females are more likely to be aware of families and friends who have children with SCD and would be aware of how these individuals and their families cope with living with SCD in the UK, especially the health and social welfare support services available to them. Males are less likely to get such exposure and their memory of SCD will often be based on their memories of Africa and the economic, health and social costs that such disease imposes on the family. It would be interesting to replicate this study of attitude among Black populations in the USA, where health and social welfare services are not readily available for those who do not have the financial resources and health insurance.

More of the respondents who migrated >15 years of age perceive that SCD is a severe disease compared to those born/ migrated < 15 years of age (Section 5.3.3.4 and Table 11). This indicates that those enculturated in their country of origin perceive that SCD is a severe disease primarily because they would have observed the clinical presentation, management and the impact of the condition on individuals and their families. The same issues already discussed apply in this case. The social experiences of SCD in Africa and the Caribbean account for the perception of those migrated >15 years of age. More of those born/migrated <15 years of age would have had experience of SCD in the UK context and few would know or remember the impact of the condition in their country of origin, especially if they migrated at a very young age, and less so if they come from a society where there is secrecy surrounding disease and illness.

However, those migrated >15 years of age would have observed and remembered individuals and their families’ experience of living with SCD in Africa, Caribbean and the UK. They would have observed that in the UK individuals with SCD can and often lead near-normal lives because they are able to access effective generic and specialist childhood illness prevention programmes and health care, which will help to reduce the clinical effect and complications of SCD. There are social welfare support systems in place to provide for the individual and the family when required. All this contributes to a less negative experience of SCD in the UK, however, the indelible mark left by the experiences of SCD in Africa and the Caribbean during the formative years can be difficult to
ignore and the notion that SCD is a severe disease remains etched in the memory of many of those migrated >15 years of age.

5.4.5.2 Level of burden

The perception that SCD is a burdensome disease is almost synonymous to perceiving it as a severe disease; hence my argument that both of these concepts are related and the arguments made for one can be applied to the other.

Dryden in Green and Statham (1996) noted that parents’ perception of the degree of burden imposed on the family by having a child with a genetic condition influences their decision in opting for prenatal diagnosis and termination of an affected fetus. Alkuraya and Kilani (2001) in a study of Islamic Saudi families at risk of having a child with sickle cell disease reported that burden of disease did not appear to influence the parents’ decision-making. However, religion did have an influence.

The findings of the current study, that more Africans than Caribbean respondents (Section 5.3.1.3 and Table 9); more of those born/migrated <15 years of age than those migrated >15 years of age (Section 5.3.3.4 and Table 11); more African Females than Caribbean Females (Section 5.3.4.2); more African Males than Caribbean Males (Section 5.3.7.2 and Table 12), perceive that having a child with SCD causes a potential burden for the family was not surprising in view of some of the arguments made earlier.

Associated with this finding is the response to the individual attitude statement ‘If a couple both have sickle cell trait they should not have children together’, with which more of the African Males ‘strongly agreed’ (Graph 6). This may help explain Petrou et al.’s (1992) observation in a London fetal diagnostic unit where a significantly higher proportion of Africans at risk of having a child with sickle cell disease opted for PND and termination of an affected fetus compared to those from the Caribbean. Why do more of the Africans perceive that having a child with SCD is a potential burden? I propose that this is related to the respondents’ previous knowledge and experience of the disease and what I term the ‘going back home’ syndrome. A large proportion of Africans are first-generation migrants and many still have a utopian notion of ‘going back home’ eventually.
Knowing that health care is costly and woefully inadequate in many parts of Africa may inadvertently influence the African respondents’ attitude; except in the case of those with strong religious convictions. The diminished social status of affected families may also be a factor that compels many Africans to avoid giving birth to a child with a life-long potentially serious genetic disorder. This may be more so for women in many developing countries who often depend on their children for social status and future economic stability. I suspect that few of the second- and third-generation Caribbean migrants harbour this utopian notion of going ‘back home’ since they are British and have less of a patriotic attachment to the Caribbean. Therefore, the issue of burden is less relevant and even where the notion of going back home exists health care facilities are readily available in the Caribbean, albeit at a cost.

The majority of the respondents in the Caribbean group were born/ migrated < 15 years of age and would have little experience of SCD in the Caribbean, and the few that do would have observed that although SCD causes major distress for families in the UK there are health and social infrastructures available to lessen the debilitating impact of the condition.

There is a myth perpetuated in the Black community, especially amongst Africans, that people with sickle cell disease die by the age of 21 years and a fortunate few may live to the age of 30 years approximately. The affirmation of this perception is demonstrated in this study (Section 5.3.1.2). Such a belief would have contributed to the perception that SCD disease poses a potential burden for the family not only financially but emotionally.

In addition the financial burden of raising a child with a lifelong chronic condition in an environment where health services are not readily available or comes at a high price contributes to the African Males’ attitude. As indicated in Graph 8, a greater proportion of African Males ticked ‘strongly agree’ that having such a child would cause financial hardship for the family, more so than any other group. This is not surprising since in the majority of cases males are often the family’s main source of income and situations that will place a greater burden on the family resources, especially in the ‘back home’ context, will create distress. More of the respondents who migrated >15 years of age are likely to have observed the financial implications of caring for such children ‘back home’.
5.4.5.3 Reproductive Drive

In examining the importance of having children the data demonstrated a highly statistically significant difference in a number of groups: more Africans than Caribbeans (Section 5.3.1.3, Table 9 and Graph 9) felt it is important to have children; more Males than Females (Section 5.3.2.1); more of those migrated >15 years of age than those born/ migrated <15 years of age (Section 5.3.3.4 and Table 11); more African Males than African Females (Section 5.3.5.2) and more African Males than Caribbean Males (Section 5.3.7.2 and Table 12) and.

Whilst children are highly valued in the Caribbean society there is greater acceptance of individual choice and preference for children. In the Caribbean society it is possible for an individual to choose not to have children thus reflecting the Caribbean respondents more ‘independent’ society’s western attitude to procreation and parenthood. Those who originate from an independent society, as described by Kashima et al. (1992) have the freedom to make personal choices that suit their own needs even where the choices made conflicts with the needs of others, especially the wider community or society. In such a scenario the decision-maker will feel comfortable with the decision made irrespective of its consequences to the wider community. Conversely those from an ‘interdependent’ society feel unable to make personal choices without consideration for the impact that the decision will have for the wider community or society (Section 2.1).

Other authors alluded to the traditional African’s lack of ability to make personal choices in respect of not having children (Maclean 1978, Madu 1994, Basden in Madu 1994, Jegede 1998 and Lips 2003). The findings of the current study affirms the assertion that the pressure to have children placed on individuals from the African society is very effective in enforcing compliance, illustrating that many African families and communities demonstrate Kashima et al.’s (1992) ‘interdependent’ society. For those who genuinely do not want children the societal pressure to have children will invariably create dissonance, since their personal value is not reflected in their behaviour. These individuals will need to find a resolution for the dissonance for example, by reducing the importance attributed to the dissonance element ‘I don’t want children’. Or by adding consonant or justification elements, for example, self-talk which states, ‘It is a cultural expectation for me to have children, so I have no choice’, ‘My parents would be disappointed’ or ‘My husband will get another wife if I don’t have children for him’. For some of the African women the last statement reflects a reality, since the possibility of finding a husband who accepts an African woman who does not want to have children is rare, it is highly unlikely that the African woman would pursue her personal preference.
In the interdependent society personal preference does not have a significant role where family, community and societal needs have to be taken into consideration and in the African society it is the responsibility of the individuals within society to fulfill their role as guardians of the family lineage and continuity of the family line is a goal that all strive to maintain. To choose not to have children is anathema in many African communities. Among the African and Caribbean respondents it is proposed that those born / migrated <15 years of age are more likely to demonstrate the ‘independent’ attitude of western society whilst those who migrated >15 years of age are more likely to demonstrate the ‘interdependence’ of the African and Caribbean culture of origin.

The finding that there is a statistically significant difference between Male and Female respondents was not surprising. What was surprising was that the Male respondents feel it is more important than Female respondents to have children, especially in view of the lower social status of women in many African communities. This finding calls into question the biological reproductive drive theory as postulated by Pearn (1979) and Finucane (1998), who argued that a person’s, especially women’s, reproductive drive is inherently overwhelming and that even the risk of passing on a disease to one’s offspring is unable to suppress this reproductive drive. Finucane (1998) said that biologically women need to satisfy their inherent desire to leave a ‘legacy’ for the next generation and argued that this is the important factor that compel women to reproduce.

In the current study more Male than Female respondents feel it is important to have children does this mean that the Males have a stronger reproductive drive than the Females? This may seem a plausible explanation. However I propose that culture is the major factor influencing the observed differences. I suggest that the Male ego in respect of virility plays a part in this regard and any inability to impregnate a woman has a huge psychological impact on the males’ perception of self, self-image and self-esteem within society, and more so in Black societies where there is greater pressure on males to reproduce.

Since we have established that having children is a major issue especially in the African community the inability to father a child will call into question not only the individual man’s virility but the family’s virility, especially once female infertility has been excluded.

The statistically significant difference between African Males and African Females (Section 5.3.5.2) on the importance of having children was bemusing. But on closer inspection it should not have been baffling. Most African societies are patriarchal and children adopt their fathers’ surname
and in most communities inherit through the paternal line (in Ghana they inherit through the maternal line). Although a barren woman’s status in the African society is precarious (Lips 2003) the stigma associated with male infertility is greater and attempts will be made to conceal what is considered a very unfortunate state. Concealment can take many forms but the most extreme include soliciting the assistance of a male relative to impregnate an infertile man’s wife in order to maintain the family line but more importantly to uphold family honour. This action becomes a family secret and can remain so for many generations. Since the introduction of routine neonatal screening for sickle cell in the UK such family secrets may be exposed inadvertently where the newborn infant’s genotype does not match those of the alleged father.

Although African Males and Caribbean Males feel it is important to have children there is a highly significant difference between the two groups (p=0.000) (Section 5.3.7.2 and Table 12) where the African Males demonstrated a greater conviction than the Caribbean Males. This reflects the differences in pressure placed on the African Male by family and society to produce offspring to carry on the family name an issue highlighted by other authors (Maclean 1978, Madu 1994, Lips 2003).

5.4.5.4 Multi-dimension Health Locus of Control (MHLC)

The Multi-dimension Health Locus of Control attempts to measure the extent to which an individual perceives the factors that influence their health and their ability to remain healthy. The three dimensions internal, chance and powerful others demonstrate the degree with which people have control over their health.

The areas observed as statistically significant were in respect of powerful others: more Males than Females felt that powerful others had greater control over their health (Section 5.3.2.2); African Females felt this more than African Males (Section 5.3.5.3). In the chance dimension those migrated >15 years of age felt that remaining healthy was more of a matter of Chance more so than those born/ migrated <15 years of age (Section 5.3.3.5). Surprisingly there was no statistical significance in the groups in respect of internal locus of control.

Calnan (1989) claimed that high scores in the Chance dimension are associated with women, older people, those with less education, and those with manual backgrounds. In a study of religion and
MHLC Levin and Schiller (1986) sampled 909 adults, some who had a religious affiliation and some who did not. They discovered statistical significance and a link between religion and locus of control, the non-church-goers scored higher in the ‘Chance’ domain. Those who are church-goers who attend a church that is heavily ritualized, traditional and strict, such as Mormon and Catholic, scored higher in the ‘Internal’ whilst Presbyterians scored highest in the ‘Powerful Others’ domain, whilst those with no religious affiliation scored lowest in the ‘Powerful Others’ domain.

The findings in the current study support the argument that there is a link between religion and locus of control in view of the high number of those (82%) who practise a religion.

In a study comparing health locus of control and cultural variation in perceptions of health among 128 Caucasian, South Asian and Caribbean women, Wrightson and Wardle (1997) noted that fatalism is an aspect of being that influenced the minority ethnic women’s perceptions of health and health behaviour. They found that Asians scored higher than white Europeans in the Powerful Others and Chance locus of control.

In the current study I propose that the differences observed in the Males and Females in terms of powerful others relate to the position of women in relation to knowledge about health and health issues. Women are exposed to health information by virtue of being the major care-giver in the family. Thorogood (1989) asserts that ‘family health is perceived as being part of women’s domain. They are seen and see themselves, as having responsibility for the maintenance of the family…sickness in the family may well be considered a consequence of bad mothering or poor housekeeping’ (Thorogood 1989: 319). Women have greater exposure to the health services and health information through their frequent interaction with such services, especially in respect of pregnancy, childbirth, attending for regular routine gynaecological investigations and caring for young children who are frequent users of health services by virtue of their tendency to childhood illnesses and accidents. The majority of men have little or no interaction with health services, at least not until they reach middle age.

Women are also exposed to health information through other avenues such as magazines and other media sources targeted at women, who are perceived rightly as the family’s gate-keeper to health information and services. Therefore women are more likely to score lower in the powerful others locus of control and higher in the internal. Few men take active control of their health and they are less likely to self-medicate or self-care.
The differences observed in the powerful others dimension in the African Female and African Male is likely to be attributable to the status of women in the African society. Although women are also care-givers in the African society men also play a significant role in health care generally. Religion may also be a factor influencing the differences in this group. I propose that religion plays a part in this deference to powerful others among African Females in support of Levin and Schindler’s (1986) argument. It is noted that Christianity is the majority religion in this group and a high proportion practise a religion (Baptist, Methodist and Pentecostal) where there is high regard and reverence of the religious elders. This coupled with traditional African reverence for the husband makes this finding unsurprising.

I argue that the finding that those who migrated >15 years of age scored higher in the chance dimension than those who were born / migrated <15 years of age is a demonstration of the strong religious beliefs and values of the former group, especially since the African respondents are the largest proportion in the >15 years of age group. The belief in a supernatural being that has control over one’s life and destiny lends itself to a higher score in this dimension. Fatalism is a common hallmark of the highly religious and is observable in many minority ethnic communities and more so among first-generation African and Asian communities in the UK. Collier and Fleischmann (2004) describe the practises of traditional African religions in many parts of the Caribbean and it is therefore possible to argue that a belief in the supernatural and a belief that evil spirits contribute to the development of disease and illness among the African and first-generation Caribbean is likely to be the major cause of the high score in this dimension, since the migrating >15 years group would have had their enculturation in Africa or the Caribbean.

5.4.5.5 Test result and selection of partner

To determine whether knowing one’s blood test result influenced selection of a partner respondents were asked, ‘If you knew your test result before starting a family did you choose your partner based on your own test result?’ and the result of the responses to this are worthy of discussion to further highlight the magnitude of the attitude to SCD.
Among those who tested positive for the sickle gene it was understandable that some purposefully chose their partner based on their test result in order to avoid having a child with sickle cell disease. However, those with normal results who also purposefully selected their partners were bemusing. It was unexpected that of the African Females who were tested positive for the sickle gene (Table 7) none chose their partner based on their own result. It was anticipated that African Females more than the other three groups would be more inclined to select their partner in order to avoid giving birth to a child with SCD so as to limit the possibility of their being rejected for giving birth to ‘sickly’ children. This finding further highlights the power of culture.

Even among educated African Females the likelihood of selecting your partner based on your own positive genotype poses a cultural problem. Firstly, in order to identify that a potential partner does not have sickle cell and in an attempt to get him tested the woman would have to acknowledge that she has knowledge of sickle cell and that she herself has sickle cell trait. This poses a risk in a society where a woman’s status is precarious and the potential to be rejected greater when it is discovered that you are a carrier of a genetic ‘disease’. Secondly, secrecy is the norm in many African communities therefore obfuscation of one’s knowledge of sickle cell is common. I propose that for an African Female to actively choose a partner based on her own genotype even among those who are educated and or westernized few would broach the subject except perhaps those who are culturally unaware or involved in an interracial /intercultural relationship. There is dissonance between the cognition that, ‘I have knowledge of sickle cell and I have sickle cell trait’ and the cognition that ‘this fact will affect my partner who will not be able to accept it’. In order to deal with the dissonance the individual may decide to lie to their partner, claiming that they do not know of the condition or their haemoglobin type. Justifications elements may be introduced in order to alleviate the dissonance that this has created. Similar to Festinger and Carlsmith’s (1959) study of students who were persuaded to lie about the enjoyment of a task given during an experiment, women in this predicament will need to internalize the belief that they know nothing about sickle cell or the implications of their carrier state. Changing the reality and their belief will help them to reduce the dissonance that would have arisen if they had merely lied, obfuscated their knowledge of sickle cell, their carrier status and its potential genetic implications.

As highlighted by Durham (1991), groups share a cultural reality, and secrecy about disease is a cultural reality shared by many African societies. Geertz (1973) claim that groups assign meanings to a phenomena and there often exists a historical interpretation of these; historical meanings are transmitted to future generations through the use of symbols, such as language and expressions.
used or made in relation to that subject or phenomena. I suggest that those born and brought up in the UK if they have sufficient exposure to their cultural group would probably absorb some of their cultural groups’ attitude to that phenomena and subsequently reflect this in their future attitude and behaviour.

It was difficult to understand why four African Males and one Caribbean Female who had normal haemoglobin chose their partners despite having normal haemoglobin themselves. It is possible that these individuals misunderstood their own result or chose their partners in order to avoid attracting the defective gene into their family line. One of the male respondents indicated that he knew there was no risk of his passing on a sickle gene to his offspring but he felt it, ‘best not to marry someone with sickle cell, so as not to bring the gene into the family’. This response further highlights the cultural attitude to sickle cell particularly in Africa. The Caribbean Female respondent indicated that she is a nurse working in London therefore it is highly unlikely that she would have misunderstood the lack of risk, perhaps she is attempting to avoid introducing the gene into her family.

Richards (1996) and Emery (2001) observed the difficulty people have in grasping information about genetic probabilities and misunderstanding about genetic chance is common among lay public even those who have received genetic counselling. In view of this observation it is possible that the Caribbean Female respondent misunderstood the genetic implications of her genotype and the fact that she is not at risk. It is possible that she understood the genetic information but chose her partner purposefully in order to avoid the defective gene getting into her family. Either way this reflects the complexity of human behaviour and this credence to Hoffmaster’s (1990) argument that foreknowledge does not necessarily result in an outcome that is considered a rational decision, if one can define rationality in this context.

5.4.5.6 Qualitative data in questionnaire

There is a common assumption that people with SCD have typifying features, for example, skin pallor, overt thinness, lassitude, asymmetrical body shape, protruding teeth, jaundice of the eyes and frequent episodes of pain requiring hospitalization. When these are not observed it is assumed that the condition is absent. Hence a number of respondents when asked why they have not been
tested or tested prior to starting a family indicated that there is no history of sickle cell in their family; also that they, their partner, their children and extended family appear ‘normal’, did not demonstrate the symptoms of sickle cell disease or display the observable features of SCD.

However, it is recognized that milder forms of SCD can remain undiagnosed in a family for many generations. This includes, for example, HbSC and HbSβThal and the benign carrier states. It is not uncommon for these to be identified through routine screening in adulthood, for example when booking for confinement of a pregnancy or going for general anaesthetic prior to surgery. This illustrates the level of knowledge about haemoglobinopathies among this high-risk population.

A survey by Louis Harris and Associates, for the March of Dimes Birth Defects Foundation, found that 99% of North Americans said they would have a genetic test prior to having children in order to avoid the birth of children with a genetic defect (Beeson and Doksum 2001). It is surprising that a significant proportion of the African and Caribbean respondents in the present study were not in strong support of pre-conceptual testing, sometimes for religious reasons. Although religion was not very prominent in the Phases 1 and 2 quantitative data, it is more evident in the Phase 3 interviews and will be considered in the Phase 3 discussions.

Beeson et al. (2001) also discussed criticisms against prenatal diagnosis, emanating not from religious groups but from feminists who were advocating the rights of people with disabilities. The feminists argued that attempts to eradicate disability create a less tolerant society, a society that does not value difference or promote the support of its vulnerable members. Therefore they argue that the desire or striving for the perfect child should not be discouraged.

Alkuraya and Kilani (2001) in a study of Islamic Saudi families at risk of having a child with sickle cell disease reported that religion influenced the at-risk parents’ decision-making in that they felt they would be going against the Islamic rules that relate to the sanctity of life. In the current study a few respondents demonstrated that religion influenced their attitude to the idea of selecting a partner based on their own Hb status, as indicated by a Christian African Female respondent, who is aware that she has sickle cell trait but not aware of her partner’s genotype as he has not been tested. She stated:

*The Lord led me to him and him to me. I trusted the Lord to have covered all the grounds, if there is anything wrong with him, we will ask God and wait for his answer [as to what we should do].*
Some of the respondents commented on the issue of people with sickle cell trait having children together, 9 Africans and 1 Caribbean respondent felt such individuals should not marry each other in order to avoid having a child with SCD. It was not particularly surprising that more of the Africans felt this way and other authors support the argument that the Africans general attitude to disease and illness is reflected in this attitude (Maclean 1978, Kondor 1993, Madu 1994, Beit-Hallahmi and Argyle 1997, Jegede 1998). All this supports the assertion that there are relevant differences between African and Caribbean attitude to procreation, disease, illness and the risk of having a child with a genetic disease. Avoidance of the potential burden of a child with SCD is more strongly advocated by the African respondents hence the promotion of the idea that 'people with sickle cell trait should not marrying each other'. Interestingly the one Caribbean who agreed with this attitude has an African partner.

Three of the African respondents indicated that they or their partner were given an incorrect ‘normal’ result when tested in Africa. It was when they were expecting a child in the UK and tested routinely they were informed of their carrier status. In many African countries the majority of those who attend for testing do so in order to identify whether they have sickle cell ‘disease’, hence the majority of testing centres offer testing based on this assumption and results are provided to confirm presence or absence of a disease state, not whether an individual has a carrier state and is therefore potentially at risk of having a child with a disease state.

One African Male with sickle cell trait inadvertently chose a partner who also has sickle cell trait. He grew up with two siblings who had sickle cell disease, one of whom died during the teenage years. The participant was tested during childhood and is aware of his sickle cell trait status. Prior to getting married in Africa he insisted on his fiancée being tested, adamant that he would not marry anyone who has sickle cell trait because he did not want to experience what his parents experienced with his siblings. The blood test result indicated that his fiancée was ‘normal’ and she did not have sickle cell. However, when the couple was expecting their first child in the UK his wife was tested routinely and found to have sickle cell trait, their first child was subsequently born with sickle cell anaemia.

This demonstrates the danger of genetic testing without adequate quality control of laboratory services and policies and without guidelines for the management of the pre- and post-test processing and notification of results.
Two African and one Caribbean respondent stated that they have had several blood tests in the past and if they have sickle cell they would have been told. There is a common assumption among the general population that if blood is taken for testing a wide battery of tests are conducted routinely one of these being sickle cell, and Black people assume that since they are in the high-risk group they would be tested without their requesting it. Society has now become knowledgeable about the moral and ethical dimension of genetic testing without a person’s knowledge, request or consent, the ethics of which are clearly outlined in HGC (2003, 2004, and 2006) publications.

This finding demonstrates the need for greater awareness and education so as to enlighten those at risk of the sickle cell gene and encourage their making an informed choice about testing.

5.4.5.7 Other concepts and variables

It was surprising that in the summary variables no significance was observed in attitude to prevention. Since significance was observed which demonstrated the perceived high burden of SCD, one would have anticipated a parallel significance in attitude to prevention.

Other concepts and variables were examined for statistical significance including marital status, employment status, blood test result, mode of notification of blood test result comparing notification by mail or face-to-face counselling, religious denomination and level of religious practice (See Graph 5, Tables 5 and 6) to determine whether they had any statistically significant impact on any of the five summary attitude variables, multi-dimension health locus of control variables and the summary ethnicity variables. They did not.

5.4.6 Conclusion

Phase 1 of the project has demonstrated that there are differences in attitude to disease and illness and in particular to sickle cell among people of African and Caribbean origin. In some instances gender has played an important role but more significant is the age at which an individual migrated to the host country (UK) and it is evident that Black people in the UK are heterogeneous even among those from the same original culture.
The data also demonstrated that although there is a degree of assimilation of a host culture the culture of origin where the individual received their primary orientation, enculturation, has a very powerful influence in shaping attitude to complex health and social issues, such as attitude to procreation and perception of the clinical and social nature of sickle cell disease.

Phase 2 of the project will aim to identify whether there are similar statistical differences observed in pregnant African and Caribbean women with sickle cell trait. This group will also be compared with Phase 1 African and Caribbean women to determine whether being pregnant has any impact on knowledge of sickle cell and attitude.

Phase 3 will aim to identify socio-cultural factors that are influencing pregnancy outcome and the choices that women and their partners make in respect of a pregnancy that has a 25% chance of resulting in a child with sickle cell anaemia. It is anticipated that this Phase will enable previously unidentified factors to emerge with the intention of giving a voice to the respondents and adding richness to the overall study.
# Chapter 6

## Phase 2 Data – African Antenatal / Caribbean Antenatal

### Demography
- 6.1.1 Antenatal - Ethnicity
- 6.1.2 Antenatal - Age group
- 6.1.3 Antenatal - Marital status
- 6.1.4 Antenatal - Educational level
- 6.1.5 Antenatal - Employment
- 6.1.6 Antenatal - Religion
- 6.1.7 Antenatal - Migration
- 6.1.8 Antenatal - At risk group

### Inferential Analysis
- 6.2.1 African Antenatal and Caribbean Antenatal
  - 6.2.1.1 African Antenatal and Caribbean Antenatal and enculturation
  - 6.2.1.2 African Antenatal and Caribbean Antenatal and general knowledge of sickle cell
  - 6.2.1.3 African Antenatal and Caribbean Antenatal and employment
  - 6.2.1.4 African Antenatal and Caribbean Antenatal and attitude to sickle cell disease
  - 6.2.1.5 African Antenatal and Caribbean Antenatal and migration
  - 6.2.1.6 African Antenatal and Caribbean Antenatal and know someone with sickle cell disease
  - 6.2.1.7 African Antenatal and Caribbean Antenatal and test result and selection of partner
  - 6.2.1.8 African Antenatal and Caribbean Antenatal and genetic counselling experience
- 6.2.2 Analysis of Phase 2 qualitative response in questionnaire
6.1 Phase 2 Demography

6.1.1 Antenatal and ethnicity

It should be noted that as the result of missing data some cases were omitted for specific analyses. As a consequence the total sample in each analysis may vary.

Questionnaires were distributed to approximately 224 African Antenatal women and 124 Caribbean Antenatal women identified via eight participating Centres. 78 questionnaires were received from African Antenatal women (34% response rate) and 42 questionnaires were received from Caribbean Antenatal women (33% response rate). Of these 3 African Antenatal women and 1 Caribbean Antenatal women were omitted because they did not meet the inclusion criteria.

Phase 2 data analysis was conducted on questionnaires received from African Antenatal women (n=75) (65%), two of these indicated that they knew nothing about SCD and were therefore excluded from the analysis on knowledge and attitude but included in all other analysis; and questionnaires received from Caribbean Antenatal (n=41) (35%) women with a laboratory-confirmed sickle cell trait result (Pie chart 2).

Pie Chart 2 - Phase 2 Antenatal Ethnic group
Similar to the findings in Phase 1 (Section 5.3.1.1) no statistical significance was observed in the ethnic orientation of the Caribbean Antenatal and African Antenatal women, both identified equally with their respective cultural group, this made comparative analysis less challenging.

6.1.2 Antenatal and age group

The age range in the antenatal women group, as anticipated is younger than in the general public sample in Phase 1 (Table 14 and Graph 1). However, it was noted that despite being almost double the number of the Caribbean group there were no African Antenatal in the 41–45 age group, which indicates a difference in social attitude and perhaps fewer opportunities to enable conceiving at a later age. For example, lack of access to affordable fertility treatment.

Table 14 - Antenatal and age group

<table>
<thead>
<tr>
<th>Antenatal / Ethnic group</th>
<th>Age range</th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>18-24</td>
<td>25-30</td>
<td>31-40</td>
<td>41-45</td>
<td></td>
</tr>
<tr>
<td>African Antenatal</td>
<td>15</td>
<td>29</td>
<td>31</td>
<td>0</td>
<td>75</td>
</tr>
<tr>
<td>% within Gender/Ethnic group</td>
<td>20.0%</td>
<td>38.7%</td>
<td>41.3%</td>
<td>.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>8</td>
<td>10</td>
<td>21</td>
<td>2</td>
<td>41</td>
</tr>
<tr>
<td>% within Gender/Ethnic group</td>
<td>19.5%</td>
<td>24.4%</td>
<td>51.2%</td>
<td>4.9%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>39</td>
<td>52</td>
<td>2</td>
<td>116</td>
</tr>
<tr>
<td>% within Gender/Ethnic group</td>
<td>19.8%</td>
<td>33.6%</td>
<td>44.8%</td>
<td>1.7%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Graph 11 - Antenatal and age group
6.1.3 Antenatal and marital status

The marital status of the African Antenatal and Caribbean Antenatal women is similar. Almost 70% of the women in both ethnic groups are married or cohabiting whilst the remainder are single, separated or divorced (Graph 12).

Graph 12 - Antenatal and marital status

6.1.4 Antenatal and educational level

Mann-Whitney U Test demonstrated that there is a statistical significant difference in educational level between the African Antenatal and Caribbean Antenatal respondents (p=0.006) \((z=-2.726)\), African Antenatal (mean=64.16), Caribbean Antenatal (mean=48.15). This is further illustrated in Graph 13. 71% of the Caribbean Antenatal women had GCE/HND compared to 33% of the African Antenatal women however, 44% of the African Antenatal women are educated to above first degree compared to 15% of the Caribbean Antenatal.
6.1.5 Antenatal and Employment

Chi-square analysis demonstrated a statistical significance between the African Antenatal and Caribbean Antenatal women (Pearson chi-square (p=0.001)). In both groups the majority of the respondents are employed. However it is noted that a higher proportion of the African Antenatal women were unemployed (37%), compared to the Caribbean Antenatal (15%); more of the African Antenatal are students (15%) compared to the Caribbean Antenatal (7%).

6.1.6 Antenatal and religion

A statistical significance was observed in religious practise between the African Antenatal and Caribbean Antenatal (Pearson chi-square (p=0.000)). Of the total population of 116 antenatal women a high proportion (90%) practise a religion frequently or sometimes (Table 15 and Graph 14) and the majority of these are Orthodox Christians (Table 16).

The impact of religion on pregnant women diagnosed with sickle cell trait and at risk of having a child with SCD is explored further in Phase 3 of the project, and that exploration provides better insight into the emotions women and their partners feel when confronted with this life-changing experience. Religion adds another dimension to the emotional experience of those interviewed and creates dilemmas that can be overwhelming.
Table 15 – Antenatal and religion

<table>
<thead>
<tr>
<th>Gender / Ethnic group</th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Antenatal</td>
<td>72</td>
<td>2</td>
<td>1</td>
<td>75</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>21</td>
<td>10</td>
<td>10</td>
<td>41</td>
</tr>
<tr>
<td>Total</td>
<td>93</td>
<td>12</td>
<td>11</td>
<td>116</td>
</tr>
</tbody>
</table>

A statistical significance was demonstrated in the practise of religion Pearson Chi Square (p=0.0000): more of the African Antenatal practised a religion compared to the Caribbean Antenatal respondents.

Graph 14 – Antenatal and religious practise

![Graph showing the percentage of practising a religious faith among African and Caribbean Antenatal respondents.]

Table 16 – Antenatal and religious denomination

<table>
<thead>
<tr>
<th>Gender / Ethnic group</th>
<th>Orthodox Christian</th>
<th>Charismatic Christian</th>
<th>Rastafarian</th>
<th>Moslem</th>
<th>Other Religion</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Antenatal</td>
<td>46</td>
<td>20</td>
<td>0</td>
<td>7</td>
<td>0</td>
<td>73</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>22</td>
<td>8</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>31</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>28</td>
<td>1</td>
<td>7</td>
<td>0</td>
<td>104</td>
</tr>
</tbody>
</table>

NB: Not all respondents completed this section of the questionnaire (n=104)
6.1.7 Antenatal and migration

The migration pattern of the Antenatal respondents demonstrated that a larger proportion of the African Antenatal women spent their most formative years in their country of origin, whilst a greater proportion of the Caribbean Antenatal women spent their most formative years in the UK (Table 17).

Table 17 – Antenatal and migration

<table>
<thead>
<tr>
<th>Antenatal /Ethnic Group</th>
<th>Born/ migrated &lt;15yrs of age</th>
<th>Migrated &gt;15 yrs of age</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Antenatal</td>
<td>16</td>
<td>59</td>
<td>75</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>31</td>
<td>10</td>
<td>41</td>
</tr>
<tr>
<td>Total</td>
<td>47</td>
<td>69</td>
<td>116</td>
</tr>
</tbody>
</table>

6.1.8 Antenatal at-risk group

It was difficult to obtain statistical data on the number of women and couples at risk of having a child with sickle cell anaemia since centres collected conglomerated data and included all risk groups not just couples with pregnancies at risk of clinically significant disease states which warrant the offer of prenatal diagnosis (PND). However I have separated the risk groups for the Brent antenatal population in order to obtain a sense of the number of those at risk of serious forms of sickle cell disease. In 2006 the total number of women at the Brent Sickle Cell and Thalassaemia Centre diagnosed with sickle cell trait (HbAS) is 139 and the number of couples at risk of having a child with the three most common and clinically significant disease states and their response to the offer of prenatal diagnosis is illustrated in Table 18.

Table 18 – Antenatal at-risk couples in Brent Centre 2006

<table>
<thead>
<tr>
<th>At Risk Couple’s Hb Type</th>
<th>No.</th>
<th>Disease Risk to Offspring</th>
<th>Number Declined PND</th>
<th>Number Accepted PND</th>
</tr>
</thead>
<tbody>
<tr>
<td>AS / AS</td>
<td>11</td>
<td>Sickle cell anaemia (HbSS)</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>AS / AC</td>
<td>4</td>
<td>Sickle haemoglobin (HbSC)</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>AS / Aβ&lt;sub&gt;Thal&lt;/sub&gt;</td>
<td>1</td>
<td>Sickle beta thalassaemia (HbAβ&lt;sup&gt;Thal&lt;/sup&gt;)</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
6.2 Inferential Analysis

A comparative analysis was conducted examining the following groups:

- The African Antenatal women and Caribbean Antenatal women.
- The Non-Pregnant Females from Phase 1 and the Pregnant Females from Phase 2
  - African Female and African Antenatal
  - Caribbean Female and Caribbean Antenatal

Maintaining a similar approach to Phase 1 statistical significance at the 1% (p≤0.01) level only is reported for Phase 2.

6.2.1 African Antenatal / Caribbean Antenatal

6.2.1.1 African Antenatal / Caribbean Antenatal and enculturation

Both the African Antenatal and Caribbean Antenatal women identified with their respective cultural origin and no statistical significance was observed between the two groups, which is similar to the findings in Phase 1.

6.2.1.2 African Antenatal / Caribbean Antenatal and general knowledge of sickle Cell

Analysis of the summative general knowledge scores did not yield any statistically significant difference between African Antenatal and Caribbean Antenatal respondents, however, a two-tailed t-test demonstrated that there was statistical difference in the paired group on an analysis of the individual questions 1 – 16 of Section 1 of the questionnaire. In response to the statement ‘People with sickle cell disease often die by 21 years of age’. 21 of the African Antenatal respondents and 3 of the Caribbean Antenatal respondents ticked ‘True’. This is the incorrect answer and shows that the myth continues to be perpetuated in African communities.

A similar difference was observed in the Phase 1 data where more of the general public Africans also ticked ‘true’ compared to the Caribbean respondents.
6.2.1.3 African Antenatal / Caribbean Antenatal and employment

Although statistical significance was observed in the employment status of the African Antenatal and Caribbean Antenatal women a greater proportion of the former group are students. The differences observed could also be a reflection of the differences in immigration status in the UK. Since a greater proportion of the African Antenatal women migrated >15 years of age the proportion who are unable to work because of immigration status will possibly be higher. This was highlighted in the Phase 3 interviews by a few of the at-risk respondents.

6.2.1.4 African Antenatal / Caribbean Antenatal and attitude to sickle cell disease

A two-tailed t-test demonstrated that there was no statistical significance in any of the five summary attitude variables but on examining the individual questions in section 2 of the questionnaire and in response to the statement ‘Science should be used to prevent the births of children with sickle cell disease’ of the 74 African Antenatal respondents 19 (25%) ticked ‘Strongly Agree’ whilst of the 41 Caribbean Antenatal respondents 1 (2%) ticked ‘Strongly Agree’, which shows that more of the African Antenatal are in favour of prevention of the birth of children with SCD. It is surprising therefore, that no statistical significance was observed in the ‘Prevention’ attitude summary variable. When this was explored through telephone communication with five of the women it became apparent that they were not referring to prenatal diagnosis or termination of an affected fetus but that science should be advanced in order to prevent the occurrence of the gene and where it does occur for science to have the technology to remove or correct it.

In response to the statement ‘Having a child with sickle cell disease can cause financial hardship for the family’ of the African Antenatal 9 (12%) respondents ticked ‘Strongly Agree’ whilst 1 (2%) of the Antenatal Caribbean respondents ticked ‘Strongly Agree’ which shows that more of the African Antenatal women perceive that having a child with SCD poses a social problem for the family, financial problems especially. Interestingly a similar difference was observed in the Phase 1 data where more of the general public Africans also ticked ‘true’ compared to the Caribbeans.
6.2.1.5 **African Antenatal / Caribbean Antenatal and migration**

Analysis was conducted comparing all antenatal women (African Antenatal/ Caribbean Antenatal) who were born/ came to the UK < 15 years of age (n=47) with those and those who migrated >15 years of age (n=69).

A two-tailed t-test demonstrated that there was no statistical significance in four of the summary attitude variables, there was a significance in Reproductive Drive, (p=0.003), those Born/ Migrated <15 years of age (mean= 3.276) (SD-1.174) and those Migrated > 15 years of age (mean=3.8971) (SD=1.039). This reflects the findings of Phase 1 and that those who spent their most formative years in their country of origin and subsequently migrated to the UK > 15 years of age perceive that having children as being more important than those who were born in the UK / migrated < 15 years of age and therefore spent their most formative years in the UK.

6.2.1.6 **African Antenatal / Caribbean Antenatal and knowing someone with sickle cell disease**

The respondents were asked whether they knew someone with SCD, **Table 19** illustrates the women’s response. In an attempt to find out whether individuals have personal experience of living with someone with sickle cell disease they were also asked to clarify whether the person they knew was a member of their family/friend or neighbour who lived or never lived with them. Although a high proportion of the antenatal women knew someone with SCD (77%) of these only 36% actually lived with anyone with the disease and had first hand experience of the impact of the condition. As expected, because of the higher prevalence of the sickle gene amongst Africans, a higher proportion of the African Antenatal women lived with someone with SCD. This variable did not have had an impact on attitude as there was no statistical difference in any of the groups.

**Table 19 – African Antenatal / Caribbean Antenatal and knowing someone with sickle cell disease**

<table>
<thead>
<tr>
<th>Antenatal / Ethnic group</th>
<th>Know someone with SCD</th>
<th>Lived with them</th>
<th>Never lived with them</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Antenatal</td>
<td>57</td>
<td>23</td>
<td>34</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>33</td>
<td>10</td>
<td>23</td>
</tr>
<tr>
<td>Total</td>
<td>90</td>
<td>33</td>
<td>57</td>
</tr>
</tbody>
</table>
6.2.1.7 African Antenatal / Caribbean Antenatal test result and selection of partner

All the pregnant women were tested for SCD since inclusion in Phase 2 of the study is dependent on their having sickle cell trait, therefore the question about whether they have been tested or not is superfluous.

Respondents were asked ‘If you knew your test result before starting a family did you choose your partner based on your own test result?’ and they were asked to clarify the reason for choosing or not choosing their partner based on their own test result. This later aspect is discussed in the analysis of Phase 2 qualitative responses (Section 6.2.2).

Compared to the Caribbean Antenatal a greater proportion of the African Antenatal chose their partners based on their own test result and statistical significance was observed, Pearson chi-square (p=0.007) (Table 20).

<table>
<thead>
<tr>
<th>Antenatal Ethnic Group</th>
<th>Yes</th>
<th>No</th>
<th>Did not know Hb type</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Antenatal</td>
<td>14</td>
<td>35</td>
<td>22</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>1</td>
<td>28</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>63</td>
<td>31</td>
</tr>
</tbody>
</table>

It was noted that 18 African Antenatal and 10 Caribbean Antenatal were at risk of having a child with sickle cell anaemia. It should be noted that not all the women answered the question relating to selection of partner therefore the figures in Table 20 will not match the total number of women in this section.

Table 21 illustrates how some women selected their partners based on their own sickle cell trait result and the establishment of risk before conception.
Of the 10 African Antenatal women who did not choose their partners pre-conception and were at risk of having a child with SCD, 2 reported that knowing pre-conceptually would not have altered their decision to be with their partner, basing this decision on their religious beliefs; 5 said it would have altered their decision and they would have chosen an alternative partner, and 3 respondents did not indicate a reason for not choosing their partner.

Conversely, none of the 7 Caribbean Antenatal women who were at-risk and did not choose their partners said they would have altered their decision to be with their partner, this is in spite of the genetic risk.

Table 21 – African Antenatal / Caribbean Antenatal Selection of partner based on own haemoglobin status

<table>
<thead>
<tr>
<th>Antenatal Ethnic Group</th>
<th>(1) At risk Couple despite choosing partner preconception</th>
<th>(2) Knew risk but did not choose partner preconception</th>
<th>(3) Knew risk chose partner who is HbAA preconception</th>
<th>(4) Did not choose partner but by chance he is HbAA</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Antenatal</td>
<td>3</td>
<td>10</td>
<td>11</td>
<td>18</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>1</td>
<td>7</td>
<td>3</td>
<td>8</td>
</tr>
</tbody>
</table>

Key to Table 21

(1) Women who were aware of their sickle cell trait before conception, who supposedly chose their partners based on their test result but still were at risk of having a child with sickle cell anaemia.

(2) Women who were aware of their sickle cell trait before conception but did not choose their partners based on their test result, and whose risk of having a child with sickle cell anaemia was not established until antenatal testing of partner.

(3) Women who were aware of their sickle cell trait before conception chose a partner with normal haemoglobin (HbAA) and avoided the risk of having a child with sickle cell anaemia.

(4) Women who were aware of their sickle cell trait before conception but did not chose their partners based on their sickle cell trait status. However antenatal testing of their partner established that he had normal haemoglobin (HbAA) and therefore the couples were not at risk of having a child with sickle cell anaemia.

One African Antenatal respondent indicated that she was tested in Africa and given a normal (HbAA) result. When she booked confinement of a first pregnancy in the UK she was identified with sickle cell trait (Hb AS). However, she indicated that had she had the opportunity before becoming emotionally involved in a relationship she would have chosen her partner based on her correct result because she would not want to deliberately put herself at risk of having a child with sickle cell disease.
6.2.1.8 African Antenatal / Caribbean Antenatal and genetic counselling experience

Respondents were asked to rate the genetic counselling they received. 1 respondent did not complete the question. Overall 71% of the pregnant women had face-to-face genetic counselling (Table 22) from a health or allied professional. It is worth noting that, as per national protocol, all the women would have been sent an information leaflet, an appointment for genetic counselling and offer of partner testing. However, a number of these may fail to attend, for a number of reasons which include having been counselled in the past, their partner had been tested in the past, his result was confirmed normal (HbAA) and they are already aware that they are not at risk of having a child with SCD.

Table 22 – African Antenatal / Caribbean Antenatal and mode of result notification and notifier

<table>
<thead>
<tr>
<th>Gender / Ethnic group</th>
<th>Mode of Notification</th>
<th>Provider of Counselling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sent by Post</td>
<td>Face-to-face Counselling</td>
</tr>
<tr>
<td>African Antenatal</td>
<td>19</td>
<td>56</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>14</td>
<td>26</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>82</td>
</tr>
</tbody>
</table>

* GP – General Medical Practitioner, MW – Midwife, SW – Social Worker

Respondents were asked to rate the usefulness of the genetic counselling received and whether it was reassuring (Table 23). Of those who responded the majority found it useful and reassuring; of the seven who did not find it reassuring 6 were counselled by a GP / hospital doctor whilst 1 was counselled by a specialist haemoglobinopathy nurse. Of the four who did not find the session useful 3 were counselled by a GP/ hospital doctor whilst 1 was counselled by a surgery nurse.

Table 23 – African Antenatal / Caribbean Antenatal and experience of genetic counselling

<table>
<thead>
<tr>
<th>Gender / Ethnic group</th>
<th>Reassuring</th>
<th>Not reassuring</th>
<th>Useful</th>
<th>Not useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Antenatal</td>
<td>52</td>
<td>2</td>
<td>54</td>
<td>0</td>
</tr>
<tr>
<td>Caribbean Antenatal</td>
<td>18</td>
<td>5</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>70</td>
<td>7</td>
<td>74</td>
<td>4</td>
</tr>
</tbody>
</table>
6.2.2 Analysis of qualitative response in questionnaire

A number of Antenatal respondents made comments in response to open-ended questions and requests for further comments in the questionnaire. These were transcribed and analysed, and a number of concepts emerged which were coded into thematic groups. The questions that attracted written comments were:

- **Question 39:** If you know someone with sickle cell disease – further comments
- **Question 56:** If you have not been tested for sickle cell please say why you have not been tested.
- **Question 61:** Face-to-face genetic counselling - comments
- **Question 63:** And explain why you chose or did not choose your partner based on your own blood test result.
- **Question 64:** General comments

Of the 116 respondents those who provided written comments were 30 Antenatal African and 16 Antenatal Caribbean women. The themes and concepts which appear worthy of discussion are listed in Table 24 and interestingly they differ from the themes obtained in Phase 1.

Six of the eleven African Antenatal respondents who chose their partners based on their own genotype added further information about their negative personal experiences of the impact of sickle cell disease as witnessed in their nuclear as well as extended family, in their neighbour’s family and friends, as a result they would not advocate deliberately putting themselves at risk of having a child with SCD. None of the Caribbean Antenatal women expressed these sentiments.

**Table 24 – Qualitative data obtained from questionnaire**

<table>
<thead>
<tr>
<th>Theme</th>
<th>African</th>
<th>Caribbean</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would have chosen my partner if I knew before getting married /</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>getting pregnant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t want a child with sickle cell disease</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Knowing / Living with someone with SCD was an unpleasant experience</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Religion – God is in control of my / my family’s destiny</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Love is more important than the risk of having a child with SCD</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
The most salient aspect is that six of the African Antenatal women indicated that they would have chosen their partners prior to getting married or becoming pregnant if they had been aware of their sickle cell carrier status, whilst none of the Caribbean Antenatal women expressed this opinion.

An African Antenatal, with a Masters degree, a practising charismatic Christian stated:

_"I knew my test result before I got married and I asked my husband to have a test before we got married. Because of my experience with a family friend and his wife and four children who all died of sickle cell disease, I chose and married my partner knowing that he did not have sickle cell otherwise I would not have married him."

Another African Antenatal respondent who is at-risk of having a child with sickle cell anaemia wrote:

_"Had I known I have sickle cell trait before I got my partner I would possibly look for someone with whom I could have kids, knowing the children would be safe. Not because I’m being choosy but for the benefit of our children and society. I believe if this can be avoided it’s best to do so. On the other hand if God created us like that then we should go forward with whatever comes our way because he has a reason. Even healthy children do die or can get other diseases that affect them throughout their lives. I think God has a reason for everything, so I will go for anything. We can avoid certain things but not all things"

This final comment demonstrates the contradictions in people’s lives and attitude to disease, illness and being at risk of having a child with SCD. The desire not to have a child with a medical condition is often negated by stronger religious values and beliefs, which makes the concept of informed choice difficult and places many women and couples in a state of dissonance. Whilst it is not desirable to have a child with sickle cell disease it is also not desirable to question God and what He has given you. In this obvious state of dissonance the quote demonstrates the use of a ‘bolster’ to help alleviate the dissonance created between two cognitions, i.e. “I believe if this can be avoided it’s best to do so” and “…if God created us like that then we should go forward with whatever comes our way because he has a reason”. As highlighted by the BMA (1998) being able to access genetic information ‘not only brings affected individuals more choices but also raises new and often painful dilemmas for which they may require specialize support’. The majority of people in society are inadequately prepared for such dilemmas.
An analysis was conducted comparing respondents who completed the general knowledge and attitude sections of the questionnaire, All African Female/Caribbean Female (Non-Pregnant Females) \((n=149)\) and All African Antenatal/Caribbean Antenatal women (Pregnant Females) \((n=115)\) were analysed. One Antenatal Female stated that she knew nothing about the subject and was not included in the knowledge and attitude to SCD analysis but is included in the biographical, ethnicity and MHLC analysis.
Comparative analysis of Phase 1 and Phase 2 Data - Non-Pregnant Females / Pregnant Females

7.1 Non pregnant Female / Pregnant Female
  7.1.1 Non pregnant Female / Pregnant Female
    - Educational level
  7.1.2 Non pregnant Female / Pregnant Female and employment
  7.1.3 Non pregnant Female / Pregnant Female and religion
  7.1.4 Non pregnant Female / Pregnant Female and general knowledge of sickle cell
  7.1.5 Non pregnant Female / Pregnant Female and attitude
  7.1.6 Non pregnant Female / Pregnant Female and Multi-dimension Health Locus of Control

7.2 African Females (non pregnant) / African Antenatal
  7.2.1 African Females / African Antenatal and enculturation
  7.2.2 African Females / African Antenatal and general knowledge of sickle cell
  7.2.3 African Females / African Antenatal and Attitude
  7.2.4 African Females / African Antenatal and Multi-dimension Health Locus of Control (MHLC)

7.3 Caribbean Females (non pregnant) / Caribbean Antenatal
  7.3.1 Caribbean Antenatal & Caribbean Females and general knowledge of sickle cell

7.4 Discussion – Phase 1 and Phase 2 comparative analysis of Non Pregnant and Pregnant Females
  7.4.1 Pregnant and Non-Pregnant and enculturation
  7.4.2 Pregnant and Non-Pregnant and educational level
  7.4.3 Pregnant and Non-Pregnant and religion
  7.4.4 Pregnant and Non-Pregnant and general knowledge of sickle cell
  7.4.5 Pregnant and Non-Pregnant and attitude to sickle cell disease
  7.4.6 Pregnant and Non-Pregnant and reproductive drive
  7.4.7 Pregnant and Non-Pregnant and Multi-dimension Health Locus of Control (MHLC)
  7.4.8 Pregnant and Non-Pregnant and test result and selection of partner preconception
  7.4.9 Pregnant and Non-Pregnant - other concepts and variables
  7.4.10 Conclusion
7.1 Comparative analysis Phase 1 and Phase 2 data - Non-Pregnant Females / Pregnant Females

7.1.1 Non-pregnant Females / Pregnant Females and educational level

The Mann-Whitney U test demonstrated a statistically significant difference in educational level between the Non-Pregnant Females and Pregnant Females (p=0.0004) (z=-3.5117), with the Pregnant Females being overall better educated than the Non-Pregnant Females. More of the Non-Pregnant Females had no formal education (25%), of those educated to Certificate of Secondary Education (CSE) level there were (14%) a few more when compared to the Pregnant Females (8%) educated to CSE. Of the Pregnant Females who had no formal education there were (5%). A larger proportion of the Pregnant Females were educated to General Certificate of Education (GCE)/Higher National Diploma (HND) (53%), and (34%) were educated to degree level compared to the Non-Pregnant Females (34%) with a GCE / HND and (27%) with a first degree.

7.1.2 Non-pregnant Females / Pregnant Females and employment

Chi-square analysis demonstrated, as expected, a statistical difference between the Pregnant Females and Non-Pregnant Females, (Pearson chi-square (p=0.000)). A greater proportion of the Pregnant Females were unemployed (30%) compared to the Non-Pregnant Female (8%). Those who considered themselves as homemakers were 7% of the Pregnant Females and 3% of the Non-Pregnant Females; 14% of the Pregnant Females and 29% of the Non-Pregnant Female (29%) indicated that they are students.

7.1.3 Non-pregnant Females / Pregnant Females and religion

A statistical significance was observed in religious practise between the Non-Pregnant and Pregnant women with a Pearson chi-square value of (p=0.004). Of the total population of 116 Pregnant women 90% practise a religion whilst 80% of the Non-Pregnant women practised a religion.
7.1.4 Non-pregnant Females / Pregnant Females and general knowledge of sickle cell

A two-tailed t-test demonstrated that there was a statistically significant difference in the knowledge score between pregnant Females and Non-Pregnant Females (p=0.002) Pregnant Females (mean=14.6944) (SD=1.513) and Non-Pregnant Females (mean=14.0364) (SD=1.838). Pregnant Females expectedly had better overall knowledge of sickle cell than the Non-Pregnant Females.

7.1.5 Non-Pregnant Females / Pregnant Females and attitude

There was no statistical significance in four of the summary attitude variables, a significance was observed in Reproductive Drive, (p=0.000) only, Pregnant Females (mean=3.6435) (SD=1.133) Non-Pregnant Females (mean=3.0940) (SD=1.022), demonstrating that more of the Pregnant Females perceive that it is important to have children.

7.1.6 Non-Pregnant Females / Pregnant Females and Multi-dimension Health Locus of Control (MHLC)

On analysis of the MHLC scores there was no statistical significance in the Chance and Powerful Others locus of control but there was significance in the Internal (p=0.006) with Pregnant Females demonstrating less of an Internal locus of control (mean=24.0948) (SD=5.167) than the Non-Pregnant Females (mean=25.7582) (SD=4.608).


### 7.2 African Females / African Antenatal

#### 7.2.1 African Females / African Antenatal and enculturation

In measuring level of enculturation on a two-tailed t-test there was no statistical difference in five of the six summary variables, there was a statistical significance in the Language domain, \( p=0.002 \) African Female (mean=2.6841) (SD=.682) African Antenatal (mean=3.0300) (SD= .656). This shows that the African Antenatal women identified with the language of their cultural origin more so than the general public African Female respondents. However, the reliability of this instrument is questionable in this particular study and for this population.

#### 7.2.2 African Females / African Antenatal and general knowledge of sickle cell

There was no statistical significance in the general knowledge score of the African Females \( (n=67) \) and the African Antenatal \( (n=75) \) women. However, a two-tailed t-test applied to each of the questions in Section 1 of the questionnaire demonstrated a numeric difference in response to the question ‘Sickle cell trait can change into sickle cell disease later in life’. Of the 74 African Antenatal respondents 5 (7%) ticked ‘True’, whilst 22 (32%) African Females ticked ‘True’, which is the incorrect answer. Expectedly, this demonstrates that the Pregnant Females have a better understanding of the unchanging genetic inheritance of SCD than the Non-Pregnant Females.

Secondly, in response to the question ‘People with sickle cell trait are just as healthy as people who do not have sickle cell at all’, 20 (13%) of the African Females ticked ‘False’, which is the incorrect answer whilst 9 (12%) of the African Antenatal women ticked ‘False’. This illustrates that despite having sickle cell trait themselves these Antenatal women continue to have wrong information about SCD and their carrier status.

#### 7.2.3 African Females / African Antenatal and attitude

A two-tailed t-test did not demonstrate a statistical significance in four of the summary attitude variables, severity of disease, attitude to prevention, genetic locus of control and level of burden. There was a difference in Reproductive Drive, \( p=0.000 \) African Females (mean= 3.1667) (SD=1.032) African Antenatal (mean=3.8378) (SD=1.060). This shows that more of the pregnant
African Antenatal women perceive that it is important to have children than the general public African Females.

### 7.2.4 African Females / African Antenatal and Multi-dimension Health Locus of Control (MHLC)

A two-tailed t-test did not demonstrate a statistical significance in two of the MHLC dimensions, Internal and Chance but there was a statistical difference in measurement of Powerful Others (p=0.002), African Females (mean=17.000) (SD=6.010) and the African Antenatal (mean=20.2267) (SD=5.954). More of the African Antenatal women perceive that other people have a greater influence on their health and ability to maintain good health.
7.3 Caribbean Females / Caribbean Antenatal

7.3.1 Caribbean Females / Caribbean Antenatal and general knowledge of sickle cell

There was no statistical significance in the general knowledge of Caribbean Females and Caribbean Antenatal women. However, on analysing each of the general knowledge questions in Section 1 of the questionnaire in response to the question ‘Sickle cell trait can change into sickle cell disease later in life’, 3 (7%) of the Caribbean Antenatal respondents ticked ‘True’, which is the incorrect answer, whilst 30 (34%) Caribbean Female respondents ticked ‘True’. This demonstrates that the non-pregnant women’s understanding of the unchangeable genetic inheritance of SCD is less than the knowledge of the pregnant women.

Secondly in response to the question ‘People with sickle cell trait are just as healthy as people who do not have sickle cell at all’, 2 (5%) of the Caribbean Antenatal ticked ‘False’, compared to 24 (28%) of the Caribbean Females. This demonstrates that a larger proportion of the pregnant women, who all have sickle cell trait, are aware that they are healthy carriers and that this will not affect their health. However, it is worrying that two of the pregnant women believe that their sickle cell trait can potentially make them unhealthy.
7.4 Discussion - Phase 1 and Phase 2 comparative analysis
Non-Pregnant Females and Pregnant Females)

The analyses that will be discussed are comparisons between: (i) African Antenatal and Caribbean Antenatal, (ii) Non-Pregnant Females and Pregnant Females, (iii) African Antenatal and African Females (iv) Caribbean Antenatal and Caribbean Females.

The lack of difference between the African Antenatal and Caribbean Antenatal respondent’s knowledge and attitude to sickle cell disease does not concur with findings in Phase 1 of the project. Surprisingly the antenatal women appear to have more similarities than differences compared to the general public population in Phase 1. The areas of statistical significance that will be discussed are: religion and migration only. The areas that are of no statistical significance but are deemed worthy of discussion are: response to pertinent individual knowledge questions and attitude statements, selection of partner and responses to open-ended questions.

Some differences were noted comparing Phase 1 (Non-Pregnant Females) and Phase 2 (Pregnant Females). The areas of statistical significance that will be discussed include: educational level, employment, religion, knowledge of sickle cell, attitude and MHLC.

In the comparison of African Female and African Antenatal areas of statistical significance relate to: cultural identity, attitude and MHLC. The areas that are of no statistical significance but appear interesting for discussion are responses to relevant individual knowledge questions.

There were no areas of statistical significance between Caribbean Female and Caribbean Antenatal women. However response to individual knowledge questions that appear pertinent will be discussed.

7.4.1 Non-Pregnant Females / Pregnant Females and enculturation

The statistical difference observed between the African Antenatal and African Females appeared baffling initially, however, on closer examination the possible reason for this is differences in age of migration. A larger number of the African Females were born/ migrated <15 years of age (26) compared to African Antenatal (16), whilst more of the African Antenatal women migrated >15 years of age (59) compared to the African Females (41). Evidently those who migrated after their
most formative years are more likely to know and speak their language of origin than those who migrated earlier.

### 7.4.2 Non-Pregnant Females / Pregnant Females and educational level

Similar to findings in Phase 1 (Section 5.1.4) the antenatal group demonstrated that more of the African Antenatal women were educated to above first degree level (Graph 13) compared to the Caribbean women. It was surprising however that this did not influence the sickle cell knowledge score since no statistical significance was observed between the two groups.

The educational difference in the population is likely to be due to the use of a convenience sample and the process of recruitment. The women who agreed to participate are likely to be women who are motivated, confident and articulate and feel able to spare the time to complete the lengthy questionnaire.

The statistical significance observed between Pregnant Females and Non-Pregnant Females was somewhat bemusing, where the former are better educated than the latter one would have expected the reverse. This can be explained by the higher proportion of African Antenatal women (64%) in the Pregnant Female group and it is already demonstrated that statistically the African Antenatal women were better educated than the Caribbean Antenatal women.

The migratory pattern of Africans and Caribbeans may account for the differences observed. The use of a convenience sample probably influenced the educational differences. A randomised sample would have provided a better sample frame and inferences about the data in relation to migration would have been more valid. Participants were self-selecting and only those who are highly motivated agreed to participate. Shavers-Homaday et al. (1997) indicated that language barrier is one of the factors that limit minority ethnic communities’ participation in medical research, especially among those where English is a secondary language. It is likely that some of those who refused to participate were those who were unfamiliar with the spoken and or written English. The request to participate invitation letter stated that a reader or interpreter will be provided if required and two respondents took advantage of this. It should be noted that one would need to have been able to read and understand the invitation letter in the first instance in order to
avail oneself of the offer of an interpreter or reader. It is possible that the length of time required for completing the questionnaire, thirty to forty five minutes, was also a deterrent.

7.4.3 Non-Pregnant Females / Pregnant Females and religion

The differences seen in the level of observance of religion among African Antenatal and Caribbean Antenatal women reflects the general trend in the two populations, and similar findings were observed in the Phase 1 population (Section 5.1.6). The general issues highlighted in the Phase 1 discussion appear to be relevant to this antenatal population also (Section 5.4.3).

Similar to the findings of Phase 1, the majority of the African group (98%) practised a religion compared to the Caribbean group (75%). This further supports the assertion that a belief in the supernatural is more prominent in the African community and highlights differences in the migratory pattern of the two cultural groups. A larger proportion of the Caribbean group were born / migrated to the UK <15 years of age compared to the Africans and the adherence to a cultural value system including religious practises continue to be perpetuated among the predominantly first-generation African migrants.

However, it is noted that the practise of a religion is high in the overall antenatal population (90%) and this supports the assertion that Africans and Caribbeans are highly religious which concurs with the findings of other authors (Howlett et al. 1992, Jegede 1998, Collier and Fleischmann 2004).

7.4.4 Non-Pregnant Females / Pregnant Females and knowledge of sickle cell

The lack of a statistically significant difference in the knowledge of African Antenatal and Caribbean Antenatal women was anticipated primarily because all the women have sickle cell trait. As per UK health policy all women identified with sickle cell trait are sent an appointment and invited for genetic counselling and testing of their partner in order to identify a potentially at-risk fetus. A health promotion leaflet is sent with the appointment which gives detailed information about sickle cell, biology, inheritance pattern and differences between a ‘carrier’ and ‘disease’ state. The majority of those invited would have attended for genetic counselling in the current or
previous pregnancy or when tested generically, not related to pregnancy e.g. post-operatively. The women who do not attend for counselling would have received a leaflet and will acquire the relevant information from this.

The statistical difference observed between the Pregnant and Non-Pregnant women was also not surprising since all the Pregnant Females are confirmed as having sickle cell trait whilst only a proportion of the Non-Pregnant Females have sickle cell trait or any other carrier state. Being aware that one has a genetic condition is likely to motivate an individual to seek information about it. Therefore it is not surprising that the pregnant women who all have sickle cell trait would have been given or sought information about the condition whilst those in the Non-Pregnant group who do not have a carrier state have no such motivation, the more so if they have been tested and told that they do not have a carrier state, which would lower the incentive to seek health information.

Cote (1982) argued that anticipated health and social problems do not nullify the reproductive drive, and Marteau and Anionwu (1996) argued that the desire to have children has a stronger influence on genetic decision-making than the perceived risk of a genetic condition, and the knowledge of being a carrier of a genetic condition does not necessarily influence the decision to have children. If this is the case it is possible that the Pregnant Females who are aware of their sickle cell trait status may make efforts to find out about the condition prior to conceiving, since evidently having sickle cell trait has not influenced their decision to have children. This is explored in more detail in the Phase 3 interviews and should offer better insight into the reproductive drive theory as postulated by other authors (Pearn 1979, Cote 1982 and Finucane 1998).

Although there was no statistical significance in the overall general knowledge score between African Antenatal and African Females there were differences in response to individual questions which further highlights the perpetuation of socio-cultural myths and perceptions of SCD. Although it was not of statistical significance a number of the African Antenatal women and fewer of the Caribbean Antenatal women believed that sickle cell trait can change into SCD later in life. This is worrying in view of the fact that these women are confirmed as having sickle cell trait. Secondly, a higher proportion of the African Antenatal and fewer of the Caribbean Antenatal believe that people with sickle cell trait are less healthy than people who do not have sickle cell at all. It is possible that the deficit in knowledge is due to a poor understanding of genetics and health information obtained from leaflets and face-to-face counselling. This may account for the slight differences seen in the African and Caribbean group.
An alternative explanation is obfuscation of medical knowledge. Similar to Hill’s (1994a) findings among poor Black women in the USA, it is possible that the women were responding to the dissonance which the cognition, ‘acknowledgement’ of sickle cell and ‘genetic and health implications’ has created for them and their family. A denial of knowledge is perhaps the most effective defence to help alleviate the cognitive tensions that these two cognitions has created, that is, ‘knowledge of sickle cell’ and ‘failing to act’ on the information.

Health professionals often assume that the majority of people are fluent and literate either in English or in their language of origin. However, a significant proportion of migrants are able to speak but not read their language of origin and the mistake of merely translating a leaflet into minority ethnic languages does not resolve the problems of health promotion. In addition health information can be very complex such that even where one is fluent and literate such concepts can be difficult to assimilate.

The findings of the present study reflect Marteau et al.’s (1992) observation that 7% of those at risk of having a child with Tay-Sachs disease, an autosomal recessive condition, wrongly believe that being a carrier will adversely affect their future health and were less optimistic about remaining healthy in future as a result of being a carrier. This finding supports Richards (1996) assertion that lay peoples’ knowledge of inheritance is poor even among those who have had genetic counselling. Emery and Hayflick (2001) concluded that implications of a carrier status are difficult concepts for lay people to understand if they don’t have the ability to grasp statistical concepts and issues relating to genetic probability. Evidently, some of the women in this study have given credence to these observations and assertions.

As in Phase 1, a difference was observed in the women’s response to the statement about people with SCD dying by the age of 21 years (Section 6.2.1.2). The African Antenatal women reflect the wider African community’s belief in this enduring myth. As discussed earlier, this reflects differences in the social experience of sickle cell disease and in cultural beliefs. In the African context, due to poorer social circumstances and lack of affordable health care, a very high proportion of those with SCD die in early childhood, so this socially constructed myth has some associated clinical truth. Despite thirty years of health promotion in the UK the myth continues to live even among the learned, who often express disbelief when told that individuals with sickle cell disease can live to old age provided they have access to a good standard of living and health care.

211
7.4.5 Non-Pregnant Females / Pregnant Females and attitude to sickle cell disease

Although there was no statistical significance in four of the five summary attitude variables, ‘severity of disease’, ‘genetic locus of control’, ‘burden of disease’ and ‘prevention’, there was statistical differences in ‘reproductive drive’.

Secondly, in response to individual attitude statements more of the African Antenatal women ‘strongly agree’ that science should be used to prevent births of children with SCD compared to the Caribbean Antenatal women (Section 6.2.1.4) which reflects the Africans desire to avoid having a child with SCD. It is likely that by prevention many of these women do not mean prenatal diagnosis or termination of an affected pregnancy, since there was no statistical significance in the summary attitude ‘prevention’. I propose that the response of the women is a plea for scientists to find a cure so as to prevent future births of children with what they perceive as a serious debilitating disease. More of the African Antenatal women perceive that having a child with SCD can cause financial hardship for the family (Section 6.2.1.4). This reflects the findings of Phase 1 and adds support to the ‘back home’ context discussed in Section 5.4.5.2.

7.4.6 Non-Pregnant Females / Pregnant Females and reproductive drive

The statistical significance in reproductive drive observed in the Antenatal women who migrated >15 years of age further supports the argument that culture plays a significant role in shaping attitude to procreation, recognizing that African Antenatal women make up 85% of the migrated >15 group whilst 65% of those born/migrated <15 years of age are Caribbean Antenatal. This finding is more of a reflection of the African women’s attitude and reflects similar findings among the women in Phase 1 (Section 5.3.1.3) and the issues highlighted in the Phase 1 discussion remain valid and apply equally to this pregnant population.

The difference in the Pregnant Females and Non-Pregnant Females’ attitude to procreation was anticipated, the pregnant women evidently advocate parenthood and value the idea of procreation, especially as they are in that state at the time of the project. I propose that it would be difficult for them to be opposed to the notion of procreation since denial of the virtues of procreation and parenting may be a rejection of their current pregnant state, which may cause psychological and emotional conflict and dissonance.
The highly statistically significant difference (p=0.000) observed in the African Antenatal and African Female was surprising: the African Antenatal had a higher mean score than the African Female. I had anticipated that these two groups would have a shared cultural value and therefore reflect each other’s attitude.

There were marginal differences in age group and it is unlikely that this could account for the differences observed in attitude to procreation. It is possible that the greater proportion of Non-Pregnant African Females born/ migrated <15 years of age (26%) compared to the (16%) observed in the Pregnant African Antenatal women may be contributing to the difference in attitude to procreation between these two groups, the higher proportion of African Antenatal women who are later migrants are more likely to demonstrate their culture of origin, values and attitudes.

### 7.4.7 Non-Pregnant Females / Pregnant Females and Multi Dimension Health Locus of Control (MHLC)

The statistical significance observed in the Multi-dimension Health Locus of Control among the Non-Pregnant Females, in the Internal locus of control, compared to the Pregnant Females shows that pregnant women demonstrate lesser control of their situation and this may be as a result of the powerlessness that many women experience during pregnancy, where the process of childbearing has become medicalized and women feel disempowered in their relationship with health and allied professionals, especially within clinical, ill health-orientated care environments.

In their relationship with their caregivers, especially obstetricians, many pregnant women feel unable to maintain control of their own body, pregnancy and childbirth. This may inadvertently be contributing to the disempowerment of pregnant women. Secondly, the Pregnant Females would have gone through the experience of genetic counselling in respect of their being at risk of having a child with SCD. Shiloh (1996) argued that despite all efforts to be objective and impartial the counselling process cannot be totally value-free and the notion of non-directive counselling is a fallacy that is impossible to achieve. Many of these women would have experienced the ‘disease’ status that has become attached to their pregnancy and indirectly to themselves, and the loss of confidence in one’s ability to have control over health is likely to be one of the outcomes. Tapper (1999) argued that the term ‘disease’ attached to the name of the condition has affected Black peoples’ perception of themselves and many who carry the gene perceive themselves as
‘diseased’. Combine this with the attitude to sickle cell among Africans it is inevitable that the Pregnant Females who all have sickle cell trait, whilst only a few of the African Females have sickle cell trait, are more likely to feel stigmatized and disempowered and are therefore more likely to have a lower Internal Locus of control.

Robinson et al. cited by Shiloh (1996) reported that health care professionals who counsel prospective parents who are at risk of having a child with a genetic disorder inadvertently influence the woman’s or couple’s decision with regard to accepting or declining prenatal diagnosis (PND). This is particularly true of general medical practitioners, who appear to be more directive than genetic nurse counsellors. Similarly, Marteau et al. (1994) supported by Green and Statham (1996), demonstrated that obstetricians were more directive than geneticists, and geneticists more than genetic nurse counsellors. These observations appear to support my proposed argument that even where the African Antenatal women may have had a higher Internal locus of control prior to pregnancy and genetic counselling the experience of health services and genetic counselling may have contributed to the loss of this Internality leaving the women less empowered and with the perception that Powerful Others have greater control of their health.

Secondly, I propose that the power structure within the Male/ Female relationship is often unequal and within society generally there is an imbalance, with males being more dominant. It is possible that many of the Pregnant Females are in marital/cohabiting relationships where maintaining ‘Internality’ is more difficult because of male domination in the relationship. These arguments are validated by the statistical significance observed between African Females and African Antenatal women (p=0.002) where the African Antenatal women scored higher in the Powerful Others locus of control.

7.4.8 Non-Pregnant Females / Pregnant Females, test result and selection of partner pre-conception

As indicated earlier all the antenatal women were tested and all have sickle cell trait, this being the major inclusion criteria for participation in Phase 2 of the project.

It was not surprising that more of the African Antenatal women selected their partner preconception compared to the Caribbean Antenatal women (Table 20). I propose that the African
Antenatal women’s reluctance to have a child with SCD reflects the common socio-cultural attitude of Africans to disease and illness (Maclean 1978, Jegede 1998), particularly to the prospect of having a child with a life-long, life-threatening, disabling, unpredictable and stigmatizing illness like SCD. This finding is contrary to findings among the African Female respondents, none of whom chose their partner based on their test result. Although there was no statistical significant difference between the African Female and African Antenatal respondents it is surprising that more of the African Antenatal women selected their partners based on their test results. It is possible that some of these women already have children with sickle cell disease and in a subsequent relationship were selective in whom they chose to have children with.

7.4.9 Non-Pregnant Females / Pregnant Females - other concepts and variables

Other concepts and variables were examined for statistical significance, including marital status, employment status, blood test result, mode of notification of blood test result (by mail or face-to-face counselling), religious denomination and level of engagement (See Tables 15 and 16) to determine whether they had any statistically significant impact on any of the five summary attitude variables, multi-dimension health locus of control variables and the summary ethnicity variables. As in Phase 1, none of these concepts or variables demonstrated a statistical significance.

7.4.10 Conclusion

The attitude of the Antenatal women in Phase 2 of the project showed many similarities with the Phase 1 general public African Females when comparing the same cultural group.

Although some statistical differences were observed between the African Antenatal and Caribbean Antenatal women these were few and the two groups appear to share a common perception and attitude to sickle cell disease and their response to being at-risk of having a child with sickle cell disease. This convergence and lack of statistical was unexpected, especially in view of the differences observed in the attitude of the general public African and Caribbean respondents in Phase 1 of the study.

It would appear that being pregnant and at risk of having a child with sickle cell anaemia has caused a convergence in the attitude of the African Antenatal and Caribbean Antenatal women and
this shared life situation has resulted in their responding in a similar way, and although African
women have a negative attitude to sickle cell disease generally when faced with the reality of being
at risk they resign to the situation and attempt to deal with it in a way that will have the least
negative emotional impact.

Perhaps having had genetic counselling and being reassured of the adequacy of health and social
care services available to children with SCD in the UK has caused a change in the attitude of many
of the African Antenatal women. If the study were replicated in Africa and the Caribbean the result
might demonstrate more marked differences since it would be in the context of the indigenous
country of origin and the available health care in those countries.

As Hoffmaster (1990) argued, when making decisions parents tailor the decision to their own
unique situation and select what they view as morally acceptable for them. This does not mean that
they accept that their own decision is appropriate or acceptable if someone else is in the same
situation. In fact they may feel opposed to someone else making a similar decision and they may in
fact be critical of people who do not make an attempt to avoid having a potentially disabled child.
They personalize the decision-making in an attempt to reach what may be a morally acceptable
solution for them personally.

Lipman-Hand and Fraser (1979) asserted that following genetic counselling prospective parents
make moral decisions by applying an approach that allows them to ‘cope with the nature of the
problem’. They play out a scenario of how they would cope in practical terms with the least and the
worst-case scenario. They then examine critically the option where the minimum-maximum loss
would be most acceptable to them. Where there is no least-loss option Lipman-Hand and Fraser
and it is not psychologically possible for parents to make a decision, they sway between various
options but feel unable to reach a decision.

I argue that the lack of difference in many areas between the African Antenatal and Caribbean
Antenatal women is their collective need to cope with their current predicament especially since the
alternative options, i.e. prenatal diagnosis and termination of an affected pregnancy, does not
appear morally, psychologically and emotionally acceptable for the majority of these at-risk
women and couples.
These findings have implications for policy-makers as they consider how to tailor services to meet the needs of what they may perceive as divergent populations where in fact certain factors, such as being pregnant and at risk, has created some convergence and an attitude change which influences decisions about an at-risk pregnancy but not necessarily the individual’s cultural attitude.
Chapter 8

Phase 3 Qualitative Data and Discussion
– African Antenatal/ Caribbean Antenatal
/ African Male Partner / Caribbean Male Partner

8.1 Introduction

8.2 Attitude to procreation and childbearing
  8.2.1 Importance of having children – a cultural perspective
  8.2.2 Barrenness - Marital instability and stigmatization
  8.2.3 Children – a pension plan for old age
  8.2.4 Religion and procreation

8.3 Knowledge and perception of sickle cell disease
  8.3.1 Nature and severity of sickle cell disease
  8.3.2 Screening - choices & responses to trait (carrier) result
    8.3.2.1 Screening choices
    8.3.2.2 Response to sickle cell trait result
    8.3.2.3 Selection of partner pre marital and attitude to at-risk coupling
    8.3.2.4 Selection of partner preconception

8.4 Factors influencing decisions about an at-risk pregnancy
  8.4.1 Experience of genetic counselling
  8.4.2 Personal experience of living with sickle cell disease
  8.4.3 Partners and significant others

8.5 Prenatal Diagnosis
  8.5.1 Factors influencing rejection of prenatal diagnosis
    8.5.1.1 Risk of miscarriage
    8.5.1.2 Religion
    8.5.1.3 Social and moral aspects
    8.5.1.4 Advanced age of pregnancy
    8.5.1.5 Other reasons
  8.5.2 Acceptance of prenatal diagnosis
    8.5.2.1 Opposition to termination of an affected pregnancy
      - preparing for a potentially sick child
    8.5.2.2 Support of termination of an affected pregnancy

PAGE

218
220
232
239
241
244
248
249
254
269
276
282
284
288
289
291
293
295
296
297
297
300
8.6 Influence of religion in decision making
   8.6.1 Dilemmas posed by religion

8.7 Possible impact of having a child with sickle cell anaemia
   8.7.1 Impact on marital / intimate relationship
   8.7.2 Impact on other relationships
   8.7.3 Impact on decisions about family size

8.8 Conclusion
8.1 Introduction

Phase 3 of the project comprise of women and partners who are at risk of having a child with sickle cell anaemia (HbSS), recruited from eight participating sickle cell and thalassaemia specialist centres and fetal medicine units in London. All women and their partners who were identified as being at risk either in Phase 2 of the project or were referrals to the fetal medicine unit for prenatal diagnosis were eligible to participate in this phase. The women only were contacted by the researcher or collaborating unit research facilitators by telephone and asked whether they and their respective partners were willing to participate in Phase 3 of the project. Anonymity was assured and if consent was not obtained previously this was sought from each participant.

The inclusion criteria were: Black African or Black Caribbean women and their partners, aged 18–45, at risk of having a child with sickle cell anaemia (HbSS), booked for confinement at one of six specialist centres or two fetal medicine units. The exclusion criteria included: women or partners below age 18 or above age 45 years, those of mixed cultural group (African / Caribbean), those with possible cognitive disability and those at risk of having a child with other types of sickle cell disease.

Of those who consented there were 22 pregnant women (African Antenatal, n=14, Caribbean Antenatal n= 8) and 7 of their partners (African Male Partner, n=6 and Caribbean Male Partner n= 1). It should be noted that in view of there being only one Caribbean Male partner the data needed to be handled sensitively. Although there were no contentious issues, a fictitious initial is used for each interviewee. The issue of being the only Caribbean Male and the possibility of his wife being able to identify him in the data was discussed with the individual during the data analysis stage and he gave his consent for the full data to be used.

A semi-structured interview guide designed specifically for the project (See Appendix 3) was used and 27 participants were interviewed at their home whilst 3 were interviewed at the local participating centre. All interviews were tape-recorded and transcribed before being subjected to thematic analysis. Coding was done using an open coding process. All relevant concepts were identified through a process of content analysis. The concepts which formed the basis of the semi-structured interview guide were pre determined using items identified from literature. However, previously unidentified concepts which emerged during examination of the data were also incorporated into the final analysis.
On examination of the data a number of relevant concepts emerged which I believe will contribute to a better understanding of African and Caribbean peoples’ attitude to sickle cell and the decision-making process when at risk of producing a child with sickle cell anaemia.

An interpretive approach was adopted in analysing the data. This was considered appropriate in view of Berg’s (2001) assertion that this approach enables the researcher to treat human activity as text. Coding the spoken and unspoken symbols will enable the researcher to uncover and capture the essence of the subject’s social action derived from transcribed data and observation notes. The primary aim is to explore the respondents’ lived experience, shared cultural values, to give them an opportunity to articulate this in their own words and for me as the researcher to present the data in a way that illuminates this under-researched subject. The data will be presented under a number of themes identified during the literature review and analysis of the data, these are: attitude to procreation, knowledge and perception of sickle cell disease, factors influencing decisions about an at-risk pregnancy, prenatal diagnosis, influence of religion on decision-making and the possible impact of having a child with sickle cell anaemia.
8.2. Attitude to procreation and childbearing

8.2.1 Importance of having children - a cultural perspective

In order to understand African and Caribbean people’s attitude to genetic testing pre-conceptually or during pregnancy, and the subsequent choices made about a pregnancy at risk of producing a child with sickle cell disease, it is essential to examine a cultural group’s social values in respect of marriage, procreation, childbearing and parenting.

As assumed by a number of authors, procreation, childbearing and parenting in most cultures are considered a fundamental aspect of maturity and adulthood (MacLean 1978, Basden in Madu 1994, Lips 2003), but the issue that needs exploration is whether the desire to have and nurture a child is inherently biological, as argued by Pearn (1979) and Finucane (1998), or whether it is influenced by social factors which are in themselves shaped by cultural environment, cultural experiences and cultural expectations of a given society. Pearn (1979) and Cote (1983) suggest that a potential genetic or health problem does not nullify an inherent biological drive to produce and nurture a child but it may influence choices about having prenatal diagnosis where a pregnancy is at-risk of producing a child with a genetic disability. Marteau and Anionwu (1996) assert that the desire to have children is stronger than the fear of having a child with a genetic condition, and knowledge of a carrier status does not influence the decision to have children but may influence decision to have prenatal diagnosis.

The current study suggests that although the biological drive theory has merit, another factor strongly influenced the study population’s attitude towards procreation, child-bearing and nurturing: a cultural attitude. Culture appears to play a pivotal role in the decision to have children, and the differences observed in the African and Caribbean respondent’s attitude appears to be more cultural than biological. Having said this, it is acknowledged that all the respondents or their partners were pregnant and it is difficult to assess whether these individuals could have chosen not to have children, whether there were any elements of coercion and the making of decisions which conflicted with personal preferences or choices.

When asked whether they think it important or not to have children the Caribbean Antenatal and Caribbean Male Partner felt that the decision should be based on individual preference, such a
decision is personal to an individual or a couple. The respondents did not consider the question inappropriate nor were they surprised that such a question was asked.

A Caribbean Male Partner stated:

\[
LC: \text{What’s the point of being here \textit{[on earth]} if you don’t have children… to me, personally it is not a choice that I would make but if someone wants to make that choice it’s their life, if they don’t want to have offspring. If that is what they want then that’s what they should do, to do otherwise they may not make good parents, so it is no point forcing them to do something they don’t want to do… In the Caribbean if someone chose not to have children I don’t think they will be rejected, not rejected, but most people I know from the Caribbean would have children… maybe there is family pressure sometimes or from friends or whatever, yes I suppose there could be but for me it seems the natural thing to do.}
\]

Conversely in asking the same question the African Antenatal and African Male Partners were often alarmed that such a question was asked especially because it is being asked by an African woman (researcher) whom they felt should be sufficiently culturally aware to know the answer to what they consider a futile question.

An African Male Partner in response to the same question stated:

\[
OH: \text{If it is important to have children? What a funny question, it’s a funny question isn’t it? Yeah? It is it’s a funny question.}
\]

The Caribbean respondents were univocal in their attitude to having children and did not feel that a person is compelled or should be coerced into having children if their personal preference conflicts with this choice. Secondly, the respondents did not perceive any negative social repercussions if an individual chose not to have children; they would not be ostracized or socially excluded by members of their community.
In response to the question some of the Caribbean Antenatal women affirmed this by stating:

TH - I think if I decide I don’t want kids there is no one or nothing that could make me have kids unless I want it…

AKO: Yeah, if you're a married couple or in a relationship and it's something you both decide you want, then yes, it's okay to have children if you want them...

IAT: I think it is a personal thing if you are healthy and it's what you want and you can give the child the love they deserve really, yeah, I think you know, women should have kids but again if you are not in that right frame of mind there is no point having one…

AA: Well, it depends on the person. If the person wants to have a child, you know... it’s not a sin... as long as they take care of it, but you have to take care of it. If you don’t have kids how will the world grow because people are dying so people need to be born obviously it’s important, even if you can’t have you can adopt.

AOH: I think it is a choice no one can put pressure on you if you don’t want it… it is human nature, what we are here for that’s what people believe. I don’t think people from the Caribbean will treat you harshly [if you chose not to have children]. We’ve got lots of friends who are single and haven’t got any children. They chose not to, they want an independent life style. People don’t respond harshly to them. I think they just say it’s sad that you didn’t perhaps you should, you don’t know what you are missing out on... people just accept that a person doesn’t want children, but it’s only a very, very small number who choose not to have them, very small.

IA: Well back home, if you want to have it [a child] you have it, and if you don’t want to have it you just don’t. There's no difference in the way people treat them. It’s not like the Africans that say you must have it, no, no, no. Even if it’s a woman if she decides she doesn't want to have children, they [Caribbeans] won't treat her bad

In contrast, the Africans’ attitude to having children demonstrates a lack of cultural permissiveness, and with sanctions against those who attempt to take such an option. The culture evidently has a very strong influence on an individual’s decision-making. To deviate from the cultural norm
suggests there would be serious repercussions, as illustrated by the following African Antenatal woman:

\[ \text{VU: Very important [to have children] because, you know in our country they say if you don't have children you are nothing, if you have money you don't have children, you are (still) nothing in the society, so it's very good for a woman to have babies...it's my priority to have babies.} \]

This respondent echoed the sentiments of the majority of the African respondents that having children is a ‘priority’ and affirms Maclean’s (1978) observation that African women are preoccupied with their ability to have children. It is surprising that in almost thirty years Maclean’s observation of this preoccupation remains even among those that are westernized and socially liberal, as illustrated by the following responses from an African Antenatal woman:

\[ \text{KS: Important? Definitely, my parents have been here [in UK] for thirty odd years so maybe they're a bit more liberal in their thinking but even they've put a little pressure ... I think for them [our parents] it's a legacy - they need to pass on that legacy and they pass that on through their children and their children's children, so for us, as Africans, it is important.} \]

This respondent reflects the strength of culture because despite having parents and she herself having a strong western cultural influence, the African cultural attitude to procreation persists. This reflects Sowell’s (1994) argument that culture is not necessarily erased by moving to another country or culture. Even where one adopts many of the traits of the host country, the deep-rooted cultural beliefs, attitudes, values and practices persist, enhancing individual members’ conformity to the group norms and to maintaining group cohesion (Atkinson 2004). Secondly, Sowell (1994) added that western education and immersion in western culture will never totally eradicate a non-western person’s cultural attitude or behaviour. They are more likely to display a complex cultural attitude and modified behaviour. Oppenheim (2003) also suggest that the deeper level of being with opinion at the basic level, followed by attitude and values as the deepest level, the more difficult it is for an individual to change their psyche. As highlighted by Read (2001), those observing from the outside may fail to appreciate the effectiveness of deep-rooted cultural learning and its impact in shaping future generations’ thinking. The deep roots of the African cultural response to procreation appears to supports Helman’s (2001) assertion that culture is partly genetic and partly
learned, and also supports Catherine Collier’s (2004) enculturation theory. However, I argue that culture is the most significant aspect and offers the most plausible explanation.

Krauss and Chiu (1998) suggest that those who have a dual culture demonstrate multiple cultural systems and are capable of switching between one cultural norm and another depending on the context in which they find themselves. However, the majority of African respondents in this study including those born and raised in the UK, still demonstrated an adherence to the African cultural response and attitude to procreation, suggesting that the European cultural influence has not had much of an impact on this group. Perhaps this can be explained by a lack of assimilation of western culture. Despite living in a predominantly European community, some minority ethnic communities choose or feel they are not able to, due to racism and alienation, integrate with the indigenous community. The exposure to other cultures in this case has had limited impact in influencing attitude to procreation.

In order to maintain social harmony some of the respondents chose to act in opposition to their own personal values and preferences. This is illustrated by an African Antenatal woman, a medical doctor, who stated clearly that personally she did not want to have children but with increasing pressure from her husband and his family she had to adhere to cultural values, attitudes and expectations:

*AAN: This was the argument between us [her and her husband] because I didn't want children...he told me I'm getting old so we have to have children... pressure, big argument, so ahh I got pregnant.*

To deliberately choose not to have children is exceptional in many Black African societies among men and women equally, thus demonstrating the deep roots of the cultural attitude to procreation.

The question is how do African women and men, whose personal preference is not to have children, reconcile this with their response to their community’s demand for them to reproduce? Evidently there is a tension between their preference and the demands of their cultural group; the personal preference, ‘not to have children’ and the behaviour ‘choosing to have children’ to satisfy cultural norms. As highlighted by Festinger (1957) there is dissonance if there is a contradiction between cognition and behaviour. The inherent need to reduce the dissonance compels one to modify the cognition or find ways of justifying the behaviour. An individual will seek information
that will help change their belief and perhaps justify behaviour that contradicts their personal belief or preference. I propose that in order to relieve the tension between the attitude ‘I do not want to have children’ and the behaviour ‘I am going to have children’ individuals will modify the importance of their belief or add a consonant element to justify and support their behaviour.

This respondent had to deal with the tensions between her attitude of not wanting children and her behaviour (being pregnant) which was a direct response to socio-cultural pressures to have children. In order to deal with the tensions that these irreconcilable cognitions would create the respondent removed one of the conditions necessary for dissonance to occur, that is a freedom to choose. Since her husband and the culture of her African society has dictated that all men and women must have children the respondent will perceive that she has no autonomy in the decision making a state of which Cooper (2007) termed a low-decision freedom. The loss of freedom to choose has automatically eliminated any dissonance she may have felt, the respondent will perceive that she has not been responsible for the decision and therefore cannot be held responsible or indeed accountable if she produces a child with sickle cell disease.

As highlighted by Harmon-Jones and Mills (1993) for dissonance to be large enough for an individual to feel its effect the psychological pressure on the individual must be minimal, too much pressure will act as justification for a change in action or attitude. The respondent illustrated above did not wish to have children, yet she was expecting her second child at the time of the interview. In order to relieve the dissonance between her belief and behaviour she needed to seek information that will help her change or modify her attitude to having children. In this case she chose the emotional ‘pressure’ emanating not only from her partner but from her in-laws, her own family and friends. The pressure exerted from these sources was the bolster and justification element which eliminated any dissonance she may have experienced in having two opposing cognitions.

The majority of Caribbean respondents felt that within their culture an individual is able to choose not to have children and their behaviour will reflect their personal preference. Conversely the African respondents recognised that in the African culture such a personal preference cannot and must not lead to the expected behaviour, which is not to have children. The majority of the African respondents feel unable to make such choices and have to deal with the conflict in the cognition and behaviour. The question is what happens to such individual, psychologically and long term? Presumably by adding consonant elements, playing down the dissonant elements, removing the freedom to choose and other strategies will help to reduce any adverse impact that any conflict between attitude and behaviour has caused.
Other respondents highlighted other potential justification elements, for example, in order to remain married to a partner, to satisfy the demand of their parents for grandchildren, prevent being ostracized and rejected by their community some individuals will insist that having a child is of more importance irrespective of the risk of disability and others perceive that the love of their partner far outweighs the threat of disability. Such justification elements help to modify the individuals belief about having children, in order to relieve the dissonance they internalize the justification element and for those who did not want children they may begin to believe that they ‘did want’ children and are able to convince themselves and others that this is the case. This reduces the dissonance and a return to a state of consonance. This argument appears a plausible since the respondent whom this pertains to a medical doctor, living in the UK it is highly unlikely that lack of knowledge of sickle cell or economic reliance or dependence on her partner and other social factors would account for her belief modification, change in attitude or acceptance to act against her attitude. But is the change in attitude a response to dissonance necessarily, perhaps the respondent is merely coming to terms with having to adhere to cultural norms and there was no dissonance or need to reduce it merely an adherence to cultural norms.

Other African Antenatal women stated:

IP: If a woman say she not want children I think maybe she not normal [noted in field notes that respondent gestured with her hand suggesting insanity]… in Zaire not normal for woman to say that she not want to have children.

AK: It’s the African culture. You know in our country, our parents are strict in a way something that is not here [in the UK]. When you finish school you want to get married, and of course if you get married you should have kids to make them [your parents] proud. To me, I think it’s the culture, the culture does that. It makes you want certain things. Yet here [in the UK] I believe if someone doesn't want to have a child they would not be seen as bad. You look at the celebrities around here, most of them like to have their kids at the age of thirty-five and at home if you try to tell someone you don't want to have kids and maybe you want to have them at a later age, they won’t look at it in a positive way. They will look at you as a very, very bad person…even if you are rich or successful you must have kids. People will like your kids to share your success, yeah or they’d like your kids to be just like you. Even if you are rich but no kids they will treat you like outcast, they will point fingers at you.
MB: In Africa they won’t accept that [choosing childlessness] from anybody, maybe in white people but in black people, something like that? No, no, no. You can never tell people you don't want to have children they will say maybe you are insane or something is in you or you are possessed [demonic] or something. They’ll say “ahh you are possessed just go away you don’t know what you are talking about”.

These findings support Maclean’s (1978) observation that women in the African context are ‘preoccupied with their capacity to bear children’, irrespective of the position they attain even in modern-day society, where many women have acquired a high status socially, academically and professionally. The attainment of the status ‘motherhood’ is still a much sought-after position.

This finding supports Kashima’s (1992) theory that people living in an independent society tend to make choices that are individualised based on personal beliefs, values and preferences. There is limited scope for inconsistencies between societal and personal values and consequent decision-making. Where such choices are made the individual is likely to experience psychological dissonance and emotional conflict. In contrast, people living in an ‘interdependent’ society may make choices that are in conflict with their personal beliefs, values and preferences without any adverse psychological effect. This is also supported by Wrightson and Wardle’s (1997) assertion that the preservation of social harmony can often override personal choices and preferences and an individual may make choices that are inconsistent with their own values.

In this study there was marked difference between the two cultural groups, the Caribbean respondents demonstrated societal independence in their attitude to having children whilst the Africans demonstrated interdependence in their decision-making.

The findings among the Caribbean respondents does not fully support the biological drive theory as proposed by Pearn (1979) and Finucane (1998) since it appears that there is a cognitive process influencing the decision-making process and not mere innate biological pressure to conceive and bear children. It is possible to choose not to have children depending on the social-cultural environment influencing the individual. It is noted that since all the respondents in this group are pregnant women and their partners perhaps their response does not negate the biological drive theory completely. It is also possible to suggest that a greater influence in the matter is culture and the pressure or lack of pressure exerted by the society determines an individual’s response to having children. However, if culture is also genetic, as argued by Helman (2001), perhaps it is the combination of biological and socio-cultural that influences the decision-making. But the tensions
inherent in a belief that one does not want to have children and one feeling pressured to have children creates dissonance which individuals need to reduce by adding consonant elements in order to justify a behaviour that contradicts their value, attitude and belief.

The findings in this Phase of the project support the findings of Phase 1, where there was a statistically significant difference, the African Males more than the African Females felt it is important to have children (Section 5.3.1.3). This was surprising in view of the potential ramifications of childlessness which often has a greater social impact on the lives of barren African women (MacLean 1978, Lips 2003). Interestingly the African Male Partners were more vocal and passionate in their reaction to the question and often seemed bemused that such a question was asked, even more so than the African antenatal women. All the African Male Partners expressed similar sentiments about procreation even those who were born and spent their most formative years in the UK. In the latter group one would have anticipated a greater western cultural influence and assimilation of western values however this did not appear to be the case among those who participated in this study including those in Phase 1 of the project.

This is amply illustrated by one African Male partner:

*SG: single in Nigeria? Yeah it is possible if they have problems... like financial problems, like not being able to perform as a man or as a woman [impotence]. Then they think there is no point in getting married if they cannot even have children or you think you will not be able to tell your partner [about the problem], but the tension will come. What's the point of marrying when you know you keep that kind of secret? In our culture I don't think it is possible to choose not to get married or not to have children, it's not done... my parents will start looking and going about to check if there is something wrong with me or my wife and asking people "please help us nothing is happening". You will find your parents going from one spiritual leader to another. They want to know what is happening to their children, if after two years and nothing they will soon start getting worried. How can anybody tell his parents that I am going to marry but I am not going to have children? No. I don't think I have heard about it in Nigeria, no, no, no. Even getting married is a hassle because they will be pressing you [to get married]. Like when I was at home, people say oh this is the right time for you to get married, you must bring somebody home, and now you say oh I am not going to have children, ahhh [a Nigerian phrase that indicates that it is not acceptable] no, no, no not possible... If the fault is from the woman 'cause they believe that*
if you can't give your husband his children they think the husband is allowed to marry somebody else so that the family name will go on, not perish.

Some of the other respondents demonstrated the depth of their cultural orientation by frequent use of culturally specific phrases, gestures and expressions, which were noted down during the interviews. Durham (1991) argued language and the use of non-verbal symbols is the most effective method for transmitting culture and the use of these symbols shapes an individual’s knowledge and attitude to their life experiences. Catherine Collier (2004) asserts that culture is a cognitive construct, the component of which must be known by each individual in the cultural group in order for them to operate in a manner that is acceptable to their group and ensures their continued acceptance by other group members.

OS: I personally want children. You want to have kids after you. Where I come from nobody actually forces you to have kids but everybody wants to know why if you don't have children. They ask why? If you grow up, unless there's something really wrong with you, it will be frowned upon, in our culture it's insane not to get married or have kids ... the moment you get married, people are asking questions even after two or three months, people ask "is your wife pregnant yet"? Society influences you, people want to know what's happening because they think when you're married that is the next step that is another psychological thing that affects all of us... it shows that you're responsible [mature].

Finucane (1998) argued that for the majority of women there is a motivation and desire to nurture and love a child in order to satisfy the inherent biological drive. The argument is that women have an inherent need to have a child in order to satisfy the inherent female reproductive drive. Whether men have this inherent reproductive drive was not made very clear by the author. I suggest that although reproductive drive plays a role in determining one’s desire to have children it is only a single factor in the complexity of human decision-making. Culture and social circumstances play a much more important role, as highlighted by this current study’s findings.

In reflecting Finucane’s (1998) biological drive theory one African Antenatal woman stated:

EU: I think the main reason [people have children] is biological for sure, but all the others definitely come into play - cultural and so on. But the key one is biological. Even if, you know, even if someone doesn't have any cultural roots or exposure to that environment they
will still have that instinct. I feel that I speak for myself, not every woman I suppose but the key is the biological, the difference between men and women...men don’t have the biological drive as much as women.

The social system in the African context suggest that an African woman irrespective of ability to be socially and economically independent still has to conform to cultural expectations of becoming a wife and mother. Not achieving this goal can lead to stigmatization, social isolation and rejection. The Caribbean females experience appears to be dissimilar in that, provided she has economic and social independence, the Caribbean society’s response to an individual who chooses or is unable to have children has less of a social and cultural impact.

Caribbean Antenatal women stated:

HM: I don’t think there is any pressure to have children. It would be OK to decide not to have them. In the Caribbean there's a little bit of pressure, but not so much, if a woman doesn't have children she's not considered unfulfilled.

AW: Really, it is up to you as an individual if you want children or not. If you know you can’t cope don’t even go there. If you’re career minded get on with your career...later you can always adopt... at the end of the day it is you that has got to look after that child not your relatives or anybody else... it is up to you as an individual if you want children or not. They [Caribbean culture] will accept if you don’t want to have children, but there will always be questions of how come you haven’t any children or why don’t you want children, but they will accept it.

As for childlessness among men, they are less likely to suffer economic and social consequences of not having children, but childlessness still has a social impact, and male infertility is more likely to affect the male ego as opposed to other social situations. Because the male is more likely to be the main earner in the family and the dominant person in the couple/ marital relationship it is unlikely that he will be ousted from the marital home or suffer the economic consequences of barrenness. Some of the African Male Partners highlighted the pressures placed on men to reproduce. In support of the stigma associated with male barrenness and the grave lengths that some will go to in order to ensure fatherhood, some of the respondents gave examples of practices that would be adopted in order to conceal the man’s infertility.
One African Male Partner stated:

SG: People [men] who are ill or have problems [infertility] will still marry to cover themselves up and then make arrangements how to get children like have their brother or get their friend to meet [impregnate] their wife so that they will have children. People would do that [laughs] ask their brother which is still the same family you know.

The impact of male infertility on the male ego is probably also true of barren Caribbean men and it is possible that both cultural groups will share similar psychological experiences. However in view of not accessing a sufficient number of Caribbean men for interview it was not possible to explore this aspect and it is beyond the scope of this study. The same cannot be said of the African and Caribbean women and their perception of the society’s attitude to female barrenness. Whilst the barren African female is likely to be marginalized, ostracized or even rejected the barren Caribbean female may not be and may find fulfillment through other life-affirming social experiences and roles, such as a career, being a responsive aunt or surrogate mother to other people’s children or adopting a child. In Phase I of this study it was demonstrated that African Males even more so than African Females feel it is important to have children. This was an unexpected finding in view of the enormous social impact of female barrenness in the African context one would have anticipated that the African Female who appears to be under greater pressure to conceive and bear a child for her husband would consider it more highly important compared to the African Male. It is possible that this unexpected phenomenon can be explained that whilst there is pressure on the Female to produce children in order to ensure social acceptance and stability in her husband’s home the pressure on the male is in order to maintain the family line, a role that is perceived in the African context as strictly a male responsibility since the majority of Black African cultures are patriarchal. There is great emphasis on producing a child but, more importantly, a son as highlighted by Maclean (1978) “It is felt to be disastrous for someone to die without sons to carry [on] the spirits of the ancestors”. It appears therefore that both male and female experience societal pressures but for different reasons that are interlinked in a rather complex way. It appears that greater social responsibility is placed on the African Male than the African Female and the social impact of barrenness differs.
One African Antenatal respondent puts this succinctly:

OG: If I don’t have children people will think I am barren… Yes, in our culture it is very important… We Africans most of us want children… Men even want to have children more than women so that their name will not disappear.

It seemed inconceivable to all the African Antenatal and African Male Partners interviewed that an individual would deliberately opt for not having children. The majority of the African respondents based their response on what Kashima et al. (1992) described as depicting the values of an ‘interdependent’ society, where members make decisions based not on their values and desires alone but that of the wider group, community or society, even where this conflicts with their personal views and preference. This is amply illustrated by one African Male partner who stated:

AL: In my culture I don’t think it is possible to choose not to have children. If it was left to me alone I don’t care but with the culture you will be seriously pressured, very seriously. I think sometimes they [family, society] think they have given birth to you it is your obligation that you should also give birth, irrespective of whether you choose to or not it is important…if you are a man or a woman without a child they think perhaps you have a problem, a medical problem…maybe during her youth a woman has aborted so much now she can’t have kids [due to damage to the womb] or she is being punished for it [divine retribution]…the way society feels about childless couples is that they are hopeless.

These extracts indicate that there is overwhelming evidence to support the hypothesis that culture has the greater influence in attitude to having children.

8.2.2 Barrenness - Marital instability and stigmatization

Marriage in many cultures is deemed an important institution and gives people stability, especially women who live in societies where women are perceived as second-class citizens or their husband’s chattels. The abandonment of women who are unable to conceive is not uncommon in societies where parenting and the value of children is deemed highly important. A woman’s major
function is mothering and irrespective of all other achievements and roles within society if this has not been achieved she is considered one to be highly pitied.

In many world communities, including western society, men remain the dominant gender in all spheres of society, making decisions at all levels that impact on government policies and affect the lives of every individual and families. Despite attempts to abolish gender inequality in western cultures it remains a major issue and more so among families from traditional cultures. A barren woman in many African cultures is likely to experience marital instability (Lips 2003) as a direct result of not bearing children; this creates stress, fear and anxiety for many African women when they get married. Some of the African Antenatal women highlighted this phenomenon. Despite their not experiencing it personally many knew women who had, and they were well aware of the repercussions of being barren within the African culture:

AH: *In our culture* [African] *when you get married and you don’t have a child in that family you know your stand there is temporary. You won’t have an opportunity to say anything in the family, whatever you say is not recognized because you didn’t produce any child in that family so your opinion does not matter. It’s a worry when you get there and you don’t have a child. But when you marry and have a child it’s like you become strong [well established] in that family, your foot is firm...People who don’t have children they are insulted if they talk harshly to their neighbour’s child they say it is because you don’t have, that is hard.*

RA: *If a woman cannot have* [children] *your husband might leave you and get married to another lady, or your in-laws can say, “We don’t want you. I want to see my grandchildren. If you can’t give us grandchildren it’s OK but he [our son] will get another lady who will have children for my son...In Africa, it’s very important to have children.*

MB: *If you are with a man two years latest three years and you don’t have children they will say [to the man] please go and get another person, because we don’t think this marriage is gonna work. Even people who got married after you they already have children... The man will call you and say I can’t go on with you anymore I’m tired... I didn’t say you should pack out and if you know you can’t cope with me getting another woman then pack your things I am going to get another person, but if you want to stay, then stay I am still married to you but I will get another wife. That’s how it is. If it was my*
mother-in-law, my husband's family, even my family they will say "ahh, what do you want us to do now you know how it is in Africa". If you are a very nice person they will not discuss it with you [because they like you and want to be sensitive to you]. They will prefer to call their son and say "What are you looking at [waiting for]? You can’t drive this woman away she is OK, she is nice, everybody loves her, but at least you can’t compromise [yourself just] because she is nice, if she can’t bear you children, then just get another person. If that one gets pregnant we will know how to tell her [first wife] gently.

None of the Caribbean respondents alluded to possible ill treatment of individuals who choose or are unable to have children and none considered that marital instability would be an issue for the infertile man or woman. One Caribbean Antenatal respondent suggested that even where an individual or couple is infertile they could adopt a child, a very rare phenomenon in the African context. It is not clear whether marital stability is affected in the Caribbean context and perhaps polygamy is practised in an indirect way in both cultural groups.

A Caribbean Antenatal stated:

\[
OY: \text{There are quite a few men out there who don’t have children. It’s a shock if I hear of a man who does not have three or four baby mothers, like [among] my partner’s friends it’s rare; it’s like different mums, so to find one who does not have kids it’s a shock. Not that it should be like that, but that is how it is, if you get those that are then it’s like there’s something else wrong, it’s never the whole picture.}
\]

It appears that there are similarities between the African and Caribbean men in terms of procreation. In the Caribbean Male context where the man’s partner is barren she is not ousted from the marital home necessarily however infidelity would ensure continuation of the male’s family line.

A Caribbean Antenatal respondent stated:

\[
HM: I don’t think there is any pressure to have children it would be OK to decide not to have them... I think Afro-Caribbean men they would have more of a problem with [you] not having children because men like children.
\]
Due to insufficient numbers it was not possible to obtain the views of many Caribbean Males and this would have helped to examine this issue in greater detail. However, the data suggest that since there is less pressure to have children the Caribbean respondents feel they are able to choose not to have children, without fear of being ostracized by their community. Since the majority of those of Caribbean origin are able to act in accordance with their belief and attitude to procreation they are less likely to experience dissonance. Interestingly the Caribbean Antenatal women that were in a relationship with African men expressed similar sentiments to the other Caribbean respondents; however, they acknowledged that a woman who chooses or is unable to have children but is involved in a relationship with an African man will find her position untenable. This is amply illustrated by the following statement from a Caribbean Antenatal whose partner is African:

IR: A person who does not have children is not a problem from my background [Caribbean]. People are not cruel to them in any way, but to be in a relationship with an African then that would be a problem. I didn't have a clue about that until I met my partner… I realized quickly when I overhearing conversations [among Africans]. One would say ‘oh that man is living with that woman for how many years?’ maybe ten years, whatever and if she don't bear a child then the family or the mother [of the man] would bring another woman [for the man] and she can't do anything because she can't bear children. So another woman will take your place and you just have to keep your mouth shut, you can't do anything if the man is not strong enough to speak and choose for himself. That is why I believe that you not giving birth would affect being in a relationship with an African but from my background it doesn't matter, I mean, people will call you names for a time, oh you are a mule or you can't do [perform sexually] but after a while it will stop, I don't think you suffer persecution so to speak…Yes somebody can choose not to have children back home.

This illustrates the unequal treatment of infertile men and women within some African societies where the woman may accept being impregnated by her brother-in-law or her husband’s friend it is highly unlikely that it would be suggested that a surrogate be found to assist the infertile woman, and in many cases the barren woman is likely to be ousted and replaced by another woman. As highlighted by Basden in Madu (1994) “a childless woman is regarded as a monstrosity”. Some of the African Antenatal women suggest that stigma is the likely consequence of being barren for men and women in most African societies but more so for a woman since she is more likely to be blamed for the couple’s inability to have children at least until medical investigations.
suggest otherwise. This is in support of Lips (2003) observation and evidently some of the African Antenatal and African Male in this study affirm this observation.

One African Antenatal woman stated:

AH: Back home we really adore children and it's like when you don't have children you do not belong. People that don't have children are insulted... If you talk harshly to your neighbour's children somebody can hurt your feelings. They say that you are being harsh because you don't have children. That is why you are treating other people's children harshly. That alone will make it hard. Some people feel if a woman cannot find a husband and she is getting on in age rather than waiting and ending up not having children, they should go ahead and have children before it becomes too late...not to have children at all is worse.

The rejection experienced by infertile women within the African society will help explain the lengths which a woman will go to in order to bear a child, irrespective of any health reason which may pose a threat to herself or an unborn child.

AAR: [a woman] will be totally rejected in the community. At a certain age in Africa you are bound to have a husband if you as a woman decide not to have children you husband will definitely go for more [other] women ... They [society] will not accept you knowing that you deliberately don't want children and no man will even go for you knowing that you don't want a child so if you have to be in that community you definitely have to think about having children ... nobody will like to be with you they will class you and begin to give you names even regard them as witches ... even when a man gets older like over 30s or 40s in Africa and does not have any wife, even if you are rich or whatever they start looking at you as irresponsible... in Africa people don't pray to have one or two kids they want more and they [women] would not like to have [them for] different men in order to prevent all that you have to get married where I come from [Zaire]. I don't think any woman would deliberately say I don't want to have a child. Maybe they will not have it for any fertility problems or other reason but not willingly.
As argued by Cote (1983) anticipated health and social problems do not nullify the reproductive drive but will co-exist with it, in support of this one Caribbean Male partner stated:

\[ LC: \text{I can only speak for myself if I had a health problem I would still like to have children. I assume that most people, you know, we all know we are going to die sometime and what we do is want to leave behind our offspring.} \]

An African Antenatal stated:

\[ ES: \text{I think I have the faith that I'm not going to have a child with sickle cell anyway but the thing is if I have a child with sickle cell too I would [still] prefer to have a child anyway.} \]

This affirmed Madu’s (1994) observation that in most African cultures marriage is perceived as an undertaking to which all adults must subscribe and bachelorhood is an aberration that is never condoned by the cultural group. Basden in Madu’s (1994) observation of traditional Igbo tribes of Eastern Nigeria also concluded that “celibacy finds no favour what-so-ever to the traditional Igbo. It is ranked foolishness as well as utterly contrary to the laws of nature…men and women particularly the latter are scorned and mocked”. Childless women being regarded as a “monstrosity” (Basden in Madu 1994) in many African cultures helps to explain why women are prepared to endanger their own lives even when pregnancy could pose a risk to their health and in spite of medical advice. It also explains why women and couples at-risk of having a child with a serious genetic condition would still opt for parenthood. This was also observed by Sheer et al. (1996), who found in a study of antenatal women that a positive HIV tests did not deter the majority of the women from the decision to have children.

The fear and anguish of barrenness is so powerful that some women would opt for having children irrespective of the risk of having a sickly child, as illustrated by the following African Antenatal woman when asked to identify the positive things to having a child with sickle cell disease:

\[ AH: \text{The positive thing is that as a woman or family you have got a child. People will know that you're not barren, you can produce only that you're not lucky enough to have a healthy child.} \]
When faced with such a challenging situation in medical practice health care professionals may feel bemused at the decisions made by what they consider a rational and sensible individual. Perhaps the biological drive theory plays a part, but I argue that culture plays a more important role, especially among African women when they consider what is at stake if they fail to bear a child for their partner.

Some respondents conceal information about their risk status in an attempt to protect their feelings from the response of family and friends.

*AAR: I didn't want to talk to my parents or brothers and sisters or any friends ... I guess I just don't want them to know. I just don't want them to tell me the bad side of it. You know sometimes when you talk to someone about something and then they tell you all the bad things they know about that thing, it's leaves you sad...When you don't talk about something you will never know, but by the time you raise that point and then someone will tell you all the different things they know about it and maybe some of those things they tell you are so bad for you to face, so you'd rather not talk about it.*

This respondent’s attitude is a demonstration of Eagly and Chaiken’s (1993) proposed modes that individual may adopt in an attempt to resolve their state of dissonance. They suggest that where the reality of the situation places a constraint which make it difficult for the individual to eliminate feelings of dissonance individuals may use ‘avoidance’ to help reduce or eliminate it. For example by avoiding information, persons or situations that will further increase the dissonance.

It is estimated that 10% of children conceived in the UK do not belong to the putative father. It would be interesting to know whether this is so within the African and Caribbean community. It is possible that a woman who experience barrenness in these cultural groups and fear rejection by a partner may, unbeknown to her partner, seek an alternative source in order to conceive and bear a child and secure their position in the marital home. But this would be done surreptitiously and attempts will be made to maintain life-long secrecy. It is possible that westernization of many African communities through the establishment of western-style religious marriage and its doctrines of monogamy and fidelity will result in fewer barren African women being ostracized, but this could be unlikely given the strength of cultural values in many traditional cultures.
8.2.3 Children – A pension plan for old age

As observed by Lips (2003), in many traditional African cultures women rely on their children to give them a status in society, but more importantly they rely on them for economic support especially during their old age in a society where a pension plan is only available to affluent members of society. In many developing countries it is not only women who depend on their children for economic support men do also, especially in old age. In societies where there is little or no social welfare, dependence on family and kin is inevitable especially among poorer members of society. Within such groups basic amenities may not be readily available, which makes children more susceptible to poor nutrition and its consequences, such as poor growth, ill health, lack of health care and lack of access to educational opportunities mean lack of opportunity to escape from poverty.

In such families children are more likely to die young hence couples feel compelled to have more children in order to compensate for any future losses. However, this perpetuates the family’s poverty and lessens their ability to get out of the poverty trap. Parents in such families are unable to gain employment that would pay them adequately to support a large family and so not have savings for their old age; hence the heavy reliance on adult children to cater and sustain elderly parents later in life is inevitable. But this is often not ideal since having a large number of children limits the parent’s ability to give their children the best education and chance to escape the poverty trap, hence their adult children are often unable to achieve a career or job that provides the level of income required to sustain a nuclear and extended family. Hence poverty continues from one generation to the next. This phenomenon is common in any society where there are inadequate human rights legislations and government programmes that ensure adequate welfare and support for vulnerable individuals and families. In such societies it would be inconceivable for an individual to contemplate the idea of not having many children and even more inconceivable not to have children at all.

The concept of having children as a pension plan for one’s old age was highlighted by some of the African Antenatal women:

AH: During your old age they [your children] are going to cater for you... when you don't have children all the help you need from people you won't get it, so everybody is struggling
to have somebody [children] who will look after you later... Back home not everybody has the opportunity to have education, work and save for old age to take care of yourself. A lot of people are not privileged enough to be able to save for old age, because of that it's still important that you have children. When you are single [and childless] in old age, who will remember you? No matter if you don't have any husband you still have to have children, they will still call you Mama somebody [the traditional way of addressing a women is calling her using the name of her first born child – for example John’s mother]. In that case even if people don’t recognize you, you still have your children to rely on.

VU: Both men and women should have babies because when you grow old if you don't have anybody to take care of you they can take care of you, even if you have money you should have children, they will take care of you. If you don’t have a companion who will take care of you? It’s your children.

ES: I believe that children are the ones that are going to inherit or look after their parents when they grow up so children are quite important in everybody's home.

African Male Partners concurred with these perceptions about what they perceive as one of the fundamental reasons for having children:

UO: I don’t know about here [in UK] but in Africa when you have children and you get older, you can't do anything for your self your children will be able to attend to you look after you that’s why it’s important to have children.

WD: When I get old maybe my child or my son will be somewhere I can pick up the phone and ring him I tell him I have a difficult situation or whatever, he will come and help me I think this is the reason why they [African society] want everyone to have children someone to look after you when you get older.
Only one Caribbean Antenatal concurred with the idea of children as pension plan for old age, and this individual migrated to the UK >15 years of age, which suggests that personal experiences of the social welfare system in the Caribbean influenced perception of the economic need for children.

IA: ... its part of our nature, some of us want children and some of us don't want children, in the longer run you want someone to look after you in old age if they are still around. When you have children some of them will disappear and be gone and some will stick around and say well this is my mum I will look after her [in old age] until the end.

This respondent demonstrates the precariousness of relying on one’s children for care during old age, something also recognized by the African respondents. Hence the need for women and couples to have many children, in order to ensure that some will survive and secondly that perhaps one or two will be compassionate and care for the parent in old age.

8.2.4 Religion and procreation

Another factor supporting the argument that culture and social circumstance play a significant role in influencing attitude to procreation is religion. This had an impact too, on choices made about an at-risk pregnancy and its subsequent outcome, which will be discussed later. The influence of religion on the importance of having children was evident in the response of some of the respondents, as illustrated by the following African Male partners:

UO: From a religious point of view God said in the Holy Koran when we grow up men and women we have to get married and have children. It’s not compulsory, but it’s good. If you have children especially if your children follow your religion that is a blessing, every day you will get blessing from God because of that.

BO - I think children are a blessing from God so to me it is important to have children.

ES: I believe children are a blessing from God.
UO: I don't feel like because I have a sickle cell trait and my wife is having sickle cell that would stop us from having children. There is no guarantee they're gonna have sickle cell disease. From what I believe, from a religious point of view, God is responsible for everything. Doctors could say your child’s gonna have sickle cell but it's God who really, really know. He can bring [give you] a child who doesn’t have sickle cell. It's possible even if there's a one per cent chance, but it's possible. So once I've got somebody who I love, we enjoy each other's company it's important to be with that person and have children, no matter whatever the condition.

A similar sentiment was expressed by two Caribbean Antenatal women who stated:

IA: It is important to have children because it's God's work.

AKO: From a Christian perspective God our Father in heaven said “Go forth and multiply”, that’s part of it [what influences people to have children].

The majority of the Caribbean respondents demonstrated a liberalism towards procreation and parenting thus affirming Kashima et al’s (1992) argument that attitudes and consequently behaviour are influenced by whether an individual originated from an ‘independent’ or ‘interdependent’ society. It is possible to suggest that in view of many Caribbean people in the UK being second-, third- and even fourth-generation migrants the respondents in this study are more likely to demonstrate the independent values of western society. Conversely, the majority of the African respondents interviewed were first- or second-generation migrants and more likely to share the social values of their interdependent culture of origin. This again supports the hypothesis generated from the Phase 1 and 2 data which suggests that age of migration to the UK plays a pivotal role in determining an individual’s beliefs, values and attitude to any social phenomena. The findings of this study conflict with Richards’ (1996) suggestion that having a genetic disorder is unlikely to influence a decision to marry though it may affect the decision to have children, this study suggests especially among the African respondents, that the idea of not having children because of a genetic condition is highly unacceptable.

They support the assertion that culture gives individuals a lens through which to view the world. Kaplan and Manners (1972) describe this as an ‘internalized’ system. The findings also support Collier’s (2004) argument that culture is a cognitive construction which governs the way in which
an individual perceives the world and operates in a manner that is acceptable to the other members of the cultural group. To deviate from a group’s cultural values often results in dissonance and the individual is likely to be ostracized or rejected by the cultural group (Berry and Kim in Maclachlan 1997). The response of the African Antenatal women and African Male Partners in this study supports these assertions, since they strongly reflect the traditional society’s cultural attitude to procreation, childbearing and parenting, as described by Maclean 1978, Basden in Madu 1994, Lips 2003.
8.3 Knowledge and perception of sickle cell disease

8.3.1 Nature and severity of sickle cell disease

It was proposed that prior knowledge and personal experience of living with someone with sickle cell disease would influence perception and attitude to sickle cell disease, that those who were aware of their haemoglobin status pre-marriage or pre-conception would be more likely to select a partner based on this prior knowledge in order to avoid having a child with sickle cell disease. Secondly it was proposed that this knowledge and experience would influence an individual’s or couples’ decision with regard to prenatal diagnosis and subsequent outcome of an affected pregnancy. The final proposition is that culture, perceptions of and attitudes to sickle cell disease would impact on the decisions made about an at-risk pregnancy. Many communities have limited knowledge of sickle cell disease, even West African communities where the gene is of the highest frequency worldwide. Some of the African Antenatal women highlighted the lack of awareness and inadequate health promotion especially in their country of origin:

MB: In Europe they tell you about these things but in African nobody knows...even if you go there [to be tested] they give wrong one [result]. A friend of mine got tested, they gave her AA [HbAA]. When she went to a big hospital with typhoid they tested her and told her she is AS [HbAS].

AK: Actually, I had never heard about... when I was told that I might have a child with sickle cell of course I was scared, because at home [in Africa] I had never thought about it. Um, in [among] all the pregnant people I’ve seen back home I never got know about it 'cause in our country I don't think they test for it maybe because I wasn't pregnant I don’t know, but I've not heard anyone talk about it. I never know the risk, when they told me I was scared.

An African Male Partner with sickle cell trait further highlights the lack of knowledge in some African communities:

UO: In Gambia in 1995 I used to play football. I had a problem with my hip. The doctor told me you've got a 'sickler' [sickle cell]. He didn't tell me sickle cell trait, no; he just said
you've got a 'sickler', so I didn't know what that means. He didn't go into detail. He only told me to be careful playing football or doing some tiring work because your blood is not the very strong, and things like that I could not understand it.

Despite opportunities to inform and educate individuals about their Hb status the opportunity was missed frequently and encounters with health professionals did not always convey the appropriate or accurate health promotion and genetic information, primarily due to lack of knowledge among the professionals themselves and or lack of ability to convey the information. It seems that attempts to deliver the message often result in misinformation. In the scenario described above the individual needed accurate information and some discussion of the genetic implications. Even family members’ attempts to convey genetic information can contribute to a misunderstanding of sickle cell. The same African Male Partner stated:

\textit{UO: I've seen someone with the sickle cell and he's still alive... He still lives in Africa. He gets sick from time to time but still lives a normal healthy life. He is my brother's son... I found out when I was already here in UK, when he was sick some time ago and his dad was actually telling me he has sickle cell. But that time I didn't even know what sickle cell is. He just told me he’s got sickle cell and it has something to do with blood, but all along I was thinking of the blood group. He [brother] didn't explain [what sickle cell is]. I asked him he couldn’t explain it for me to understand.}

When asked if his brother explained the implications of him having a child with sickle cell anaemia and its implications for his siblings and extended family he said:

\textit{UO: No, no back in Africa, we have most things in common in most African countries, our tribe in Gambia not many people will sit with their families and discuss most of these things. It's like you only go [mix] with your age group mates and so you don't normally sit with your senior brothers to ask some of these things openly.}

This demonstrates the lack of openness especially in respect of disease and illness and information not being shared even among family members. Both the African and Caribbean cultural groups expressed views about this but this was expressed more strongly among African respondents.
An African Antenatal woman stated:

AK: ... if there isn’t [any secrecy] then I would have known about SCD but I didn't know I'm getting to know everything here [UK]. So maybe there's a bit of secrecy. I don't know why it is that they don't tell us 'cause I think we have the right to know. I've grown up and I don't know anything about it. I should have known about it before now. When I had that test and was told I'm a sickle cell trait I was shocked. I didn't know. I believe we have the right to know whether we are or not. Maybe that influences our decision in the future because by the time you get to know you are a sickle cell trait, you don't have anything much to do if you are already pregnant then you have to proceed with whatever situation you are in.

African Male Partners stated:

WD: Sometimes the Ghanaian culture is secretive about sickness they think that if they have sickness and they tell me it will make me feel bad [sad].

UO: People won't talk about their health problems in Gambia. I don't normally explain things to my friends, it's my privacy. It's difficult to know who is your friend and will keep your secret. I prefer to talk to my family, especially my brothers. They [friends] could treat you differently once you tell them I have sickle cell or I have a child with the sickle cell. They may think it’s transmittable, they will not think it’s genetic.

One Caribbean Antenatal respondent in describing her African partner stated:

IR: Actually because he tends to be secretive, he doesn't tend to tell people much of his personal life. So I had to leave it at that. In a relationship we do compromise I will just leave it, when it comes to that level then I'll say it if it is needed to be said.

Other respondents who were exposed to the information did not relate it to themselves or recognize the importance of the information prior to conception.
A highly educated professional Caribbean Antenatal woman stated:

"HM: Everyone I know thinks, "Oh sickle cell, I know someone with sickle cell trait." But you don't really mention it in my circle of friends and family, it's not really mentioned. They all know that I've got trait but they don't think, "Oh, do I need to go and get tested and what does it mean?" I used to attend events like when the radio station did something in conjunction with the sickle cell society but you just attend you were not really involved... I didn't apply it to myself nor do most people out there... I just think I have more knowledge now than what I had before. I think I was a lot more ignorant before. I knew that my mum had the trait but I never thought it would be me who has the trait or have a child with sickle cell disease...when I found out that she [daughter] has it I read up a lot more about it and her having two crises has increased my knowledge.

A Caribbean Male partner demonstrated extensive and in-depth knowledge of sickle cell, including the protection that sickle cell trait offers against malaria:

"LC: I was warned at an early age by a doctor that I have the trait and that when I grew up that I was going to have to take it into consideration, so I knew it for a long time. So when my partner became pregnant and we went for the test it is something that just came to the fore but I have known for a very long time. I thought about it, even we both did, but you know at the end of the day, I thought, we both came to the decision that well there is not really much you can do about it, you just have to go with it.

A common misconception observed, particularly in the African community, is the notion that people with sickle cell disease die by a certain age. An African Male partner whose brother died at the age of forty as a result of complications of sickle cell disease stated:

"SG: Our belief in Africa is that if you are twenty-one years old that means you have passed the age of dying from sickle cell, he [his brother] shouldn't have died again, he was here in England [when he died].

This finding further highlights the findings of Phase 1 and 2 of the project. In Phase 1 double the number of Africans agreed with the above perception compared to the Caribbean respondents (Section 5.3.1.2). The reason for this perception is probably due to differences in the respondents’
experiences and area of acculturation. A greater proportion of the African respondents grew up in Africa where infant mortality is high even among those with no underlying illness; a large proportion of the vulnerable children with sickle cell disease would have died at a young age from a myriad of childhood ailments. Other vulnerable periods are teenage years due to hormonal changes, stresses associated with teenage living [experimenting with smoking, alcohol, sleep deprivation due to a highly active social life, poor self-care] and its associated psychosocial experiences, including such things as college and university examinations. Pregnancy and childbirth bring additional stresses and a period of vulnerability. Those from more affluent families may live longer by virtue of their families’ affluence, possible better education of the parents and their ability to access better health care. As the affected individual progresses toward adulthood their knowledge of how avoid complications and maintain good health improves. Individuals and families become more adept and capable of managing the illness hence the perception that once one reaches adulthood death is less likely. Interestingly, there remains a lack of understanding about the benign nature of sickle cell trait: 9 (12%) African Antenatal and 2 (5%) of the Caribbean Antenatal women believed that those with sickle cell trait are less healthy compared to those without a carrier state, this reflects Marteau et al’s (1992) observation and suggest a need for greater clarity in explaining the nature of carrier states.

8.3.2 Screening - Choices and response to trait result

8.3.2.1 Screening choices

Some of the antenatal women interviewed did not appear to make an informed decision about being tested for haemoglobinopathies. This reflects Marteau’s (2001) assertion that many pregnant women are not given an opportunity to make an informed choice for or against testing for a myriad of conditions during pregnancy. Marteau and Anionwu (1996) and Marteau and Dormandy (2005) also assert that, compared to White women, Black and other minority ethnic women were more likely to be tested without being given adequate information on which to base an informed choice about testing. This is reflected in this study even where they consented to testing some of the respondents had no knowledge of sickle cell until they received post-testing result and genetic counselling, thus confirming that they did not make an ‘informed’ choice pre testing, which goes against the principles of genetic testing as highlighted by the Advisory Committee on Genetic Testing (1997) and a series of reports by the Human Genetics Commission (2003, 2004, 2006).
A Caribbean Antenatal woman stated:

EU: It's only when we went to the antenatal clinic that they did the blood test, they do it for Afro-Caribbeans you know, I just thought it is part of the routine so I just accepted it, I didn't know what sickle cell was then.

The offer of universal antenatal screening in high prevalence areas was adopted in England in 2007. All pregnant women are offered testing for haemoglobinopathies irrespective of their ethnic group. The espoused theory and policy is that women can decline the offer. However clinical experience has demonstrated that a highly significant proportion of women are not even aware that they are being tested until they are called for counselling following a positive test result. Haemoglobinopathy testing is often done as part of the battery of routine tests done on pregnant women, alongside tests for iron deficiency and identification of infections which can endanger the life of the woman and her baby. Haemoglobinopathy testing is now perceived as part of this routine assessment and many fail to acknowledge the potential ramifications of this genetic test. Bartels et al. (1993) raised a pertinent concern that with increasing acceptance of genetic screening and scientific advances to prevent the birth of those with genetic disorders society will come to regard screening programmes as a wholly acceptable routine part of care. And the desire for the perfect child is likely to become a norm as argued by Green and Statham (1996).

**8.3.2.2 Response to sickle cell trait (carrier) result**

Discussing a study conducted by Bekker et al. (1994) examining anxiety levels in a population based screening programme for cystic fibrosis on a sample of 467 participants, Marteau and Anionwu (1996) reported that individuals who were already aware of the presence of cystic fibrosis in their family were less anxious about being found to be carriers than those who were not already aware of the gene in their family. The authors concluded that prior knowledge was an important factor influencing the former group’s response to a carrier test result. In the current study the respondents’ attitude to a positive test result varied. When told that they are at risk of having a child with sickle cell anaemia, the first response is often one of disbelief, anguish and anxiety. Women and couples are confronted with an anguishing dilemma as they attempt to understand the potential impact of the information not only to themselves but to their nuclear and extended kin. An
African Antenatal stated:

MB: I felt this can break my home but my husband understands that we are not in Africa. The woman [nurse] at the hospital told us that some women say “please don’t tell my husband that I am AS, because I know him very well, it will bring a lot of problems into my family”, but in my situation my husband said “OK, when you go to the hospital and they say this baby is SS you have to terminate it, we’ll try again, there is no problem with that”.

The African Male partners, a significant proportion of them were not aware of their carrier status prior to their partner’s pregnancy, were fairly consistent in their attitude to being confirmed as being a carrier. Some were reluctant to accept the result because a large proportion of lay people perceive that those who are physically strong and appear well are unlikely to have the sickle gene, including a carrier state. Stigma is also associated with illness or disease in many African and Caribbean societies and the reluctance to accept a positive result, albeit carrier state, may relate to this. This is a similar finding to that of Jegede (1998) in the description of stigma associated with having a genetic illness in the West African context. Some people believe that the carrier state is a milder form of sickle cell disease and give rise to physical symptoms or perceptible characteristics, particularly thinness and appearance of lassitude. Few are aware that the carrier state is asymptomatic: there are no physical signs and no clinical or negative health impact. Due to lack of knowledge some of the African Male partners were reluctant to attend for testing. One of the

African Antenatal women, a medical doctor from East Africa, stated:

AAN: I was asking him to do his test. I asked him which one is your own [Hb type]. He says, "Oh I don't know". He told me because he is very strong, when he was born he was 4kg, a big baby, so he is strong, he told me “me I don’t have a problem”. But I was not very confident with what he told me. In Africa they think if you are slim then you know you are OK. Now because I'm pregnant, I was sure he knew there was something wrong. He told me, "oh, you know, maybe, maybe..." I said, "No, we have to make sure", I told him "I think you know something so you don't want to tell me". We went to the hospital, we saw the doctor. The way it was explained even the doctor said "You [husband] may know something, but we have to do the test to make sure". One day after the test the doctor say he has sickle cell trait, ohhh I was so down.
Denial is perhaps a feature of the general negative attitude to sickle cell in Africa and a consequential reluctance to be associated with such a social taboo. Attending for testing affirms one’s psychological acceptance that it could be in one’s family, and emotional preparation is required for what could a pain-inducing result which may also be unacceptable. Failing to seek information and not attending for a genetic test are further illustrations of being detached from the reality of the information and an example of the avoidance measures that individual may adopt in order to reduce the dissonance that their awareness of the potential risk of carrying the faulty gene has created. Where an individual feel that they have been coerced into being tested for sickle cell they may fail to request their test result or attend an invitation for face-to-face genetic counselling.

In describing her partner’s response to his carrier result one African Antenatal woman stated:

\[MB: \text{He just said} \text{ “ohh no, no, no it can’t be, I just have to go there and see the result myself”. He rang and asked “can I have the result, are you sure this is my result, can we check it again, it doesn’t cost anything to do it again and send it down”. But she [the nurse] explained there is no mistake, even if we do it again there is no mistake, it is your blood. Then he said, “OK”.}\]

The last two respondent’s partner’s attitudes affirms the findings of Duster and Beeson (2007) that men appear to feel more shame about having a potentially ‘harmful’ gene and are less likely to share the information with others, including researchers and prospective partners. They also have difficulty accepting the role they play in their child’s genetic condition. This is a very common experience witnessed in the clinical field by the current researcher and often creates a great deal of tension among couples and their extended families. A Caribbean Antenatal married to an African man expressed feelings of worthlessness, a possible psychological response to having produced two children with sickle cell disease in the past:

\[AKO: \text{I was really feeling down, feeling I'm not good, I'm not worthy of having children, things like that. I think it really did start to have an effect on my mind and when the last child was born, of course after the test said Hb AS I was relieved. At least I know this one is also OK [PND has confirmed result of current pregnancy] so I can go through it. In this pregnancy, I really did go through a real trying time, with the decisions that I had to make, what the outcome would be if it turned out to be sickle cell [anaemia]. Thankfully it turned out be another trait.}\]
Cote (1982) suggested that the use of terminology contributes to peoples’ reaction to a genetic condition. Sickle cell is described as a ‘disease’, and society, particularly the African society of the respondent’s husband, tends to view it negatively. Thus the respondent’s reaction is predictable. The aspect of feelings of worthlessness would be of interest for further research, comparing different ethnic and cultural groups and their response to producing a child or children with one or other serious genetic illness. Contrary to Richards’ (1996) argument that many people focus on the probability of their child inheriting a disease the current study shows that a larger proportion of the respondents focused on the probability of the child not inheriting the disease, a Caribbean Antenatal woman stated:

\[ AA: \text{I was worried but I tend not to worry too much... I’m putting it out of my mind because it’s not 100\% certain that the child will develop it and there’s a chance that he actually will not so I’m just trying to think positive, focus on the fact he that he/ she may not have it.} \]

Other Caribbean Antenatal women stated:

\[ AOH: \text{I think it didn’t matter because sort of personally we knew the risk is there but it’s not 100\%. The way it works out it could be or couldn’t. I mean my whole family are all carriers but my parents, with seven children obviously you never know which one could get it, but none of them have it, I don’t think it mattered then.} \]

\[ OY: \text{I was fine really, I told my partner that our chances are smaller because we already had our daughter and she is fine, it is nothing really to worry about. Maybe I’m more flippant about it, but it’s not been a worry.} \]

And an African Antenatal woman stated:

\[ KS: \text{...I did not want prenatal diagnosis due to the high risk of miscarriage which is more than the 25\% risk of having a child with SCA. I feel that the 75\% chance of not having a child with SCA is better and positive for me to focus on.} \]
Another African Antenatal respondent stated:

ES: … When I found out I was AS, I was a bit down but we just told ourselves that we would carry on because he [husband] has got 4 or 5 siblings and only 1 has got sickle cell [disease] so we just say it's the last but one anyway, maybe we may not even have a child with sickle cell [disease] at all… I know that it's 25% chance… I'm just saying [out of five children] the first didn't get it, the second didn't get it and the third and fourth didn't get it and the fifth got it. So I'm just thinking that we may not have that number of children anyway, if we are lucky, but! OK my niece is the first child and she has got it so it doesn't really matter whether it's the first or the second is it, I think?

Despite knowing two very different scenarios that both affirm the randomness of this genetic condition, this respondent was still having difficulty grasping the concept of probability, continuing to focus on what she perceived as positive outcome for her parents-in-law and hoping that her experience would be similar. This is an illustration of dissonance. This respondent is averse to having a child with SCA. In an attempt to justify not opting for prenatal diagnosis (PND) and possible termination if an affected fetus by comparing and contrasting her situation with that of her parent in-law she is adding consonant elements that will help alleviate her dissonance and reestablish equilibrium. The fact that genetically her parent in-law’s situation has no bearing on her own reality did not prevent her from attempting to justify her not opting for PND. Richards (1996) highlighted the difficulty people have understanding probability: people who have had one affected child find it inconceivable that they could have another affected child and fail to recognize that ‘chance has no memory’. This was also observed by Emery and Hayflick (2001). It is possible that the respondent above is adopting a cognitive ‘self talk’ that will help her cope emotionally with her current predicament. A lack of understanding about probability was not a common finding of this study. The majority of those interviewed understood the probability, but most focused on the chance of not having a child with sickle cell anaemia. Many of these were influenced by religious beliefs or a need to find a mechanism for coping emotionally or reducing the dissonance that their reality is creating.
8.3.2.3 Selection of partner pre-marital and attitude to at-risk coupling

Zimmern et al. (2001) alluded to the need to take into account issues beyond the clinical and health-impact when establishing genetic screening services: importance need to be given to issues such as social impact on individuals and families. With the recent sequencing of the human genome people are going to rely on genetic information when making life choices, including decisions about parenting. Although health care providers perceive that society value genetic screening services it is incumbent upon them and policy-makers to ensure that the services do more good than harm and reasoned public opinion must be taken into consideration.

A number of researchers highlighted the difficulty that arises as a result of knowing one’s genotype and risk of having a child with a genetic condition. Richards (1996) acknowledges that ‘little is known of the extent to which genetic disorders affect the choice of marriage partners or decisions to marry or to have children’. A number of authors highlighted the difficulties inherent in prior identification and knowledge of genetic risk and the distress associated with this knowledge and having to make genetic choices (Press et al. 1998, Shiloh 1996). Zimmern et al. (2001) also refers to the fact that increasing scientific research has greatly increased social expectations of being able to have ‘genetically and biologically’ normal children and the onus for making genetic choices has been placed on poorly informed and ill-equipped members of society. This creates tensions and anxieties, some of these tensions emerged in this current study.

In a study of African-Americans at high-risk of sickle cell and White-Americans at high-risk of cystic fibrosis Duster and Beeson (2007) found that families who were ‘more religious and traditional’ advocated and were willing to accept premarital testing but were opposed to and rejected prenatal diagnosis, whilst the highly educated egalitarian and less religious couples were more accepting of prenatal diagnosis. However both groups may resist premarital testing because it interferes with their concept of romantic love. In the current study the majority of the respondents, including the highly educated practise a religion and this may account for the less than enthusiastic attitude to premarital testing, except among those who have first-hand experience of living with someone with sickle cell disease, most of whom advocated pre-marital testing.

Of those who had prior knowledge of their sickle status some consciously disregarded the information and failed to select their partner or opt for strategies that would reduce their chance of
having an affected child. Some African Antenatal women who were aware of their genotype before meeting their partners stated:

_KS:_ Some people say you have to check a person's blood before you get married but I don't think you can plan your emotions like that. Do you walk around with a big sign saying all AS over here or what? It's not possible.

_LS:_ Yeah, even if he had sickle cell trait I would go with the relationship, you can't stop the relationship just because of the genetics, at least he hasn't got a disease, no…no it would [did] not influence my having a child with him, no not at all.

An African Antenatal woman who already has a child with sickle cell anaemia was very reluctant to respond to the question of whether she would have knowingly married someone with sickle cell trait. She stated:

_OG:_ You know in Nigeria I didn't even know about the IVF and pregnancy test [PND] all these things. In UK it's OK but if I was in Nigeria I would know that I don't have any medical help so if there is that risk of having a child with sickle cell ... would I choose somebody else uhhm, uhhm? [Interviewee needed prompting] I would choose somebody else, maybe one with AA.

Some respondents were aware that their partner has sickle cell trait prior to getting married or having children. A Caribbean Antenatal nurse, who has extensive experience of caring for people with sickle cell disease, had been aware of her carrier status since being a teenager and her partner was tested during childhood. The couple understood the information but this did not influence their decision-making when selecting a partner or deciding to have children. She stated:

_AOH:_ When we met he did mention it to me [that he has sickle cell trait] but I felt it didn’t matter because personally we knew the risk is there but it’s not 100%, it could or couldn’t happen. My whole family are carriers even both my parents, but my parents have seven children obviously you never know which one could get it, but none of us have it [disease]. Therefore I don’t think it mattered. In fact I haven’t even thought about it, I only thought of it recently, but no it hasn’t even crossed my mind at all, it didn’t really matter, I can think
of other conditions that people have to put up with, I think one just has to handle it, that’s the way of life.

This reflects Sherr et al.’s (1996) findings among HIV positive women where the decision to conceive a pregnancy was unaffected by the presence of disease and Cote’s (1982) argument that genetic probabilities is a subjective concept and the mathematical figure is often irrelevant.

People’s response to genetic information depends on the individual’s perception of the seriousness of the illness. Evidently the respondent above, despite having in-depth knowledge of the condition, did not perceive that sickle cell anaemia is serious enough to warrant pre-selecting her partner and consequently testing the pregnancy before birth. Her feeling of being ‘at risk’ did not compel her to seek options for avoiding or reducing the risk by pre-selecting her partner or opting for pre-natal diagnosis. It is noted however that despite having working knowledge of the condition the individual did not have day-to-day living experience of caring for someone with the illness. Perhaps such experience may have had greater impact and changed her opinion of the illness.

A contrasting view came from another Caribbean Antenatal woman, married to an African partner. They have two children with sickle cell anaemia, she stated:

**AKO: If I had known before that I had AS, I definitely would not marry a man with AS, definitely...no matter how much I love the person, if I understood, maybe if I had seen a relative with it and known what's involved, I definitely would not have married some one with AS definitely, no way...In the Caribbean we need to inform people of sickle cell. It should even go back to school days, secondary school days where there should be an awareness of sickle cell being taught in school, so that people will be aware of all these things that could happen to their child...They should make it compulsory to have a blood test...If you decide to get married check because it’s painful, it’s painful to watch your children growing up in pain, it's painful. But at the end of the day, it's up to the man and the woman to decide whether I [they] really want to go through with this or not, if after knowing they decide to go ahead then it’s up to them.**
Another Caribbean Antenatal respondent, a highly educated professional woman who already has one child with sickle cell anaemia from a previous relationship and was at risk in a second current relationship stated:

HM: ...when I first found out I had sickle cell trait and my [first] partner had sickle cell trait, it didn't play any part in my decision [in the first pregnancy] but I think it does now because I've actually experienced having a child with sickle cell I actually know now... We always have this image that it's not going to be me, even when you know someone that has it you never think it's gonna be you until you get in that position... My first partner wanted another child but because I knew I was the one who is doing most of the work looking after my daughter I thought no... it definitely would have influenced my decision, it would have stopped the relationship. Well, it did stop the relationship, 'cause there was a lot of stress conflict of opinion. He wanted more children and I didn't because I kept thinking what if I have another child with sickle cell I'm going to be left with the burden. Like now, I'm doing all the work, we are not together now, he'll come and go but emotionally I'm the one whose there for her and I'm the one that's dealing with it.

The same respondent reported that her first partner was aware of his haemoglobin status but this did not feature in their decision when planning to get married and have children:

HM: He’s already got other children, with his first child too he knew he has sickle cell trait but the girl [daughter] didn't have sickle cell [disease] but he knew, he discovered that his [first] partner has sickle cell trait and there was a risk but at the time he mentioned it to me we had gone past that because we’d fallen in love already.

These findings demonstrate that despite an awareness of his haemoglobin status the respondent’s first partner did not use the information to make choices about relationships nor informed his partner at a stage when perhaps it may have been easier for them to make a decision about the continuation of the relationship. This is similar to Duster and Beeson’s (2007) findings. When asked her opinion about at-risk individuals having children together the same respondent stated:

HM: ...a lot of them [my friends] have trait so I tell them any partner you have make sure he gets tested, but they still don't. In my experience I think it would be a lot easier if the other partner didn’t have trait... at the beginning of the relationship it’s OK but once you
know things are getting on like when you’re considering getting pregnant and having children then I think it does play a big part. I wouldn't encourage two people with a trait [to have children] but if they are already together then I would. I think at the end of the day it's their decision whatever decision they want to make, but based on my experience I would say no.

Evidently the last two participants have extensive experience of living with sickle cell disease and this has influenced their attitude. The first respondent felt pre-marital awareness would influence her decision and her conviction is that had she known about the potential impact of sickle cell disease she would have made different marital choices. Interestingly, the second respondent knew the risk but subsequently embarked on a second relationship that placed her at risk again. Sadly this decision was not explored in depth during the interview. It would have been useful to explore her reasons for not pre-selecting her partner on this occasion. She did however have prenatal diagnosis but not with the intention of terminating an affected pregnancy but in order to prepare for a potentially sick child. The result confirmed the child did not have sickle cell anaemia.

Some African respondents were also aware of their Hb status from childhood but did not use the information to make genetic choices. This is a consistent observation by a number of other researchers and authors, including Evers and Kiebooms (1993), Shiloh (1996) and Duster and Beeson (2007).

An African Male Partner in the current study who was tested when he was very young failed to act on his prior knowledge of his haemoglobin status. He stated:

OS: Personally, I do know a little about sickle cell because my sister has got it but when I met my wife I never knew that she had sickle cell trait, we hadn't checked... When it came out I knew the chances, even before we went for counselling I knew the chances of us having a child with SCA... It wasn't a shock to me but I was disappointed because I knew what I was going into...I only found out when we had actually married. But I don't think if I knew before that it would have changed my decision anyway because we had been going out since primary school. She's my childhood sweetheart so we were not going to break up, breaking up wasn’t an option.
It was surprising that despite knowing about his own Hb type and having lived with a sibling who had sickle cell anaemia the respondent did not purposefully select his partner in order to avoid having a child with the same condition. As he stated, because they had courted from a very young age and the depth of their emotional involvement had deepened, it became difficult to terminate the relationship. These findings are also in keeping with Hoffmaster's (1990) assertion that foreknowledge does not always lead to what others may consider a rational decision. Emotions can be difficult to control and outcomes difficult to predict. Especially in view of the dissonance that such genetic dilemmas create in the lives of individuals.

The respondent added:

*OS:* ... *A lot of people don't know what they call sickle cell trait for starters so they get into a relationship, obviously it's difficult to break up with a relationship because you find out that your partner has got sickle cell trait or this and that, it's a difficult issue... if you knew before and you went dating with a woman or you're courting and you haven't really got into the relationship and you know that your partner has got a sickle cell gene and so have you it's difficult, you say, 'alright, do I really want to get into this or should I just back out now?', knowing before or knowing afterwards [getting married] is just as difficult. It would be difficult for me to break up the relationship just because my partner has got sickle cell trait perhaps if I knew before courting, I probably wouldn't get into the relationship... for the benefit of hindsight, if I knew that she had it, I probably wouldn't have gone ahead because I know what the risks are.*

In many African communities there is a strong belief that people with sickle cell trait should not have children together and the difficulty of contemplating terminating an established relationship was illustrated by the following African Antenatal respondent:

*MB:* ... *you know at home [in Nigeria] once you are AS and he is AS you can't be together... once you are in a relationship, for me it was for the past eight years and you are having a baby which I had been planning for four years [before conceiving her first child], after being together so long all of a sudden someone said you're at-risk of having a baby with sickle cell, ahhh nobody is going [wants] to have a baby with sickle cell. You know to be with them is very hard and she said you are having a sickle cell I said “Oh God, oh God”.*
Others expressed views on whether it was permissible for two people with a carrier state to be in a long-term relationship and to have children.

Other African Antenatal women stated:

**AK:** If I knew I would be at risk I would have changed my mind about the relationship before I got pregnant. Although if I happen to be in a relationship with someone who doesn’t have it and things don’t work out I think I would go for someone who has sickle cell trait...that is if I tried different relationships with people who are OK [do not have sickle cell] and the relationships turned out to be bad I think I would take the risk and go with someone who has sickle cell trait if that person makes me happy... but I wouldn’t choose someone with sickle cell trait if I can manage.

**MB:** This is Europe. Here they say its OK you are AS he is AS you can marry and stay together but once you are pregnant you must come for test [PND]. What if I say [to my partner] I don’t want you, I go with someone else, what about the other person [he may also have sickle cell trait]...even if we were back home I would still continue with him, we love each other at least we can still say this is my baby [referring to older child] and she’s OK, and this is the second one [current pregnancy], this one is OK as well.

The respondent’s attitude highlights the difficulty that would be encountered if attempting to purposefully select a partner based on her own haemoglobin status, especially since one in four west Africans have sickle cell trait (Serjeant and Serjeant 2001). The chance of meeting someone from her population who also carries the sickle cell gene is relatively high. Another African Antenatal respondent who reported that she is highly religious stated:

**AH:** My advice to people who are not yet married is that, [just] because things have gone well with me [does not mean] it will go well with another person because everybody has his or her own belief, so I would advise people, if you know that you're AS rather than keep on being worried, you have to choose a partner that is not AS don’t be like me, I know [trust] my God. There're some people who may not even know how to kneel down to pray. That sort of person when they are in that sort of situation it's like a big issue, so you have to choose your partner.
An African Male partner who had a sibling with sickle cell disease and knew he had sickle cell trait from a young age was asked how he felt his family would respond to him being at risk, he stated:

OS: Uhm they would be disappointed because even though I know the risk I still went for it anyway. I think my wife and I as parents we can cope with it but I'm sure that I'm going to get support from my family... my sister is still alive and she's got it and she's doing well so fingers crossed we can also do it.

Some of the antenatal respondents who were aware of their sickle cell trait status prior to conceiving did not get their partners tested before conception or during early pregnancy. The majority waited to be sent an appointment for counselling and partner testing. This is similar to Hill’s (1994a) findings among Black American at-risk women who already had a child with sickle cell anaemia and obfuscated their knowledge of sickle cell in a subsequent at risk pregnancy. The majority of the respondents in the current study had not had children before nor received prior genetic counselling. It is therefore possible that they did not act because they were unaware of their carrier status, options available to them and what actions they could take. A few women and partners who had received previous information had been misinformed and were either unaware of their carrier status or were unaware of its genetic implications. For example, one African Male partner stated:

SG: I was tested in Nigeria that was a long time ago, my family got to know something about sickle cell because I've got a brother and sister who have it. There was a lot of awareness that people should get tested for sickle cell at that time so I went for the test and I was told I was AS and I did it again, because I was hoping that I would be AA but it was still AS. He [the doctor] said to me the only thing I can [should] do is marry someone who is AA... I took her [his girlfriend who later became his wife] to the hospital myself to get tested and to be sure it is done, we went back for the result and the doctor said that she is AA...here [UK] we discovered she is AS, ahhhh...to challenge about the result in Nigeria ahhh not possible? They will even deny that they have any record that you came to their hospital. I am talking about eight years ago when we had the test.
Misinformation and misconceptions abound. An African Antenatal woman who was tested before meeting her partner stated:

*MB: I know that I'm a carrier but I didn’t know that my husband could be a carrier because he is a strong man, very strong. When we went to the hospital for counselling, they said to him "I'm sorry sir you're a carrier". He said, "No, I can't be, I cannot, I haven’t fallen sick at anytime". She [nurse] then said, “You know most men say they are fine, they are OK”.*

The same participant was asked whether she was invited for counselling and offered the option of partner testing during her first pregnancy, a pregnancy that subsequently resulted in the birth of a child that was later diagnosed with sickle cell anaemia (HbSS):

*MB: Yes, yes I just decided not to do anything [go for counselling] because my husband said that he is AA. He said, “I’m OK I don't want to go through any stress, I’m AA”. He kept saying I’m AA. He said “I'm OK, I haven’t fallen sick at any time, I am strong, so, it’s you that has it you fall sick all the time, you’re always tired maybe because of your sickle cell remember you have one S, but for me I’m OK”. He kept saying he is AA, later he was so surprised that he said, “ahhh me I’m AS?”*

A Caribbean Antenatal woman who was at risk during a previous relationship and pregnancy that culminated in the birth of a child with sickle cell trait received counselling following the birth of her daughter. She was asked whether she got her present partner tested prior to conceiving. She did not; he was tested when the pregnancy was already established. The pregnancy was tested and confirmed the fetus has sickle cell anaemia (HbSS). At the time of the interview she was undecided about keeping or terminating the pregnancy. When asked if she would have made different choices about the current pregnancy if she had been more vigilant about the information after the birth of her first child, she stated:

*IAT: I would have probably tried to get a bit more information. Until now I can't say that I was completely happy with the information I did get when my daughter was born ten years ago, I suppose because she was healthy there was no real need for them to give me any other information but then if I had gone on with her dad and there was the possibility of having a child with sickle cell anaemia I would have gotten the information, I would have liked to have known a little bit more about it. I suppose the only thing I would have done*
differently, what I thought I would do differently, is talk more and get as much information as possible but I don't think it would have stopped me having a child with my current partner just because he has sickle cell trait as well. You meet someone and you want to share that special thing and the one thing you can share between yourself is a baby, you know there's a one in four chance and you just hope for the best really...even if I knew that he had sickle cell trait I would have still tried to have a child with him.

It was interesting to note this respondent’s attitude to information given when her first daughter was born, although she was given information she was not happy with the depth of information given and felt it did not meet her needs however she did not pursue obtaining further information so as to gain clarity. This may be interpreted as denial or a response to the anxiety provoked by the knowledge and an attempt to ignore the importance of it.

Other respondents were also aware of the genetic condition in their family prior to getting married, or before conceiving did not act on the information. An African Antenatal respondent stated:

AH: I went to test my blood that was before I got married, to know what my group is [Hb type]. I found out that I'm AS. So I had the reassurance that I was only a carrier. I was sure that I was just a carrier so it didn’t bother me, it wasn’t when I was pregnant before I was told, I already knew before getting pregnant... I understood what it meant... no I didn't have any counselling ... I did not use it [knowledge of my Hb status] to choose my husband, when my husband proposed to me, we didn't initially talk about it, we had got really, really deep into the relationship before we found out (that he is also AS). I prayed over it ...because already we had gone far and there was nothing we could do.

On further exploration it became evident that this respondent had a full understanding of the genetic information but decided not to take it into consideration when selecting a partner nor mention it to her partner until after they were married. Another African Antenatal woman stated:

KS: I knew my sister had it [sickle cell trait] but then I hadn't had a need to go and have blood tests and things like that so I never knew. My mum knew when we were little but it wasn't information that was passed on to me ... I remember going and having a little prick on my thumb and putting it on the glass thing and I think from there she knew that my sister
and I were sickle cell trait but my other sister wasn't and that was it...our uncle is a doctor so I think it was just a regular check up.

The respondent went on state that it was highly unlikely that her mother would have been informed of the genetic implications of a carrier state since the aim of testing was to exclude sickle cell disease. As she was a child at the time, the relevance of the information twenty or more years later would probably not have been highlighted. This warrants the question ‘is there any value in giving parents carrier results for their newborn infants if the genetic relevance is not fully explained through face-to-face genetic counselling and or provision of a written result?’ I suggest that if face-to-face information is given and the genetic implications of a carrier state discussed in sufficient detail parents are more likely to remember and will convey the information to their child when the information becomes relevant. However, will traditionalist African parents convey such information if they perceive that disclosure may inadvertently reduce their child’s prospects of being accepted for marriage? The temptation to obfuscate such knowledge may over ride fears of having a grandchild with sickle cell anaemia. A teenage African Antenatal respondent stated:

*LS: I got tested when I was really young [11 years old], I got a letter from the specialist and went with my mother to get the result [counselling]. I didn’t understand it at the time but as I got a bit older I did but I never thought about it until I got pregnant I thought about it but I didn't know what I could do about it.*

The effect of receiving genetic counselling at an age when the information cannot be fully understood probably contributed to this respondent’s inability to act on the prior knowledge. A Caribbean Antenatal respondent, who at the time of the interview had already received the diagnosis from PND that the fetus has sickle cell anaemia, was contemplating what to do about the affected pregnancy:

*IAT: ... My daughter from a previous partner has sickle cell trait so I was quite relaxed. I suppose a little bit too much because she had just come out with the trait I was a little bit ignorant in the sense that I just assumed that you know the first one was fine and this was going to be fine as well. As well as not having a lot of information when she was born ten years ago, I just kind of assumed that, you know, this baby was going to be ok as well.*
This reflects Cote’s (1982) assertion that interpretation of genetic risk can be subjective and depends on an individual’s view of the condition and it is the, ‘feeling of being at risk that counts rather than the mathematical figure’.

When asked whether he considered selecting his partner based on his knowledge of his Hb status a Caribbean Male responded:

   LC: I just figured she’s a West Indian woman, the risk is going to be there. I didn’t think my sickle cell trait was relevant because we were attracted to each other. I knew what sickle cell is and I know that there is always going to be a risk so, you think about what the options are but being realistic I thought to myself well to hell with it really. West Indian people, African people we’ve been having children since the beginning of time so it’s just a risk and you move on.

The findings of this study suggest that a number of respondents, who attended for testing in other countries especially some African countries, were given false positive results; probably because they attended for testing in order to exclude sickle cell disease not presence of the sickle cell gene in any form. They were not told they have sickle cell trait and the possible future genetic implications. Rather than any obvious obfuscation this may have contributed to their inaction. Despite attempts to select a partner who does not have the sickle gene pre-marriage, misinformation and inaccurate blood test results placed some individuals at risk inadvertently. A man who has siblings with sickle cell anaemia one of whom has died, and knew he has sickle cell trait since his youth, made every effort to avoid marrying a woman with sickle cell trait. Prior to getting married he took his wife to be for testing and was told she has normal HbAA but during her first pregnancy in the UK she was found to have sickle cell trait. The African Male Partner stated:

   SG: All the while I had it in mind that if I am going to marry, I am not going to get married to somebody who has sickle cell trait because I know the situation. I went out with other people and when they are AS we break up that’s what I did...at the initial stage [when he found out his wife has sickle cell trait] it was a shock and a big disappointment ... I think I have done everything possible to avoid it but, that's why it took me that long to get married, I thought I would take my time and get married to the right person [someone with Hb AA]. At the end of the day the same thing we are running away from [tried to avoid] we came across we just have to take it as our fate there is nothing we can do about it.
When asked what advice they would give to their offspring or someone who has sickle cell trait, two African Antenatal women stated:

\[
MB: \text{Ahh well I don't want them [my children] to make the mistake that I made. I have to tell them you are AS, if you were AA you can have [marry] anybody you are OK, but you are AS you cannot have an AS partner, I'll tell them my story and explain that it’s only because your daddy really understand because we love each other if not we may have parted and maybe we would even not have had you. Just choose AA, don’t go through the stress that I went through, it’s not good that SS, just choose somebody who is AA, I’ll keep everything on record so they know I am not lying... I will tell them (when they are) about fifteen years or going to eighteen, I just have to tell them.}
\]

\[
AH: \text{My advice to people who are not yet married is that, I wouldn’t say that because things have gone well with me it will go well with another person because everybody has his or her own belief. I would only advise people, if you know that you're AS rather than keep on being worried, you have to choose a partner that is not AS … When they are in that sort of situation it's like a big issue so you have to choose your partner.}
\]

Another African Antenatal respondent raised the issue of the difficulties that can arise when a relationship is already established:

\[
VU: \text{If I knew before getting married it would not stop me marrying my partner. Everybody should be tested before getting married, it's good to know so that if two people are AS before they get married I think they should go and look for someone with AA, not going through this pain. But if they love each other [nervous laugh] I think they should go on.}
\]

Quite a number of respondents alluded to the notion that love is an important issue and that if they love someone that takes precedence over their and the prospective partner’s haemoglobin genotype. They feel that they would still marry the person believing that love can conquer the challenges ahead even if they were to have a child with sickle cell disease. This is similar to the finding of Duster and Beeson (2007) and demonstrates the complexity of the human experience, behaviour and decision-making. Religion and fatalism played a significant part in some of the respondents’ attitude in respect of selecting a partner or having children.
One African Antenatal woman stated:

\[ AH: \ldots \text{When my husband proposed to me, we didn't initially talk about it as we had got really, really deep into the relationship before we found out [about the sickle cell]. So actually when we found out I prayed over it because I know that it's God that gives children so I handed everything to God for him to take control because there is nothing I can do. Already we had gone far and there was nothing we could do.} \]

The attitude of some of the African Male partners reflected the women’s, when asked if knowing their haemoglobin type pre-marriage would result in their making different choices when selecting a partner they responded:

\[ UO: \text{Yes, at that time it can influence my decision because if I had been told well in advance before I got married, if somebody had told me exactly how this thing works it would have an impact, maybe if I meet somebody who I wanted to marry, of course I will think I've got sickle cell trait, I will not like to have somebody who has sickle cell trait. I might have the compulsion to do a test [to see if she has it] and I can also take her for counselling to make her understand exactly what is happening. I think I would have done that, I would choose someone who does not have sickle cell because of the children.} \]

\[ AL: \text{I knew from secondary school that I should get tested before going into marriage. I didn't do that so when I got to know that we were both AS, I felt very, very bad, very, very bad. I learnt about it in science I was very much aware of the whole thing, but I didn’t test before getting into marriage if I had it would have made a difference seriously, definitely. I would have gone for somebody who is AA rather than AS, definitely I would choose somebody who doesn’t have sickle cell so that we just prevent giving birth to an SS baby, just prevent it.} \]

The second respondent reflects Duster and Beeson’s (2007) finding people do not always act on their test result or prior knowledge.
Raising the issue of pre-marital testing with a partner can be difficult, as outlined by the following African Male Partner:

OS: I'd encourage them [people] to find out how best you can deal with the situation because like I said, it's very painful I mean to break up a relationship just because uhm of the risk of sickle cell, for me its very painful [nervous laugh] because the risk is there. I think people [scientists] should discover how we can best solve the problem of sickle cell. It's very difficult especially where I come from [Ghana] to educate people not to marry people with sickle cell trait. It'll be very difficult, I mean, people don't go checking if their partners has got HIV before they get married, let alone sickle cell. You don't start dating someone then ask questions like are you AS, no that's not the attraction is it? And people having AS is not going to put you off marriage, it might put you off having kids but you can still marry if you decided not to have kids.

Is there a realistic option about not having children in Ghana? The same individual stated earlier ‘in our culture it’s insane not to get married or have kids’. This suggests that the option of getting married but choosing not to have children is highly unlikely in his culture. The difficulty of selecting a partner is highlighted by some respondents. Many asked the pertinent question, “at what point in the relationship does one approach the subject and reveal one’s own Hb status?”

If one approaches the subject early in the relationship it may be considered presumptuous yet later in the relationship it is likely deep emotional attachments would have been forged which as respondents indicated makes it emotionally painful to terminate the relationship. As suggested by Emery and Hayflick (2001) a fatalistic approach to the genetic risk may be adopted in order to help the individual cope emotionally with what they perceive is beyond their control, since one’s genes is beyond one’s control. This fatalistic attitude appears to reflect Abelson’s (1959) description of individuals’ attempts to reduce dissonance; where there is conflict between belief and action in an attempt to alleviate the dissonance that this creates individuals may add an argument or (consonant) element that will help justify their action. Not being able to control one’s genes may be considered viable justification for taking no action. The fact that there are alternative options for avoiding having a child with a genetic condition, for example PND, will not be explored as this will create greater dissonance rather than alleviate it. In a study of Asian, Chinese and Caribbean people Dickinson and Bhatt (1994) noted that fatalism was a commonly adopted response to disease and illness among the Caribbean female respondents and illness sometimes has a divine purpose. It is
possible that respondents in the current study who have a religious affiliation also perceive that there is a divine purpose to their having a child with sickle cell disease and their risk should not be perceived as wholly negative.

### 8.3.2.4 Selection of partner before conception

A Caribbean Antenatal woman recently arrived from the Caribbean with very limited knowledge of sickle cell stated:

*IA: Even if I had known we have AS, AS I would still have a child with him, we'd still have a child... He's got another girl who is pregnant for him as well but even then if I knew about the sickle cell I would still have a child with him.*

This demonstrates an opposing view to Atkin et al. (1998) who stated that where people are given sufficient information they will make what the majority of society would consider a rational decision. However Hoffmaster (1990) and Shiloh (1996) argued that fore-knowledge does not always lead to rational decision-making. Perhaps this respondent’s action reflects Hill’s (1994a) assertion that some women obfuscate medical knowledge or ignore information in order to defer making a decision because of their inherent need to have some control over their fertility because the ability to have children, healthy or not, enables especially low-income women to have some power in this area of their life. The desire and ability to produce a child is more compelling than the risk of having an unhealthy child. It is also possible that in view of the strong cultural attitude to procreation perhaps many African women may also ignore the information in order to maintain some control. Even if they have a child with sickle cell anaemia, at least they have a child.

Some women had difficulty persuading their partners to be tested because of lack of knowledge, and a few refused testing due to needle phobia. One African Antenatal respondent stated:

*AAN: He refused to go for test [pre conception]. Now because I'm pregnant I was sure he knew there was something wrong. He told me, 'oh, you know, maybe, maybe', I said, 'No, we have to make sure'. I told him, 'I think you know something but you don't want to tell me'. We went to the hospital, we saw the doctor. The way it was explained even the doctor said 'You may know something, but we have to do the test to make sure'. One day after the test the doctor say he has sickle cell trait, ohh I was so down.*
Other respondents who received counselling in the UK still did not fully appreciate the potential health and social implications of caring for a child with sickle cell disease.

One Caribbean Antenatal married to an African man stated:

_AKO_: ... The first two children were actually born in the West Indies and the rest for my present husband, from the third child down. I found out with the third pregnancy that my husband and I were AS and even then we didn't really understand what that meant. Because the pregnancy was far gone I just decided to put it behind me. Thankfully after I had the child they tested her and she turned out to be a trait AS. I didn't have any more talks with any medical staff or any sickle cell counsellor or anything after that one... When I got pregnant [again] I didn't get offered the chance of counselling or even a chance to test [the pregnancy] for sickle cell. After I gave birth, they tested her and said she has sickle cell anaemia. Even at that time, to be honest, we didn't fully understand what it meant to have a sickle cell child... although we had counselling, we didn't fully understand what having a sickle cell child meant. If you have a couple where they're married and they're both sickle cell trait, I think there's a lot of thought that needs to go into it and they would have to think about how do we cope with a sickle cell child.

Despite knowing that she was at risk of having a child with sickle cell anaemia during a third pregnancy and having had genetic counselling the respondent was not proactive in seeking genetic advice in order to make an informed choice about a subsequent at-risk pregnancy but stated that she was not offered counselling or prenatal diagnosis at that point. This finding is similar to Hill’s (1994a) report of North American Black women at risk of having a second child with sickle cell disease, who despite being told to attend as early as possible in a subsequent pregnancy so as to avail them selves of the opportunity to discuss the genetic options and possible interventions, mostly did not do so and obfuscated knowledge of the advice given in the previous pregnancy. A possible alternative explanation is the individuals’ response to dissonance, by failing to acknowledge the magnitude of the problem helps to relieve the dissonance which has been evoked by having some awareness.

Richards (1996) noted that women and couples ‘may avoid contact with genetic counsellors because they do not wish to hear the expected advice’. This may be in order to protect themselves psychologically and avoid the emotional pain and conflict associated with having to confront the
issue, make a decision about accepting or declining prenatal diagnosis and the ultimate decision about what to do with an affected pregnancy. Eagly and Chaiken (1993) argued that this is also a common response to dissonance, avoiding persons and dissonance inducing situations, and not seeking further information about an issue helps to relieve the negative effect of the information and consequently the dissonance that it creates. As the respondent stated, she had little understanding of the condition prior to the birth of her first affected child. During the course of the interview it transpired that after having had two children with sickle cell anaemia and acquisition of greater knowledge and first-hand experience she became resolute and did not wish to have another child with sickle cell anaemia and hence contacted genetic services early in subsequent pregnancies and opted for prenatal diagnosis. A number of authors suggest that the birth of a previous child with a genetic condition affected a parent’s future choice in terms of attitude to the condition, prenatal diagnosis and termination of an affected pregnancy. Another Caribbean Antenatal woman in response to being at risk and stated:

*IAT: Because my daughter from a previous partner has sickle cell trait I was quite relaxed, I suppose a little bit too much because she had just come out with the trait, I was a little bit ignorant as well, in the sense I just assumed that you know the first one was fine and this was going to be fine as well, I just assumed this baby was going to be OK as well.*

The respondent had prenatal diagnosis and the fetus was found to be affected prior to the project interview and she was attempting to deal with the dilemma of whether to continue or terminate the pregnancy. As highlighted by Shiloh (1996), the freedom to make genetic choices has brought increased anxiety, guilt and psychological burden and this respondent was having great difficulty making a decision about the affected pregnancy. It appeared that a number of respondents failed to act on their prior knowledge of their sickle cell trait status. Some of the respondents stated that they did not receive counselling or relevant information about their carrier status therefore they were unable to make an informed decision. As outlined by Marteau (1995), an informed decision is dependent on the individual having the correct information and understanding it in order to make choices that do not conflict with their personal values. However, this is in opposition to Kashima’s (1992) argument that it is possible to make choices that conflict with personal preferences depending on whether one’s values are based on experiences in an ‘interdependent’ or ‘independent’ cultural society, with the former having little or not adverse emotional effect if and when conflicting choices are made. In this current study of the 78 women who knew their Hb type pre-conception 19% said they chose their partner pre-marriage or pre-conception (Phase 2
questionnaires). Of those who knew their Hb type some had misconceptions about the effect of the carrier state.

One Caribbean Antenatal respondent stated:

EU: I did not have a clue what it meant but I knew before [pregnancy] I just thought I feel healthy, I've always been health. As far as I was concerned I've got a trait I can't feel anything physically so I should be alright and I just left it at that until now.

Some of the respondents perceive that sickle cell disease is not serious enough to warrant making specific choices preconception. As highlighted by Dryden in Green and Statham (1996) the degree of burden of a condition influences perception of the disease and choices made. One Caribbean Antenatal woman stated:

OY: Yeah, even knowing that risk, that's who you love. Even if I knew before having our first child [she has sickle cell trait] I would still want to have children with him... we could have said because of the sickle cell we don't want to have no more because but that's not a good reason that's not fair, to me it's something you can live with.

An African Antenatal woman stated:

AK: If I went with someone with sickle cell trait to choose not to have children? No, no I don't think so [nervous laugh], part of me will always feel maybe I would have a child who does not have sickle cell, I think I would have that in mind knowing that, I would just give it a go, after all there is a chance that child might not be sick, but if I had known that there is this risk, I would watch out for the people I would be going out with and choose somebody who does not have it.

Although there are many misconceptions and a lack of understanding about the likelihood of their having sickle cell trait and the chance of their offspring inheriting the gene, some respondents appear to make a conscious decision about the relevance of the information available to them and the choices made in respect of personal relationships. Some respondents were aware of the genetic information, either in their own or their partner’s family, but decided to continue with the
relationship without attempting to clarify whether it would place them at risk of having a child with sickle cell disease, whilst other respondents actively chose to ignore the information irrespective of the possible outcome. An African Antenatal respondent who knew that her partner has sickle cell trait prior to their marriage when asked why she continued the relationship or did not get herself tested prior to getting married stated:

ES: Because the relationship had gone on for quite a long time, I didn't know that I was AS [Hb AS]. I’ve always known that I didn't have any sickle cell [disease] but I knew that he was AS [Hb AS] because he has a sister who has got sickle cell [disease]. Throughout our relationship we said to ourselves that even if I get tested and I've got AS we would still continue anyway. When I found out that I was AS, I was a bit down but we just told ourselves that we would carry on because he has got four or five siblings and only one has got sickle cell [disease] so we just say it's the last but one anyway, maybe we may not even have a child with sickle cell [disease] at all. I know that it's 25% chance... I'm just saying [out of five children] the first didn't get it, the second didn't get it and the third and fourth didn't get it and the fifth got it. So I'm just thinking that we may not have that number of children anyway, if we are lucky, but! OK my niece is the first child and she has got it so it doesn't matter whether it's the first or the second is it, I think?

The respondent appeared to be rationalizing the decision to continue an at-risk relationship. Since her partner and three of his siblings do not have sickle cell disease and the affected sibling was conceived late in the order of children she appeared to be seeking coping mechanisms that would protect her emotionally from the decision to continue the at-risk relationship and the possible at risk pregnancy. This reflects an attempt to justify the decision made about an at risk pregnancy, which is not to opt for PND, and since this did not reflect her desire not to have a child with SCD she is experiencing dissonance and has to find a way to relieve this emotional state. Secondly, the respondent has a niece who has sickle cell disease. This suggests she may have been aware of sickle cell in her own family before embarking on the relationship with her partner. However, on further exploration she stated that she did not relate this information to herself or consider the genetic implications to her wider family. This reflects Duster and Beeson’s (2007) observation where many of the respondents in their study found the notion of pre-marital testing and partner selection incompatible with their social values in respect of courting and ‘falling in love’. However, for the majority of people interviewed their attitude was that following the selection of a partner testing becomes relevant in order to make reproductive plans.
It is unclear whether the respondent understood probability but contrary to Richard’s (1996) assertion that people focus on the often lower probability of having the disease as opposed to the higher probability of not having the disease this respondent focused on the probability of not having an affected child. This was not an uncommon finding in this study where a number of respondents in an effort to cope with the emotional conflict adopted a process of cognitive ‘self talk’ persuading themselves that all will be well since the probability of not having a child with sickle cell disease is greater (75%) then the probability of having a sick child (25%). This suggests that a person’s response to risk is likely to be dependent on personality traits and perhaps the need to cope psychologically outweighs the mathematical aspects of the genetic information.

A number of women experienced difficulty persuading their partners to attend for genetic testing and the most common reason verbalized by the African Antenatal women is the populations’ misconception that those with sickle cell trait are symptomatic and or have physical characteristics to demonstrate that they have it. An African Antenatal woman stated:

*AAN: I was asking him to do his test. I asked him which one is your own [Hb type]. He says, "Oh I don't know". He told me because he is very strong, when he was born he was 4kg, a big baby, so he is strong, he told me “me I don’t have a problem”. But I was not very confident with what he told me. In Africa they think if you are slim then you know you are OK. Now because I'm pregnant, I was sure he knew there was something wrong. He told me, "oh, you know, maybe, maybe...” I said, "No, we have to make sure", I told him "I think you know something so you don't want to tell me". We went to the hospital, we saw the doctor. The way it was explained even the doctor said "You [husband] may know something, but we have to do the test to make sure". One day after the test the doctor say he has sickle cell trait, ohhh I was so down.*

Some women stated that their partners did not reveal the information until they were pregnant a Caribbean Antenatal with an African partner stated:

*AA: I wasn’t sure I had it and he knew but he didn’t tell me, well we didn’t think about it and we didn’t talk about it at all until I got my results [during pregnancy] and then he said he had it.*
When asked if they had been aware of their risk status prior to having children whether they would still have wanted children with a partner who is HbAS, one African Antenatal respondent who had already had prenatal diagnosis which confirmed that the fetus is like the first child HbAS, stated:

MB: This is Europe. Here they say it’s OK you are AS he is AS you can marry and stay together but once you are pregnant you must come for the test [PND]. What if I say [to my partner] I don’t want you I go with someone else, what about the other person [he may also have sickle cell trait]...even if we were back home I would still continue with him, we love each other at least we can still say this is my baby [older child] and she’s OK and this is the second one [current pregnancy] this one is OK as well.
8.4. Factors influencing decisions about an at risk pregnancy

8.4.1 Experience of genetic counselling

The aim of genetic counselling is to offer individuals and their families an opportunity to gain knowledge and understanding of the genetic condition usually already manifested in a family member and for them to be able to consider options available to them in terms of marriage, procreation and parenting, enabling them to select the best possible outcome for their own circumstance (Hoffmaster 1990).

All the women and partners in this phase of the project have been identified with sickle cell trait and the majority have received their first and initial genetic counselling from a specialist nurse or midwife at a specialist sickle cell and thalassaemia centre. This is the point at which the woman or couple would have decided whether to opt for prenatal diagnosis or not and those who do would have further genetic counselling and information usually from an obstetrician, haematologist or specialist at the fetal medicine unit. A number of authors suggest that the quality and satisfaction with the counselling received, whether it was directive or non-directive, and the professional discipline of the person providing the counselling, influences individuals’ perception of the illness or genetic condition and has a direct impact on subsequent decisions made (Robinson et al. in 1989, Marteau et al. 1994 and Green and Statham 1996).

Of those who attended for genetic counselling the majority of the respondents had a positive experience and felt supported and informed, an African Antenatal woman stated:

*EU: I was quite happy about that [specialist counselling] because that's what I needed to know when I first spoke to [specialist nurse]... she just explained it as much as she could on a basic level I suppose just about what it was about and you know in terms of any risks it may cause or if people are having children and what you can look out for and things you might expect, so it was good, I was pleased, I needed more information anyway that is what she is there for, so I was very happy with counselling.*
A Caribbean Antenatal respondent whose pregnancy has been diagnosed with sickle cell anaemia and is undecided about continuing or terminating the pregnancy:

*IAT:* The genetic counselling helped me understand what sickle is all about. I must admit I got a lot of more information at that counselling session than I did after having my first daughter [who was diagnosed with sickle cell trait], and it was very helpful to get just that little bit more ‘cause I think any parents in this situation will need some sort of reassurance to at least know what to expect from something like this, and it did help ‘cause you know I got a lot of more information. I actually knew something that I thought before was actually wrong they were sort of put right so that made me feel a lot better just getting more information, helped me to sort of deal with it or come to terms with, you know what it was I had and what my daughter had as well and what to sort of expect for the future so.

Other genetic counsellors gave hope. An African Male Partner stated:

*UO:* Yeah, it [genetic counselling] was good. It was really assuring because you know exactly the kind of problem you have and there is still a chance since it’s not 100% sure that your child is gonna have sickle cell, it's like fifty-fifty. It could either have sickle cell trait, or sickle cell disease, or it could be a normal healthy person. Still, you just cross your fingers that you have a child who is a normal healthy person or at least (worst) sickle cell trait.

A Caribbean Male Partner stated:

*LC:* I think it [specialist counselling] was useful in bringing it to the forefront of my mind I suppose to that extent it was useful and the fact that there are alternatives. But I have to be honest none of it appealed to me so, the nurse didn’t pressure us, she just laid it out on the table. I don’t think she was out to make us make any decision either way...she presented the possibilities and left us to decide.

An African Antenatal respondent stated:

*OG:* She [specialist nurse] just gave us advice that everything is all right that the children with sickle cell are being taken good care of that I should not worry about anything, that all will be OK.
Richards (1996) claimed that encouragements about future treatment or cures influences peoples decision about having children even where there is health or genetic risk. The respondent above had the experience of counselling during a previous pregnancy and said she felt reassured by the counsellor who like herself was also of African origin. However, it is unclear whether this reassurance occurred before or after the respondent had decided against prenatal diagnosis (PND). If it is before it is possible that this reassurance played a part in inadvertently influencing her decision not to have PND and the pregnancy resulted in the birth of a child with sickle cell anaemia.

An African Male partner also felt hopeful at the prospect that science could help in future if his child in a current pregnancy is born with sickle cell anaemia.

*UO:* Well, my wife asked if we happen to have a sickle cell child since I know about the capability of [science] in this country not like back home, how is our baby going to be looked after? Our [genetic] counsellor told us that there is a possibility because we are all sickle cell trait, it's possible maybe if your first child happen to come as AA, if you then have a child with sickle cell [disease] they can take the first child’s blood to treat the [sick] child, this blood is gonna be taken from the bone [bone marrow transplant]. She said there is a chance you can have that treatment and that can work sometimes… they can even extract from another healthy person [unrelated donor] to give your own kid … that’s another strategy they can use it it’s good yeah.

The interviewer discussed the low success rate of bone marrow transplant with the respondent and this did not influence his feelings of hope for a cure for an affected child in future. Other elements of hope for the future related to future processes for conceiving, an Antenatal African stated:

*OG:* Yes I would have preferred PIGD [Pre-implantation Genetic Diagnosis] instead of going through the prenatal test and everything else. Because in this case [current pregnancy] if the baby has got sickle cell I have to terminate it I don't think it is right because I don't like abortion but I don't have a choice now you know because I don't want to have another child with sickle cell. I would have preferred what you call pre-implant.
A few respondents felt pressured, being coerced or poorly supported with their choices. Genetic counselling aims to support and inform but the content must be appropriate for the age and cognitive ability of the recipient.

A nineteen-year-old African Antenatal woman stated:

*LS: I got tested when I was really young. I got a letter from the specialist and went in to get the result. I didn’t understand it at the time but as I got older I did but I never thought about it until I got pregnant. I thought about it but I didn't know what I could do about it. The counselling I had [at age 11 years] I think that's what did it, it made me scared… I thought they said I couldn’t have children or because I was so young I didn’t understand it, then my mum had to calm me down. That’s why when I became pregnant I didn’t go for the counselling because I was worried if it would be the same as what had happened before if I went for the counselling I think I would have been a lot worse…so I just blocked it out.*

The effect of receiving genetic counselling at an age when the information cannot be fully understood contributed to the respondent’s decision to block out the information and not act on it later at a time when the information became relevant. It is also possible that this respondent did not fully appreciate the significance of the carrier state and as a child the decision to be tested was probably made for her with the intention of excluding sickle cell disease, not the carrier state. Was it useful to attempt to convey such complex information to a cognitively immature individual?

Other respondents felt overtly pressured by the counsellor to pursue certain options or decisions, for example, an African Antenatal respondent who was counselled by an African counsellor was very hesitant to relay her experience and had to be reassured of anonymity before stating:

*AK: Part of me felt like she [specialist nurse] wanted me to [very hesitant to speak]... she wanted me to ... I don't know how I can say it ummm, like to go with someone else in terms of if I move with [select] someone with sickle cell I can have a child with sickle cell she was encouraging me not to go about with someone with sickle cell trait...hmm, yes, that’s what I feel. Even my health visitor was encouraging me she told me if my son [older child] has got sickle cell trait then I should try as much as I can to encourage him not to have a relationship with someone with sickle cell trait, she is from Ghana also.*
This reflects the strength of culture. The counsellor and the health visitor in this scenario are of African origin and although they would have been trained to provide non-directive counselling and would be aware of the services available to support individuals and their families with sickle cell disease in the UK the common belief, by many African communities, that people with sickle cell trait should not have children together persists. This affirms Sowell’s (1994) assertion that education or crossing continents does not change deep held attitudes and beliefs, irrespective of professional training. An African Male Partner who was also counselled by an African counsellor added:

*AL: The nurse specialist had to drive to this place [their home] she counselled us. At the end of the day she made the decision to [for] us because she didn't have anything good to say about it at all.*

The counsellor in this case has had a major effect on the respondent’s attitude to sickle cell disease as perceived by the respondent and it is possible that an unbiased view of sickle cell was given to the client although it is possible that fear of having a child with a serious genetic condition made the client focus only on the negative aspects and failed to listen or cognitively register information given about positive or other aspects of the disease. This reflects Marteau et al. (1994) and Green and Statham’s (1996) observation that a directive manner and the content and way genetic information is given influences client’s decisions. This was also observed by Shiloh (1996), who suggested that where emphasis is placed on the likelihood of the child not having the disease the pregnancy is more likely to be accepted. Conversely, if emphasis is placed on the likelihood of the pregnancy being affected the pregnancy is likely to be rejected.

Another African Antenatal respondent stated:

*KS: I felt I was almost being pushed towards going to have that test [PND] on the child before the child was born, that's the only thing I didn't like about it (counselling). My husband particularly hated it. Somebody called from the Society [centre] not the one who gave us face-to-face counselling, someone else and was like ‘well why don't you want to have this test?’ and I said ‘well it doesn't make a difference anyway’. But they said, ‘it's a very simple test’ and I was like, ‘I've made up my mind I don't want it’. ‘But why have you decided to make that decision?’ And I'm thinking, well I don't see what the pressure is, I don't want to have the test because, even if it's a half percent chance of a miscarriage, I...*
don't want it because nothing would change my decision anyway, I will have the baby whether it's got SCA or not. I just felt, it was more the woman from the Centre who was pressuring me - yeah, I felt pressurized by her and then she said, 'It's OK'. I spoke to the other counsellor again, and told her that I wasn't happy about how, whoever it was who rang. I just thought I really don't need this.

This supports Beeson and Duksom’s (2001) report that a number of feminist groups were highly critical of a negative cultural attitude towards people with disabilities, directive genetic counselling and a positive attitude to increasing technology which is having a major impact influencing women towards having prenatal PND and subsequent termination of an affected fetus. The respondent above perceived that attempts were being made by the specialist nurse counsellor to coerce her into having PND. Perhaps if she had been less well educated and more inarticulate she would have been persuaded to have this test being recommended by the ‘expert’, even though such a choice conflicts with her values. This would affirm Marteau’s (1995) and Marteau et al (2001) asserting that a significant proportion of women make choices that conflict with their personal values thus denying them their ethical and moral rights and the freedom to choose. Shiloh (1996) questions the validity of being non-directive and a counsellor’s attempt to be neutral in the client-counsellor relationship; and perhaps joint decision-making is a preferred option and an option often requested by some counsellees. It is possible that in an attempt to support the client the counsellor has misjudged the requirements. It is unknown whether the counsellor in this case was also African, Caribbean or any other cultural group and whether this influenced the counsellor’s attitude to sickle cell and the counselling approach adopted.

Robinson et al. (1989) suggested that the health care professional who provides the genetic counselling influences prospective parents’ decision in respect of prenatal diagnosis (PND). A higher proportion of those counselled by GPs were more likely to opt for PND compared to those counselled by genetic nurse counsellors. However, I suggest that the cultural lens through which the health care professional views sickle cell may also influence the portrayal of the condition and the outcomes available to the client. Counselling is of value only if the recipient perceives or can be educated to recognize that there is a problem that needs solving. If his or her perception is that the condition is not serious then attending for counselling may be a futile exercise since the full impact expected from the giving of the information may not be achieved and the client may make decisions not based on a full appreciation of the situation but on possibly a pre-constructed perception of the situation.
A Caribbean Antenatal respondent stated:

_AKO_: ...although we had the counselling, we didn't fully understand what having a sickle cell child meant...I still didn't really take it seriously even though we had the counselling. We had people supporting us and things like that...but still it didn't really like sink in as such...They told us about two weeks after she was born that she had sickle cell, even then I don't think it really sunk in until she was about three months old, when she started having pains, infections, and things like that.

It is possible that in an attempt to cope with the magnitude of the problem or to protect her emotions the respondent may have unknowingly blocked out the information or her ability to understand the information. As highlighted by Richards (1996) this is not an uncommon phenomena. Some people will avoid health care professionals in an attempt to avoid hearing the information and advice given or dealing with the problem, such as making a decision about an at-risk pregnancy. In my experience some clients will attend for counselling but be inadvertent passive ‘resisters’ of the information by disengaging their brain from the information being given. There are also clients who genuinely fail to appreciate the magnitude and significance of the information.

8.4.2 Personal experience of living with sickle cell disease

A number of respondents had personal experience of living with sickle cell disease and it appears that this had a greater impact on their attitude to their risk status and decisions about an at-risk pregnancy more than most of the other factors identified. The women who had a child with sickle cell disease already expressed greater anxiety at the prospect of having another child with sickle cell disease. A Caribbean Antenatal respondent who already has two children with sickle cell disease and was persuaded, against her Christian religion, to opt for PND in a current pregnancy and despite her reluctance to have PND in two previous pregnancies, was asked which aspect of having another child with the condition worries her:

_AKO_: The pain. They can have pain in any part of the body and the fact that in one of the crises, you could literally lose the child that is the scary part, knowing that because of the crisis a child could die, it's worrying and it's painful for the parents. For myself I spend
more time with my children, especially when they're in the hospital and it's a real worry not knowing what to expect. When my older child was about ten months old and teething, I don't really know whether we were told what to watch out for. I think that we were told how to check for the spleen and things like that, but I didn't really take it that seriously, but when she was teething I remember waking her up, she woke up and went back to sleep, then I woke her up for lunch again she didn't get up to eat. I said OK let her sleep then I kept on waking her up at certain times, she would get up but it was like she was so sleepy. At about six o'clock, I said that's enough sleeping she has to get up and eat. And when I went to wake her up she didn't respond and she was all floppy and I'm like, ‘What is this, what's going on here?’ And then we decided let me check for the spleen and when I felt it, I said, ‘Oh my God.’ Panic set in and I said ‘What do I do now, what do I do now?’ I quickly phoned my husband and said come back home quickly I don’t know what to do here when he got back we had to call the ambulance and took her to the hospital. I think we eventually got to the hospital about seven or eight. And they told us if we had got there one hour later, she would have died because the spleen was that big. That has affected my mind in the sense that any little thing or any little scratches like I really oh I’m very, very sharp now.

A Caribbean Antenatal woman with a half brother who has sickle cell anaemia but did not live with her was undecided about prenatal diagnosis and felt discussing the matter with others would be useful. She stated:

OY: Apart from people who have children I would talk to my brother since he has it... to know how he feels, even when he is in hospital we’ve never really ever sat down and say ‘like ‘what does it feel like when your blood is clotting’ and all that. I would just want to find out how, when, and how everything happens, when it happens, what are his symptoms, how do you feel when it’s coming on everything, I would want to know from someone who has experienced it.

An African Antenatal respondent stated:

IP: No, no, I do not want that child [with sickle cell disease] ... I watched it in my family. My brother, there was two, one died a long time ago, the second at twenty eight, he too young, his body very small, he very anaemia, he was very sickly as a child. Ohh pain here,
The experience and pressure of having had a child with sickle cell disease had a bigger impact on future decisions about an at-risk pregnancy even among those who considered themselves as highly religious. A Caribbean Antenatal woman with two children with sickle cell anaemia expressed the deep emotions that one feels when at-risk of having a child with a serious genetic condition like sickle cell anaemia, and the conflicts and dilemmas that one experiences when one has a religious faith:

_AKO: I couldn't cope with another child with SCA because I'm bringing up my children without family from my side here, I don't have anybody around me, I felt this is too much the load is just too much to bear. If I did have another sickle cell baby, I would get rid of it, I knew what the consequences were, even though it went against my religion, my own faith, I didn't think I would cope with another child with sickle cell. I really feel pressured within myself. In the last three pregnancies I was beginning to feel like a failure. I was really feeling down, feeling I'm not good, I'm not worthy of having children, things like that. I think it really did start to have an effect on my mind and when the last child was born, of course after the test said AS I was relieved. In this pregnancy, I really did go through a real trying time, with the decisions that I had to make, what the outcome would be if it turned out to have sickle cell anaemia. Thankfully it turned out be another trait son... it's painful to see your own children go through pain and you can't really do much about it._

### 8.4.3 Partners and significant others

Marteau (1995) asserts that the views of significant others has a greater influence on decisions about prenatal diagnosis and termination of an affected pregnancy. And the seriousness of the condition is a major predictor with regard to decisions about termination of an affected pregnancy.
In this study a number of women in making a decision about prenatal diagnosis and the decision to terminate or continue an affected pregnancy were strongly influenced by their partners. One African Antenatal woman was very strongly influenced by her partner had accepted a termination of a previously affected pregnancy even though this was not her personal choice but the decision of her partner. Other African Antenatal women illustrated the influence that significant others can have on their decision-making:

AK: My partner can influence my decision about the baby, like get rid of it, but then that would be very hard for me. I think it will take a very long time for me to decide to get rid of it. If I can look after my child I think I’ll go through with it [keep the affected pregnancy], but if there's a risk of me not being able to look after my child without the support of my partner, then I wouldn't carry on, I would take the pregnancy out, but if I can care for my child well... I wouldn't mind if he does not want to stay...him leave, OK.

MB: I told my husband this baby will be OK but he said if anything comes [if the baby has SS] and you have not allowed us to have the test done that’s when we will fight because now you see they say the baby has got SS.

An Antenatal African respondent who appeared to be demonstrating feelings of being traumatized by the experience of terminating an affected previous pregnancy:

VU: It was a very hard decision to make, because being pregnant for about five months you see that child as human. So we quarreled a lot. We had a tough time of deciding what to do. Being our first child I didn't want to terminate it, having gone through five months, I don’t know how it will be, but he ... [reflective pause, then long silence] my husband told me it's not proper to keep this child, so I went [for a termination] [became tearful]. For him the child will suffer in years to come, with problems he would need medication and all that. The child would not be able to make it to adulthood, maybe even get married or something, it would have a tough time. I did not want to abort it no, no, no...I would have kept it because I’m a Pentecostal Christian, my Bible didn’t tell me it’s OK to have abortion, my religion is against abortion, it wasn’t my decision to have the abortion. This one [current pregnancy] has been tested and is OK...if it had been SS we would see the counsellor [specialist nurse]. We will have to get ready for the baby but we will not have any more.
This highlights the difficulty where partners have opposing views about what to do about an affected pregnancy. Clearly this respondent felt unable to act against her partner’s decision about the pregnancy and perhaps the possible repercussions if she had. When asked what would have influenced her decision about prenatal diagnosis a Caribbean Antenatal respondent with a current affected pregnancy stated:

*IAT:* My partner and probably my family as well [could influence her decision]. The more people don't know the more scary it can be and the more negative you [they will] think. When I had my daughter [last pregnancy] I wasn't offered as much information I was a little bit ignorant and sort of I didn't go and get any more information and once they found out she just had the trait, she was healthy nothing else was done. I wish I had the information then and know what I know now. People close to you and who love you don't want to upset you and you don't want to hurt them; they may say OK this is the right thing to do [terminate an affected pregnancy] because it's not fair on the baby [to keep the pregnancy] and stuff like that. If I had done it [PND] earlier than twelve weeks I would have considered definitely having a termination. Because I had sort of stood firm and said that I am not doing it at this late stage and I can't everybody will have to deal with it whether they like it or not.

An African Antenatal respondent stated:

*MB:* He said if this one is SS, you can't deal with SS, you cannot, it's difficult to deal with them and at the end they can die off any time then it’s going to pain you that if I had known from the start I could have abort this baby...he [husband] said don’t worry everything will be OK just let’s go there [for PND] if they say the baby is SS, don’t think because you are four months pregnant, morning sickness and all that, just forget about it we terminate it and try again...he [husband] said even if this one is SS if you decide not to terminate it well it’s our baby God gave us we will have it, we will have it, we will face our problem, so I said “OK fine”.

An African Male Partner stated:

*OS:* I think it’s fair to say if I have an AS kid now [current pregnancy] and I decide to have kids again, I probably will say to my partner right do you want to test it now [the second
pregnancy] before the birth which is allowing you to have the opportunity to decide whether you want to keep it or take it out and if uhm the test results prove that its SS you might want to terminate it, that's my point of view I probably wouldn't, you know, uhm because its not on religious grounds but you don't want to have two SS [the decision] is not based on religion no... [decision is based on] caring for SS yes.

Shiloh (1996), Beeson and Golbus-Mitchell (1985), Sorenson et al. (1986) and Marteau (1995) all suggested that there are gender differences in attitude to having an affected child and men were less accepting than women. But Durosinmi et al. (1995) observed an opposing view among a Nigerian cohort.

Other authors have suggested that the health and social care professional providing counselling can influence decision-making depending on the content and the way the information is provided, directive or non-directive, in discussing decision-making (Robinson et al. 1989, Marteau et al. 1994, Green and Statham 1996, Michie and Marteau 1996, Burton 2002).
8.5 Prenatal diagnosis

In a survey conducted by the Human Genetics Commission (HGC 2006) it was highlighted that there are differences in the opinion of clinicians who provide prenatal diagnostic services and the recipients of such services. Some providers are of the view that such an invasive procedure with its associated risk of miscarriage should only be done if the woman or couple will consider termination as the outcome for an affected fetus. The HGC noted:

…even among those pregnant women who would not consider a termination of pregnancy for any reason, many choose to proceed with prenatal diagnosis…the prior knowledge of their child’s condition can be helpful for practical as well as emotional reasons…early warning allows parents to prepare emotionally, physically and psychologically for their child as they learn about the implications of the disorder…Some respondents to the consultation felt that invasive diagnostic procedures such as amniocentesis should be carried out only where the woman would consider a termination of pregnancy in the case of a positive diagnosis…because these procedures involve a small but significant (1%) risk of miscarriage.

(HGC 2006: 31 and 33)

This study and others demonstrate that a large proportion of women and partners are not of this view and are willing to undergo testing for other reasons some of these are outlined below. Accepting or declining the offer of PND and termination of an affected fetus demands the making of a moral decision and in view of all the respondents professing to practise a religious faith this created an enormous dilemma for them as they attempted to find a solution or resolution that fits with their cultural values, their religious ideals and the pervading society’s values and expectations. As described by Lipman-Hand and Fraser (1979) a decision that allows one to cope with the nature of the problem is the solution parents often seek and some of the respondents in this current study demonstrate that. Dryden in Green and Statham (1996) noted that degree of burden caused by the disease influenced parents’ decision-making.
8.5.1 Factors influencing rejection of prenatal diagnosis

The most significant and popular reason for declining offer of PND therefore is risk of miscarriage. This reflects the most popular reason for wanting to opt for PND, which is to prepare for a potentially sick child. Confronted with the risk of miscarriage associated with the procedure some of the respondents feel unable to justify such a risk in order to obtain fore knowledge.

8.5.1.1 Risk of miscarriage

As observed by a number of authors and researchers the potential risk of miscarriage is one of the reasons given for women and couples declining offer of PND (HGC 2006). Two Caribbean Antenatal women stated:

IR: Yes, I decided not to test the pregnancy because even though it was little, one in a hundred chance of having a miscarriage, I did not want that, I don't want it. I will just continue. Religion was not the problem at that time 'cause it would be good to know but when they said about miscarriage I decided I don't want to, because I went there [to the fetal medicine unit] but when I went they explained about the miscarriage I said no I'm not doing it.

AA: If I have it [PND] there is a risk so I said forget it miscarriage! You don’t know what can happen because the fact that you can’t see – there is no way that the womb should be troubled or bothered at all until the child is ready to come out. The fact that they are going to be messing around I don’t think… I wouldn’t do that it could affect the baby growing as well [development].

A Caribbean Male Partner stated:

LC: …There are alternatives [to having an affected baby] but none of it appealed to me. They mentioned some sort of test where you test the fluid, but then you run the risk of miscarriage and I suppose the ultimate alternative would be to terminate. Neither of those appealed, to be honest.
African Antenatal women stated:

AK: I was ready to go back [for PND] but when she told me I could have a miscarriage that was when I decided not to have it, otherwise I would have gone for it. If I have another pregnancy I would have it tested if there is no [risk of] miscarriage.

AAR: She [specialist nurse] explain to me what can be done like different tests, different stages and whether I would like to do any of them. But like after asking her some questions and they said it has a risk of miscarriage as well, I said no. I ask them if they found the child having it if there is anything they can do like treatment before the child is born they said no, and they said there is the risk of miscarriage so I just looked at it that I want my pregnancy to continue and I want the baby even if they do the test there is nothing that they can do so there is no point testing which might put me in a risk of having a miscarriage and loosing the baby altogether

ES: I understand the condition and I know what they go through but the thing is, even if I get tested and I know there is a tiny risk of miscarriage, I would not have it because don't want to lose the child, at the end of the day if I tested and they tell me my child has got sickle cell I will still have my baby so what's the point of having it?

An African Male Partner stated:

OS: I would be worried about having a child with it [sickle cell anaemia] because I know that it's the most serious of the sickle cells and it would be difficult to look after the child. It will need a lot of attention and without attention, your child might not even live that long. It's frightening to think you've given birth to a child who's going to die in a couple of years anyway, that's the bit that scares me. To have the pregnancy tested? Yes and No. Yes, because if we were 100% assured that the test was going to be carried out safely without the possibility of a miscarriage or anything like that I probably would have. But if there's no guarantee and even if it's a 1% change of miscarriage ahh, if it was not for the miscarriage risk I probably would have gone ahead with it [PND] but the fact that there was this 1% risk, that did not appeal to me.
8.5.1.2 Religion

Religion appeared to be a major factor influencing the response of both the African and Caribbean respondents towards both PND and the consideration of termination of an affected fetus. The majority of the respondents report that they practise a religion and mainly Christian, 90% of the women and their partners practice a religion. In view of this it was not surprising that religion played a significant part in influencing decisions about an at-risk pregnancy. A Caribbean Antenatal respondent stated:

*IR*: I strongly believe that religion played a part, spiritual, because a lot people want children and can't have them so even if I bear a child and the test show that the child has sickle cell [anaemia] it does not give me any right, who am I? I can't do it [terminate], I know that I can give to the child by the grace of God who supplied me with this situation... We know about miracles we hear that people get cured miraculously.

An African Antenatal woman stated:

*AH*: When I had the first baby, I didn't go for it, I had already talked to God about it that all the children he has to give me I don't want to have any with sickler, I have established that faith in him. I had the first one I didn't go for the test and it happened that the child is AA, so I still have that strong faith that the one coming should not be a sickler. The God that made it possible for me to be pregnant is going to take care of me. I talk to God what I want, if I'm going to have a sickler let it not come, there are ways you can present your prayer to God, if I'm going to have a sickler then I don't want to have it let God block it, it's me that request it and He has to do it. They had arranged for me to go for the test [PND] and I had to call them that I'm a Christian I can't go for that test... I said because I trust God so I'm not going to have it, then they said they will test the baby when the baby comes [after birth] so I said fine, at least I'll have the baby, it will be there so whatever God says I will have I will have it I trust God that he will not disappoint me... It's God that gives children...you worry, but as a Christian you have faith in God he is the one that put the child there you have no right to question [it]. So for me to be crying every day “the baby I have will it be a sickle cell”, is foolish of me because I know that God made it possible for the pregnancy to be there. That is one area of life where what you don’t know you don’t know, when you begin to question the unknown you are bound to get into trouble so for me...
to question what is in my tummy whether it has sickle cell or not is just creating more problems for myself. One thing is just to have faith because without going to find out [PND] I wouldn’t known whether it’s a sickler or not, so it’s for me to just leave everything for God, I believe that he’s the one that has the right to decide.

The same respondent stated:

AH: No, it's really not in my place me to be scared about the future, I still trust God I know, even if I'm due to have another one [baby] before I go into it I will ask God, but if I'm going to have a sickler then so be it I won’t do anything about it [have PND or termination] I will still have it no matter what.

A Caribbean Antenatal woman who was expecting twins stated:

AW: … at the end of the day they [twins] are mine, I have one child already with sickle cell and they [current pregnancy] may come out AS not necessarily SS, so it is by the will of God if he is going to give me another sick two children well... I can’t do it [abort], I don’t wish it on myself I would like them to be healthy and even AS would be nice but if I wasn’t meant to have them I would not be carrying them. I believe in God strongly and I know that he is there for me all the time... No I don’t think [religion] has anything to do with my decision.

An African Male Partner stated:

UO: I don't think there's any point for us to have the pregnancy tested because even if we had the pregnancy tested, we're not going to have abortion...My decision would be we carry on with the pregnancy until birth. We will then see what happen. The decision [against PND and termination if fetus is affected] is mainly from the Islamic point of view. As a human being you're supposed to accept what you are given especially pregnancy, it's a gift from God, you can say this or that is going to happen to the baby but when it is born it could be a different story, even if the pregnancy is tested and its positive you’ve just got to have the baby...My religion would not allow it, it is bitterly forbidden.

When the respondent was asked whether his religious attitude was due to the Islamic (Fatwa) ruling about terminations he said he did not know what the ruling is but knew that it is against his religion
to extinguish a living soul. A similar attitude was observed by Alkuraya and Kilani (2001) in their study of thirty-two Saudi families at risk of having children with a major haemoglobinopathy; the respondents expressed a similar perception of the Fatwa ruling. The authors, however, were able to identify that the respondents had inaccurate knowledge and information about the Islamic law in relation to termination of a diseased fetus. When reeducated that it was permissible to terminate before ‘ensoulment’, which was deemed to occur at twelve weeks pregnancy, almost 50% of those who were originally opposed said they would consider termination of an affected fetus. The remainder felt that God ‘Allah’ gives children and what ever the outcome they have to accept it.

8.5.1.3 Social and moral aspects

Some of the respondents were opposed to PND on the basis of the potential expected outcome for an affected pregnancy. Similar to Duster and Beeson’s (2007) findings that few parents would consider PND purely for the anticipated intention of terminating an affected pregnancy. The majority of respondents in the current study were also opposed to PND that has the aim of selective abortion of an affected fetus. Although many would consider PND this is purely in order to prepare for an affected child, when they were confronted with the potential miscarriage risk associated with the procedure most of them declined the offer of testing, they did not wish to endanger the fetus.

A Caribbean Antenatal woman stated:

IR: I think that whatever comes just comes. I know people who are born with a lot of stuff [disabilities] and they are still living. Who am I to take my child's life at that stage? I don't know what he can become… I've watched numerous things on telly people born with so much disability and they still survive, so who am I to take my child's life, when I don't know what the future might hold, what the child will become right. The child even with sickle cell could be a blessing to my family, to some stranger, to someone, so I couldn't really

An African Antenatal woman stated:

KS: We are from different places in Ghana, yeah. So, his beliefs are total ‘we just don't do that where I come from’ that's exactly what he would say. And I don't believe in it either it's
not necessarily because of cultural upbringing or any thing it's just the morals of what I've grown up with.

A Caribbean Male Partner who is vehemently opposed to termination states:

LC: ... I suppose an ultimate alternative [for having PND] would be, OK you find out that the baby has full-blown sickle cell then you start having counselling, but whether you know beforehand or whether you find out after you’re still going to have to deal with the situation, so I didn’t really see the point in having the test before the baby is born.

A number of African Male Partners stated:

WD: First of all it means that I commit murder so I am not going to do it simple, I am Catholic so because of my religion if I do that [terminate an affected fetus], I commit murder so that one I cannot do it. I told my partner if they test it whether it has or don’t have it, it’s still a baby leave it, I am not going to you know… [terminate it].

OH: About the miscarriage I don’t care how much percentage no; I really can’t do it [PND] we’ll wait until after the baby is born. If there was a test with no risk I don’t know maybe we would do it so we would be prepared that’s just it so we would be prepared [for the baby with sickle cell]. No, no, no that [termination] is out of the question, totally out of the question, I wouldn’t like that, even if you talk to me again that would be the last thing I would say that’s my child, that’s my child, no I wouldn’t take my child’s life. There are lots of people out there living with it why not my child? I don’t think any parent in their right mind would terminate their child, whether they knew the child has sickle cell or not I don’t think so, I could not see a logical reason just because the child has sickle cell unless they don’t know that much about it then I can understand them choosing that [option] but otherwise no.

An African Antenatal respondent stated:

AAR: I can’t just abort a child because he or she might be carrying the disease. There is also a chance for the person to survive in life. I believe it is not a disease like HIV where I would say the child has no chance in life at all or whatever. Sickle cell people have lived
With the exception of those who already have a child with the condition, a resistance to PND on social and moral grounds was expressed by some Caribbean and African respondents, suggesting that having limited personal experience and not having to deal with caring for a child with the condition already influences attitude to prenatal diagnosis and termination. The idea that one accepts what-ever ‘fate’ allots was expressed strongly and the whole notion of questioning this appears to be in conflict with some of the respondent’s values and beliefs. Some researchers found that having a close family member already living with sickle cell disease influenced respondents’ view on PND and possible abortion of an affected pregnancy because testing and aborting calls into question the value of their affected sibling or child’s life (Duster and Beeson 2007). They wished for their family member’s life to be seen as a life worth valuing despite having a serious genetic condition. In the same study those who felt able to select PND because of an already existing child and the wish not to have another affected child described the level of emotional conflict they experienced.

In the current study a number of respondents opted for PND, the majority with the intention to terminate an affected pregnancy because they had experienced living with a sibling or an affected child or children with the condition. Some respondents expressed a strong disinclination to have another affected child because of their vivid experience of the suffering undergone by their existing child. In some instances they were pro-PND because of the perceived level of burden that having such a child or another child with the condition would place on their family.

**8.5.1.4 Advanced age of pregnancy**

A few respondents felt unable to consider PND or possible termination of an affected pregnancy because of the advanced stage of the pregnancy. Weatherall (1991) and Hill (1994b) suggest that the more advanced a pregnancy the less likely women would opt for PND or termination of pregnancy. I suggest this would be even more difficult if the woman has started experiencing fetal movements and if family and friends are already aware that the individual is pregnant. In such circumstances perhaps the feelings of guilt, shame and emotional trauma would be exacerbated.
A Caribbean Antenatal respondent stated:

\[
\text{HM: What I found difficult is 'cause I didn't go for the counselling or the testing in my first pregnancy, the second time it happened I didn't know that I could actually refer myself do a self referral to the hospital to get the baby tested, so I waited a month for him [partner] to get tested, by that time I was 16 weeks pregnant. I regret not getting my first pregnancy tested then I would have known what to do [when the baby arrived].}
\]

8.5.1.5 Other reasons influencing rejection of prenatal diagnosis

A few other reasons were given for declining the offer of PND and these seem just as valid to the respondents. Two African Antenatal women stated:

\[
\text{LS: Even if I know [that the baby is SS] I wouldn’t have an abortion anyway. I remember when I did find out I said I wish I knew earlier but maybe I could have done the amniocentesis but then again it would not have made a difference even if I did have it I would not have a termination because I’m scared I won’t be able to have more kids ... there’s the risk of having an abortion I was told it damages your body, your womb!}
\]

\[
\text{RA: If I give birth and I find out that my baby has got the disease. Are you going to treat my child? Okay, fine, that's why I said I wish that my child is healthy and if my child is not healthy, you [health services] will treat my child for me. That's why I wouldn't terminate my pregnancy. And I hope that in the future my child will be helped.}
\]

Green and Statham (1996) argued that following PND if an individual or couple choose not to terminate an affected pregnancy there are no other options available to them except ‘inaction’ and the human psyche does not comfortably support a state of inaction. It is possible to suggest therefore that perhaps some of the respondents felt PND is not a viable option since inaction would not be seen as a viable option. Since respondents feel that termination is an unacceptable option, having PND without taking the next step of terminating an affected pregnancy will be emotionally difficult for them to manage. This again reflects elements of dissonance. In order to avoid the tensions which will arise if following PND the fetus is found to be affected the individual who chooses not to terminate the pregnancy may, in order to avoid dissonance, choose inaction.
(avoidance) as a viable strategy for dealing with the risk of having a child with SCD.

I argue that a lack of personal experience of living and personally caring for someone with sickle cell disease, especially a seriously affected individual, is a major factor influencing decisions about PND and possible termination of an affected pregnancy. This is in keeping with Petrou at al’s. (1992) observation that 94% of women who attended the fetal diagnostic unit and had an affected child already opted for PND with a view to considering termination of an affected fetus, whilst first-time mothers were less likely to take this option.

8.5.2 Acceptance of prenatal diagnosis (PND)

The reasons for accepting PND varied but the majority of respondents did not consider termination a possible outcome. A very small proportion accepted or felt they would consider PND with a view to termination.

8.5.2.1 Opposition to termination of an affected pregnancy – preparing for a potentially sick child

In keeping with the findings of other authors (Weatherall 1991, Petrou et al. 1992, Modell et al. 1997, Greengross et al. 1999, HGC 2006) a significant proportion of the pregnant women who accepted PND or felt that if they had the opportunity they would accept it in a future pregnancy were making the decision for the purpose of preparing for a sick child as opposed to opting for termination of an affected pregnancy. Anionwu et al. (1988), Modell et al. (1997) suggest that 25% of Black women at risk of having a child with sickle cell disease opt for PND. It is unclear whether this figure remains the same today. A Caribbean Antenatal woman with one affected child who had PND and the fetus was found to be unaffected stated:

HM: I don’t believe in it [termination]. When I was at Catholic school I know that the Catholic faith is definitely against termination. At the end of the day it’s a gift from God and who are we to terminate that gift. If it had been SS I think I would have still gone through with it [continuing the pregnancy] partly because religion played a part, but also partly because I think I would have had a nervous breakdown if I had terminated the
pregnancy. I would have felt a lot of guilt. I had the test just to prepare myself to be there for the child if the child has a crisis, because no two children are the same.

A Caribbean Antenatal respondent who had been too advanced in pregnancy to take advantage of PND stated:

IR: I would have it [PND] to know what type of preparation to make how to make sure everywhere is creased [gotten ready] properly make sure the heating work properly because of health you know those things does affect, yeah that was the main reason.

Another Caribbean Antenatal woman stated:

OY: The only point to it [PND] is so that one can be a bit more prepared. I don’t think sickle cell is enough to have a termination, I couldn’t see myself having a termination just because the baby has sickle cell that’s not enough no. Maybe hearing my child is brain damaged or something like that I may go for the test to find out and all that but I still wouldn’t get rid of it anyway, it’s so that I can get books and find out how to look after him. Unless they could they can say [having the test] will help you to prepare otherwise there is no pint you might as well wait until when they come out.

African Antenatal women stated:

AK: I would have it tested because I would be anxious. I would really like to know whether my child would be having sickle cells or not... I wouldn’t have terminated I would have got myself ready for [the sick child] whatever the result. Find out how people with sickle cell kids cope, what they did to their kids and what they think I should do so that I will get myself ready for that, terminate the pregnancy no I would feel guilty that would haunt me all the time. I would keep the baby since there is a possibility that they can live, grow up and succeed in whatever they want to do, I think I will proceed with the pregnancy and be there for my child.

AAN: I had test to find out if baby would be SS or AS or AA I didn’t think about abortion. I wanted to know so when I give birth to know how the baby will be, I wanted to prepare before birth...it was not to terminate the pregnancy.
These findings reflect the Green and Statham’s (1996) observation, supported by the HGC (2006), that a significant proportion of women opt for PND in order to prepare for the birth of a sick child not to avail themselves of termination of an affected fetus.

A Caribbean Antenatal respondent stated:

*IAT: Initially I decided not to have it [PND] but then I changed my mind mainly because I needed to know and I needed to have more information, and if it was going to be the case that, you know, the child was going to have sickle cell I needed to prepare myself mentally and emotionally for what the next stage was going to be, you know, between me, my partner, the baby, my family, everything that was going to be involved in this. So in a way I did want to know. I wanted to know this time because the option was there, whereas before I can't remember having the option [of PND], having been asked if I wanted to have my daughter [last pregnancy ten years ago] tested.*

A Caribbean Antenatal woman with an affected pregnancy contemplating whether to have PND or not stated, expressed deep feelings of indecision, an inability to decided what to do and was in a dilemma for several days:

*IAT: I think if it [PND] was done earlier within twelve weeks and having all sorts of pressure from other people telling me what they thought and what they felt I should do I would have probably considered having a termination without sort of getting enough information about it, I would have been more influenced by what people had to say than going and finding out [for myself]. Because it was done so late I definitely know that I don't want to put myself through that [termination] because now that I know that the child can be quite well you just don't know what to expect. I am willing to take that chance now as opposed to what I think would have been a lot easier before to just get rid of it, it would have been easier.*

This respondent’s cogitative state reflects Lipman-Hand and Frazer’s (1979) observation that in such situations individuals or couples seek a least-loss option and where there is no least-loss option it is not possible psychologically to make a decision and parents sway between options. This tends to be an anguishing state.
An African Male Partner stated:

*OS:* I would have the test if there was no risk of miscarriage to get prepared for the baby even if we had done it [PND] and it was SS I don't think I would have gone for termination. It for getting prepared for it [child] really and hoping that nothing unfortunate happens I wouldn’t terminate it, no. When we went for [genetic counselling] we had an idea of what we were going to get into before we got there, the nurse told us about the disadvantages and options that are available if we wanted to check beforehand and told her come what may, were going to lean on the 75% [chance of child not having a disease] rather than the 25% [chance of child having disease], so we basically took a chance she did give us in detail the pros and cons of having the sickness.

As highlighted by Foster and Parker (1997) and supported by Oppenheim (2003), attitudes do not follow a logical pattern necessarily whilst individuals may have a strong opinion about something, such as being anti-abortion, due to strong cultural, social, moral or religious grounds they may also feel compelled to take that course of action when faced with the personal dilemma. Thus life experiences can change one’s attitude to a given situation.

### 8.5.2.2 Support of termination of an affected pregnancy

A number of respondents had strong views about terminating a pregnancy that tests positive for sickle cell anaemia. Although some women and couples were unsure what they would do if they were in such a predicament they did express their opinion about why they would consider termination of an affected pregnancy. The reasons for accepting termination of pregnancy varied but the majority focused on their personal knowledge, experience or perception of the burden of caring for a child with sickle cell anaemia and the impact the disease would have on the individual themselves. A number of respondents who were in support of termination of an affected fetus considered a number of factors, the most significant is their perception of the social and health burden of sickle cell disease. An African Antenatal woman stated:

*MB:* It's difficult to deal with them and at the end they can die off any time then it’s going to pain you that if I had known from the start I could have abort this baby…he [husband] said.
don’t worry everything will be OK just let’s go there [for PND] if they say the baby is SS, don’t think because you are four months pregnant, morning sickness and all that, just forget about it we terminate it and try again...he [husband] said even if this one is SS if you decide not to terminate it well it’s our baby God gave us we will have it, we will have it, we will face our problem, so I said “OK fine”.

Another African Antenatal woman who recently came to the UK and lived with siblings, one of whom died as a result of sickle-related complications a few years ago, stated:

IP: Yeah, every time my brother he needs to have the medicine, it’s expensive ahh [deep sigh of anguish] in Africa you pay for hospital, if you don’t have money they don’t touch you, you must pay for every thing, they threaten you if you don’t have money they will not give you anything they just say ‘go home’. I am frightened of having a child with sickle cell if one day I want to go to Africa, the hospital no medicine, cost more, yeah lots of money

Another African Antenatal respondent who already has a child with sickle cell anaemia stated:

OG: ... if the baby has got sickle cell I have to terminate it. I don't think it is right because I don't like abortion, but I don't have a choice you know, because I don't want to have another child with sickle cell, although she [first child] is healthy I don't want to take that risk of having another one. I know I've got the medical help, everything is here [in UK], definitely I don't like abortion but I don't think I have a choice in this situation, if the result come back and they say hmmm [long pause] well I will abort it I just don't want another child with sickle cell.

A Caribbean Antenatal respondent stated:

AKO: I had other pregnancies and the ones that I actually decided to test in fact they all turned out to be AA or AS. I was happy that I didn't have to go through having another sickle cell baby. If I did have another sickle cell [pregnancy] baby, I would get rid of it. I knew what the consequences were, even though it went against my religion, my own faith, I didn't think I would cope with another child with sickle cell no I couldn’t cope with another child with sickle cell.
Some respondents battled with the moral, ethical difficulties inherent in such decision-making, the dilemmas posed by religion and having to disregard religion in order to make a decision that suits their own personal needs. An African Male Partner, who already has a child with sickle cell anaemia and grew up with siblings with sickle cell anaemia who at the time of the interview was awaiting the result of prenatal diagnosis stated:

SG: What's the point (of having the baby) when you know the baby is going to suffer a lot and at the end of the day it might still die very young, when you are used to the baby then he's gone what do you do? When you terminate it I think at least it will be [long pause]. Yes it will be better, at least [long pause]. I am a Christian but I swear I haven't any [group] denomination. If I am going to follow religion I wouldn't have made the decision to have the pregnancy tested or consider abortion. If you permitted your religion to get in the way it's a really hard decision to make.

The last two respondents have a child and one has two children already with sickle cell anaemia and their attitude reflect Petrou et al.’s (1992) observation that those who have a child already are more likely to opt for PND and termination of an affected pregnancy. The current study identified that the three women (African 1, Caribbean 2) who already had a child with sickle cell disease opted for prenatal diagnosis, whilst seven of the twenty who did not have a child with sickle cell anaemia already opted for PND.

An African Male Partner stated:

AL: I wanted to know [before the baby is born] it's just we didn't want to have a baby with sickle cell, zero tolerance. I just don’t want it the fact that this is sickle cell that’s it. With the last one [pregnancy that was affected and terminated] she told her parents and I told my parents. We went for the test and after we had decided that if the result is SS we were going to terminate we found out both our parents didn’t support terminating it, because her parents didn't support termination she decided not to do it.

The respondent’s wife subsequently had a termination following persuasion from her husband.

An African Antenatal respondent stated:

OG: If the baby is tested and the baby has sickle cell yes I would abort the pregnancy if the baby has got sickle cell, I do not want a sickler.
Another African Antenatal woman who had had prenatal diagnosis and knew that the fetus is unaffected stated that prior to receiving the PND she and her husband discussed what they would do if the fetus is affected:

MB:.. My husband and I we have been together for a long time and I don’t want something like this to split us apart. He said it’s not your fault and it’s not my fault, this is biological we just have to face this. If you want to stay with me [I will] just accept that this is my baby and I will take care of it if you don’t want to get rid of it, but to be on the safer side I don’t want to have an SS baby. Anytime you are pregnant we [should] go for the test. If the baby is SS we will stop it. And I said OK fine.

Beeson et al. (1985), Sorenson et al. (1986) Marteau (1995) and Shiloh (1996) suggested there is gender difference in attitude to having a child with a genetic disease: men were more opposed to having an abnormal child than were women. Durosinmi et al. (1995) reported opposing findings in a study of Nigerians; women were less accepting of having a child with sickle cell disease than men. The number of respondents in Phase 3 of the current study is not sufficient to be able to lend support to either view. However, more of the African Antenatal women felt strongly that having a child with sickle cell disease will make their status as a wife untenable but not having children at all will make their position even more precarious than having an unhealthy child.

An African Male Partner whose partner had terminated an affected first pregnancy and was expecting their second child, (prenatal diagnosis has confirmed that the fetus has sickle cell trait), stated:

AL: ...By the time we went through all the process last time she was twenty-five weeks [pregnant]. She didn’t feel like she wanted to terminate the pregnancy that is why she said we should go through with having the baby, but... this time we started early and everything went well.

The findings of the current study does not support the HGC’s (2006) argument that the majority of those where a fetus is diagnosed with a serious genetic condition will opt for termination. In this study the majority do not even opt for prenatal diagnosis primarily because of the risk of miscarriage, despite it being a low risk of 1-2%. Even those who opt for PND or feel they would opt for PND, do not intend to terminate an affected pregnancy and merely want to prepare for a potentially sick child.
Moreover, the findings of this study differ from findings of Dryden et al. as reported by Green and Statham (1996), where 93% of women opted for PND following identification of a chromosomal defect that has a proven clinically serious prognosis compared to 39% among those where the prognosis is unknown or unclear. It appears that the difficulty in clearly identifying the possible prognosis of sickle cell makes it difficult for many parents to opt for PND or termination except in a few cases where personal experiences of serious cases has had a major impact and influenced the individual’s perception of the disease.

Petrou et al. (1992) in a review of 170 couples at risk of having a child with sickle cell disease reported that of the 52% who opted for PND 94% had a child with SCD already and 94% of those with an affected pregnancy opted for termination. Dryden in Green and Statham (1996) also noted that the degree of burden that a disease caused influenced parents’ decisions about PND and termination of an affected pregnancy. The few women and men in this study who were pro-termination had a child with SCD already or had strong negative experiences of living with a sibling with sickle cell disease. This supports other authors’ and researchers’ findings that personal experience and the perceived degree of burden that the disease creates has a greater impact and significant influence on decision to have PND or termination of an affected pregnancy.

The majority of the respondents, sixteen, did not opt for prenatal diagnosis, and of the seven who did one had an affected fetus. At the time of the interview she was undecided about continuing or terminating the pregnancy. The reasons for accepting or declining the offer of prenatal diagnosis have been discussed previously
8.6 Influence of religion in decision-making

As discussed in the literature review and identified in Phase 1 and Phase 2 of this study religion plays a significant role in the lives of the majority of Black African and Caribbean people and influences many aspects of their lives. This study found that religion has a direct impact on decisions made about an at-risk pregnancy, attitude to prenatal diagnosis and the possibility of selecting termination of an affected fetus. Many authors have highlighted the high levels of religious belief among African and Caribbean people (Kondor 1993, Jegede 1998, Petrie et al. 1998, Henley and Schott 1999, Read 2001) and the impact this has on their lives and decision-making.

All the women and men in this phase of the project practise a religion. The majority is Orthodox or Charismatic Christian and two are Moslem. A common strategy used by a number of respondents is bargaining or appealing to God in an attempt to produce a child that does not have sickle cell disease. This common adaptive process is often symbolized by the use of prayer to appeal to God in an attempt to avert the birth of a child with sickle cell anaemia.

A Caribbean Male partner stated:

*LC: Ultimately let’s say you have the test and the child is going to have sickle cell [anaemia], the decision is either you go ahead with the pregnancy or terminate the pregnancy. To me, I felt that’s like playing God…even if the pregnancy had been earlier I would not consider terminating it. Both my parents have passed away but my mum taught me that at the end of the day you put your trust in God, that’s it… I know what her view would be. I know what my father’s view would be…If I didn’t believe in God well, but I do and that’s who I am, so to that extent maybe I would have made an alternative decision, but I am who I am.*

A Caribbean Antenatal woman stated:

*HM: I go to church occasionally, but I do believe in God. I read my Bible; I went to a Church of England school and later a Catholic school. I think religion does play a big part in my life, my family and my mum, they do still say if God didn’t think you could deal with it he wouldn’t put you in that position in the first place. I pray a lot and I see that God*
delivers, I can pray for something not to happen but I say may his will be done even in regards to my daughter [who has sickle cell anaemia].

A Caribbean Antenatal who has two children with sickle cell anaemia stated:

AKO: I'm Pentecostal... I believe that God will change the situation with that one [pregnancy of second affected child] that it would be different [not have SS] so I turned it [PND] down. I was disappointed when they told me that I had another sickle cell baby. From there I decided if I ever got pregnant again I would go for the testing. That didn't really change my opinion of religion, it didn't affect my belief I was disappointed and said “Oh God didn't you hear me”. After a while we actually accepted it that this was our portion.

When asked why she felt God did not respond or answer her request not to have another child with sickle cell anaemia she responded:

AKO: Well, put it this way, I could have had a disabled child. Instead, I didn't have a disabled child I had a child, who apart from the sickle cell, is completely healthy, for that I was grateful, even though I didn't like to see them suffering pain I'm still thankful for the fact that I have them. So it didn’t really alter my religious thoughts or anything like that. I thank God all the ones that I did test turned out to be OK and the two I didn’t really test well [long pause]. I wouldn't say I'm really disappointed but it's painful to see your own children go through pain and you can't really do much about it.

An African Antenatal woman stated:

MB: There is a God once you believe that my god will do this he is going to do it, if you believe, even this pregnancy before we went to the hospital and had the test [PND] I said to my husband “this baby is OK, it's going to be OK” I feel that the baby is going to be OK. We will go for the test but I know it’s going to be OK. I believe it’s going to be AA or AS and it’s going to be OK. It’s to do with belief, if you believe that your God will do it, he will do it, don’t doubt. I believe that even if I have four of them and I believe that they are all going to be OK, they will be OK. I am a Moslem and I always pray, I didn’t pray for SS so SS will not come to my family... even if you have SS if you have belief that it’s God that
In a study of decision-making among those at risk of having a child with cystic fibrosis Henneman et al. (2001) found that religion influenced the respondent’s decisions about PND, more than clinical severity. A high proportion of the men and women in Phase 3 of this study expressed a religious view at some point in the interview and, although it may not have influenced the final decisions made with regard to PND and termination of an affected pregnancy, it plays a role in shaping their values and attitude. This reflects Durosinmi et al.’s (1997) findings in a study to examine attitude and acceptability of PND and termination of affected pregnancies among 433 Nigerian men and women with normal haemoglobin, sickle cell trait, haemoglobin C trait and sickle cell disease, 55% expressed opposition to terminations of pregnancy of these 73% stated religion and moral values as the main reason for their opposition. It was interesting that the professed influence of religion on decision-making was in respect of not taking any action. None referred to religion influencing them to take a specific action; for example, some respondents declined PND on religious grounds but none had the procedure for religious reasons.

8.6.1 Dilemmas posed by religion

Even those who feel compelled to make choices that are in opposition to their religious convictions were tending to make the decisions under a great deal of duress and anxiety because it often conflicted with their religious beliefs and values. Yet in view of their predicament they feel unable to make any other decision.

A Caribbean Antenatal respondent stated:

AKO: After I gave birth [to first affected child], they tested her and they said that she has sickle cell [anaemia]. It still didn't really like sink in. I went on to have another pregnancy and moved [house] and they offered me the test, but being a Christian, I was hoping, believing in God for a change in the pregnancy, so I turned down the offer of a test. I was disappointed when they told me that I had another sickle cell baby. From there I decided if I ever got pregnant again I would go for the testing... If I did have another sickle cell [pregnancy] baby, I would get rid of it... I knew what the consequences were [difficult
caring for sick child], even though it went against my religion, my own faith, I didn't think I would cope with another child with sickle cell...If it [current pregnancy] had turned out to be another sickle cell child, I would ask God to please forgive me, I have to go through a termination, I don't want to go through this kind of thing.

An African Antenatal woman stated:

IE: People in my country, family and friends will tell you, don’t have SS baby have termination because when the baby has disease it is a big problem. The church say you can't have termination God can do anything Jesus can change the blood, the church has miracle, they tell you many people have problems but God can change it, everything comes out a surprise [miracle] even babies, this is what Jesus can do if you believe. But people in the road [general public] they will tell you go for the termination because they don't believe in God. The church say to kill is not good, even if it’s only one week pregnant it’s a human being. So I would not tell the church because I believe God will not do something to me he knows my heart I can do what I want to do if it was not for the other [blood disease] condition I would have the test and if it is sickle cell I would abort it; no, no, no, I can't tell the church because when you tell the church they will tell you no

The finding of this study is that those who regard God as the creator of the universe and believe that God’s design should not be interfered with are less likely to opt for PND irrespective of the clinical severity. The majority of respondents and a large proportion of health care professionals assumed that the sole objective of PND is to terminate an affected pregnancy.

A number of African Antenatal women stated:

AH: When we found out [we were at-risk] I prayed over it because I know that it's God that gives children so I handed everything to God for him to take control because there is nothing I can do because already we had gone far [in the relationship] and there was nothing we could do. We made a covenant with God, if you know your God you can’t be having a double mind [doubting] so it’s only when you have a double mind that you’ll be worried, I’m not so worried even when I had my first child. I know my God and I trust Him and I believe that he is going to answer me. I can’t tell them not to check the baby when it is born, when I had my first child when we checked her she is AA, when they check this one
well I know my God [long pause] it's a covenant that I have made with him, God will answer me

ES: I've always prayed about it since I got to know that we were both AS because I've just told God that I want to be able to go through this even if I have a child with sickle cell. I have the faith that I'm not going to have a child with sickle cell anyway, I think God can perform a lot of miracles, even if I have a child with it… at a point in time I was telling my husband that I prayed to God that if there's any pregnancy and the child has got sickle I don't want the baby to start growing in me...maybe all the children that came through before [that resulted in two miscarriages] had sickle cell and that's why I never got pregnant for a long time [short term infertility] but this one hasn't [miscarried] so maybe I don't know... I've prayed to God that even if the child growing in me is sickle cell he should do something about it, but on the other hand too what ever the outcome maybe it doesn't matter because I believe in God…maybe if the child has sickle cell there’s a reason God has given me that child yeah, not that God didn't answer my prayer I'm sure that God maybe has a purpose for it. God knows what he is doing anyway, so even if I have a child I'm sure God will make me strong enough to cope with it, so it doesn't matter, that wouldn't make me lose my faith in God.

EU: ...something that will come into play would be my faith, I am Christian and my Christian faith would help me a lot. If a child of mine does happen to have sickle cell anaemia that is what would help me deal with it. [We] would go to the doctor first as well as pray for the child, because I believe in prayer that would be the main thing. I think because I feel that God is in control of my life I will see that if I have a child with that kind of illness I will see it as something that I was meant to [have] that child with that illness it is something that I am meant to deal with and it is something that even though it may look like a negative thing it will bring out something good for me and for the child, when children have some illnesses you learn a lot from them in terms of their resilience...In terms of my relationship with God I think it will be pretty much like challenges or a test of my faith and a test of my inner strength, I feel it will be a test, I won't see it as how could God do this to me, I feel it is something I am meant to get over as a person where else with another child [well child] I may not appreciate that this is a test of my faith.
An African Antenatal who has a child with sickle cell anaemia already stated:

OG: I am Christian [Redeemed denomination]. I know my religion doesn't agree with abortion, abortion is a sin and all children whether sickle cell or not are all children from God they are a gift from God. So it puts me in a dilemma… as a Christian it's a painful decision to make but I am still believing and hoping that everything will be well and that I don't have to go through that abortion, yeah. I have been praying about it that all is well and I don't have to do the abortion praying that the baby will be AA…If the baby comes SS [long contemplative silence with nervous pained laugh] God knows, he knows what he is doing, I mean, I don't have to complain to him because he is the giver of everything He does everything according to his will even if this baby is SS I would still feel, I will be OK, because I know he is God, he is a faithful God and I know he will take care of the children for me, whatever God does is OK.

These statements further illustrate the deeply held religious beliefs shaping the lives of many Caribbean and African people and the decisions made about this important issue in their lives. It also illustrates the deep anguish that results from a desire not to have a child with this serious genetic disease, yet due to a religious conviction not being able to make choices that will prevent this from occurring. This increases the likelihood of dissonance.
8.7 Possible impact of having a child with sickle cell anaemia

8.7.1 Impact on marital / intimate relationship

Having a sick child can affect relationships and family interactions. The respondents were asked to give an opinion about how they perceive that having a child with sickle cell disease would impact on the relationship with their partner, other children if any, their extended family and family-in-law.

An African Antenatal respondent stated:

KS: A previous miscarriage had the impact of bringing me and my husband closer together, I feel this may have the same effect that having to deal with a sick child may have a positive effect on our marriage. I don’t think it will pull us apart. However my husband will have to help care for the sick child.

An African Antenatal woman with a sibling with sickle cell anaemia had already had PND which confirmed that the baby is unaffected stated:

AAN: [effect on] my relationship with my husband? It's hard for African men we don't have the same mind, except for my husband when the doctor ask the question "if the baby is SS, what are you going to decide?", he said, "we're going to stop the pregnancy" but I didn't tell him this was my answer I didn't agree, because some people like my brother, lived until he was 45 years so you can lose your life anytime, you don't know...even if the baby has sickle cell for me it's me who's carrying the baby, not him, it's the woman who look after the children not the men. My relationship with him if I keep the baby I don’t know maybe it cause separation, maybe, it can be [happen].
A Caribbean Antenatal respondent who at the time of the interview had already had prenatal diagnosis which confirmed that the fetus is affected and she attempting to make an anguishing decision whether to continue or terminate the pregnancy:

*IAT:* I think it would be hard. Mainly because he has two kids already they are healthy. They have the trait. He's actually said to me that that is his worst nightmare, having a baby with sickle cell and not being able to deal with it. He wasn't sure he was going to be able to deal with, so it's going to be very tough on this relationship. I can't say what will happen. I am hoping that we don't end up going our separate ways. His initial reaction is to get rid of the baby. He is scared of getting information. He thinks it would be easier if he didn't have the baby. Because he doesn't want to deal with it, whereas I want to deal with it and I want to give it a go. I want to keep my baby even if it doesn't last very long. I don't want to just get rid of it for the sake of making things easier. He's still trying to come to terms with [the fact] that I want to keep the baby and I am going to keep the baby. We haven't sort of drifted apart as such, but it is still very difficult for me to accept [the current situation] not knowing what to expect after the baby is born. It makes it that much harder. I suppose I have to be strong for everybody in the relationship right now. I don't know whether he will stay. My friend thought I should get rid of it. Her initial view was “What is society going to think?”, and I said “I don't care what society thinks, this is my baby. I wanted it for so long and I am gonna keep it”. We did talk a bit more deeply about what is going to happen and she still sort of felt that she thought that I should terminate it, because of the problem with my partner not wanting a sick child. The fact that I would probably be on my own coping with the baby with sickle cell, she [said], “I don't think you should keep it”. She actually used the words that if I had the baby it would be like having a dead baby. I thought well you don't know very much about it so you can't say that. I really didn't take it to heart, because when people who are ignorant [about something], it is easy to be negative. What she is trying to say is that it’s not easy if you are going to deal with it by yourself. She took the view that my sister took, that is [the baby is] not going to live for very long. I thought maybe that is something I need to find out, and I want to find out. Even if I do have the baby and it does not live for very long that is still my baby and it is a part of me. I just can’t go and get rid of it because everybody else thinks that is the right thing to do.
An African Antenatal, who appeared to have been coerced into terminating a previous affected pregnancy by her husband, had PND for the current pregnancy and is expecting an unaffected child at the time of the interview stated:

\textit{VU: It's a difficult situation, how to go through this painful thing, maybe I will, we will decide not to go on with the marriage and choose someone else.}

Some of the women with an existing child or children with sickle cell anaemia (African Antenatal n= 1, Caribbean Antenatal n=3) highlight the stress that having a sick child places on their personal relationships especially with their partner. The Caribbean Antenatal women stated:

\textit{HM: My first partner wanted another child, but because I knew I was the one who is doing most of the work looking after my daughter I thought no... It definitely would have influenced my decision. It would have stopped the relationship. Well it did stop the relationship, 'cause there was a lot of stress, conflict of opinion. He wanted more children and I didn't, because I kept thinking what if I have another child with sickle cell, I'm going to be left with the burden. Like now, I'm doing all the work, we are not together now, he'll come and go but emotionally I'm the one whose there for her, I'm the dealing with it.}

\textit{AKO: I think because we have God on our side that is helping us. So I think if we were not Christians, not having an outside influence from God this relationship would have crumbled a long time ago. From my husband's side maybe he would have felt “I want healthy children”, that might have influenced him to go out and look for another woman who can give him healthy children. I think on the outside that could have taken place, but because we have God in our life, walking with him daily that’s why we are still together.}

The one African Antenatal with one child with sickle cell anaemia already did not comment on the issue of the impact it would have on her marital relationship. However she said somewhat hesitantly and after some encouragement that if she had known that there was a risk before getting married she would have made selected someone who did not have the sickle gene in order to avoid the risk.
8.7.2 Impact on other relationships

A Caribbean Antenatal was asked what effect she felt having a child with sickle cell disease would have on her relationship with her older daughter:

*IAT: I think it can only bring us closer together. I have explained to her. She is only ten and a half, you can't go into too much detail, but I have explained to her that the baby might be unwell at certain times and I am gonna need to focus a lot of my attention on the baby. She is really looking forward to having a sibling regardless. She said “I am going to help you as much as I can”. I think regardless of what happens she will love that baby, just like I would, unconditionally. I did ask her “How would you feel if anything bad was to happen?” It’s as if she knew. She said, “You are not going to get rid of it are you?” I think we are on the same wave length in that we are willing to accept it. She knows it is going to be a little bit difficult for her, because she has been an only child for so long, but I think she will cope quite well and we will just get closer.*

8.7.3 Impact on decisions about family size

Some authors suggest that having a child with an illness already influences people’s decisions about having future children

A Caribbean Antenatal respondent stated:

*HM: I think two is enough. Originally I wanted four, but maybe not knowing that I have trait and he has trait I'm always worried. This time around I think I’ve worked through most of my stresses and worries. With my first relationship it was different, whereas this time with him [new partner] I knew that, all right he’s got trait, it’s just something we’re going to have to deal with and work through. If we are both strong and supportive then I don't see a problem with having another child with him, but to get tested [PND] earlier, much earlier. I think he would need a lot more counselling to be able to deal with it. The possibility of having another child with sickle cell disease to a degree has influenced it [whether to have more children], but if I do it'll just be a matter of getting tested earlier. Not to get rid of it but just for peace of mind so I can get ready for the baby.*
AOH: I don’t know yet because we haven’t decided about our family size but it’s not on the basis of sickle. Obviously if we have a child with SCD there will be more responsibility. We have to think of other things like family income and other things long term: private schools, other costs and all that. Sickle wouldn’t be the issue but how we deal with family income and things, for example, if I am not able to work because of the child.

Having a child with sickle cell disease appears to be influencing some of the women’s and couple’s decisions with regard to having more children. When asked whether they would consider having more children and whether the risk of sickle cell would influence their decision, some of the African Antenatal women stated:

IE: More children? No. I say if this one comes out nice [with no sickle cell disease] I don't want to take a risk anymore. No, I don't want to risk it because when I am pregnant my heart is scared, waiting, waiting [for neonatal test result].

AAN: No, no more children. I don't want to be disappointed. Because today I'm pregnant the baby is AS [has had PND], but tomorrow I don't know if it'll be SS. I’m scared. Yes, two is enough. If not for sickle cell I may have three, but there's not much difference between two and three, two is enough.

ES: Whether I have a child with sickle cell or not wouldn't stop me from having any more kids. The only thing would be I'd leave it a longer time than if the child didn't have sickle cell disease, because you have to pay attention to the sick child before having another one.

Two African Male Partners stated:

OS: uhm [nervous laugh] that's a million dollar question. The thing is, under the circumstances, yes [the risk of having a child with sickle cell disease influencing having more children], it will because fingers crossed, if I give birth to a child that hasn't got the sickle cell now I will probably be inclined to take the same decision again. But if I have a child with sickle cell now, I probably wouldn't go ahead, because obviously, my inclination to have another child is going to be influenced by the fact that the first one has got sickle cell, so why do you want to have another one? So my decisions at that time will basically depend on this first child definitely.
OH: Yeah, I wouldn’t mind *having more children* the sickle cell would not influence my decision, no not at all

It appears that the risk of having a child with sickle cell anaemia did not influence some of the respondent’s desire to have children and this supports Petrou et al. (1992), Shiloh (1996) and Marteau and Anionwu (1996), Duster and Beeson (2007) and other researchers assertion that the risk of serious illness did not influence many people’s decision to having children. However, it may influence the size of the family especially after one or more affected children are born.
8.8 Conclusion

The interviews affirmed that culture is the lens through which individuals view their world. It shapes an individual’s and group’s attitude and behaviour (Kaplan and Manners 1972, Helman 2001, Oppenheim 2003, Haralambos and Holborn 2004, Catherine Collier 2004). Culture determines the internalised way of being in the world within a social group. This is amply demonstrated in the attitude of the respondents interviewed and the differences observed between the African and Caribbean respondents, especially in respect of procreation and attitude to sickle cell disease. The complexities that genetics brings to the human experience has been amply demonstrated and this study confirms Zimmern et al. (2001) and the BMA’s (1998) observation that painful dilemmas will arise as a result of increasing public access to genetic services and advancing technologies.

The respondents’ attitude to sickle cell, to being at risk, to making choices about pre-marital and pre-conceptual selection of a partner and decisions made about being at risk of having a child with sickle cell anaemia are complex. There are many contradictions in the human experience as observed in this group of respondents and nothing seems to be well-defined. The interpretation assigned to being at risk of having a child with sickle cell anaemia was very varied but there were significant cultural difference in the attitude of the majority of African and Caribbean respondents. The Africans expressed a negative experience of people’s attitude to sickle cell in their culture while the Caribbeans were less negative and this I suggest influence their pregnancy decisions.

The data has demonstrated that cultural aspects are important in formation of attitudes and decision making but psychological aspects are also significantly important and the two aspects are related and have relevance in influencing each other, a discrepancy between these two dimensions can and often create dissonance for individuals, couples or groups, especially when faced with the dilemma inherent in life changing decisions. In this study cognitive dissonance theory offered a useful insight into people’s response to discrepant cognitions when faced with difficult genetic decisions. The ability to choose whether to avoid having a child with a serious genetic condition placed many of the respondents in a psychological state of dissonance. The data showed some of the methods that individuals adopted in an effort to reconcile irreconcilable views and reduce the dissonance that this has created, for example, adding consonant elements such as religion, moral values,
society’s rejection of certain decision options and individuals changing their perception of the importance of one or more of the cognition elements.

The Africans appear to have an inherent need to conform to their cultural pressure to produce offspring, yet they must avoid producing a ‘sickly’ child. This creates a great deal of tension and was a dominant feature among the African respondents interviewed. The majority of the African respondents had an unquestioning view of the world with regard to procreation, such that their being at-risk of having a sickly child did not influence their desire to have children. This demonstrates how effective and well internalized culture is. In many instances the cultural attitude was so deeply entrenched that individuals were unaware that they strongly reflect their cultural group, especially among the Africans. This depth of culture was described by Helman (2001) as the primary level, and the author asserts that this level of culture is often unspoken and individuals believe and act often without consciousness and questioning. The few that question the cultural norm and acknowledge it still conform to the cultural norm and feel unable to resist the strength of the cultural pull for conformity. All attempts at resistance eventually lead to their having to succumb to the cultural pull, to fall-in-line with their family’s cultural expectations, even where this caused some feelings of internal anguish, resentment and dissonance.

Another very strong pull factor for having children among the Africans but less so among the Caribbean respondents is the need to create an social, emotional or financial ‘pension plan’ for old age. Among the Caribbean group the goal is primarily social and emotional support, whilst for the Africans it is all three, but the need to ensure future financial support was dominant, and this difference reflects differences in the social environment of Africa and the Caribbean. In the former there are fewer social welfare structures to provide for vulnerable members of society, the majority of the African respondents are first-generation migrant and have a notion of ‘going back home’ especially as they advance in age. The majority of the Caribbean respondents are second- and even third-generation migrants and the notion of ‘going back home’ does not feature in their life plan, since they perceive England as their home. Hence there is less of a need to plan for the potential burden of old age since there is an ample welfare provision in the UK.

There was demonstrable difference between the African and Caribbean respondents in their attitude to sickle cell disease and the risk of having an affected child. Although the majority of the Africans were similar to the Caribbeans in being opposed to PND and termination of an affected infant the Africans appeared to have greater emotional turmoil. On the one hand they are forced to
acknowledge their society’s rejection of birth of ‘sickly’ children yet feel unable to choose to prevent the births of such children since God ‘gaveth’ and one cannot interfere with divine’s intentions. Some of the respondents had difficulty reconciling their evident desire not to have a child with a ‘disease’ with their desire to maintain a cordial relationship with God. This conflict was faced by some couples on more than one occasion, they had to confront the dilemma in more than one pregnancy and in some instances they had to make a decision that does conflict with their religious values but at a price, perpetual feelings of guilt and psychological trauma. These emotional conflicts and painful experiences were at times painful to observe as a researcher.

In order to deal with the dissonance created between attitude and behaviour and a clash between cultural (societal) values and personal values some of the respondents added new consonant cognitions, the most common of these was religion, others included a fear of rejection by their family, community or wider society, since choosing not to have children is perceived as unacceptable in some. This was observed among the African respondents especially.

There was strong undercurrent of ‘people with sickle cell trait should not marry each other’, especially among the African respondents. Again this is a belief perpetuated strongly in the African culture and less so in the Caribbean culture. In the latter group the idea that ‘love’ should over-ride the risk was apparent and most felt love was more important than the risk, hence the notion of choosing a partner based on one’s sickle status was abhorrent to most respondents and more so to the Caribbean respondents. This is similar to Duster and Beeson’s (2007) finding among African-Americans at high-risk for sickle cell and White-Americans at high-risk for cystic fibrosis.

In the current study I suggest the African respondent’s greater knowledge and negative experience of the potential impact of sickle cell disease has contributed to their less than ardent support of the notion that ‘love’ can and should over-ride the possible repercussions of having a child with sickle cell disease. The few Africans that bought into this emotional acceptance of the risk did so precariously and often expressed strong feelings of anguish as they await the outcome of allowing love to influence their decision. There was turmoil and often inconsistencies in people’s response to their situation and the decisions made.

Both the Caribbean and African respondents were accepting of PND but not for the reason of terminating an affected pregnancy but in order to prepare mentally and physically for the potentially sick child. The majority opposed abortion. The few that were pro-abortion were those
who already have more than one affected child, those who have experience of living with a sibling or siblings who were seriously affected clinically, and those who felt a strong sense of their culture’s rejection of the birth of children with sickle cell disease and the anticipated burden that this would load on to their family, especially their extended family and wider community. They also took into consideration the potential financial burden and the possible emotional repercussion of caring for a child who, as is generally perceived will die at a very young age, thus causing them and their family heartache. Overall the Caribbean respondents seem more tolerant of sickle cell and their risk of having a child with sickle cell disease whilst the Africans were less tolerant and I suggest this reflects cultural attitude to the condition and their experience of it in Africa, the Caribbean or UK. The country of an individual’s enculturation plays a part in their perception of the illness.
Overall Discussion

9.1 Phase 1, 2 and 3 overall discussion
   9.1.1 Ethnic group – cultural and social similarities and differences 321
   9.1.2 Knowledge of sickle cell & attitude to testing 324
   9.1.3 Importance of having children 340
   9.1.4 Attitude to sickle cell disease 348
   9.1.5 Decision making in Pregnancy 357
   9.1.6 Impact of religion 363

9.2 Reflection on theoretical models 369

9.3 Implications for future practice 379

9.4 Implications for society 382

9.5 Limitations of study 383

9.6 Suggestions for future research 386

9.7 Personal reflection 388
9.1 Overall discussion – Phases 1, 2 and 3

The data demonstrated that although there are many similarities in the attitude of African and Caribbean respondents there are also areas of difference and many of these relate to cultural orientation and the tensions that arise where there is a mismatch between cultural attitude and expectations and an individual’s personal preference and or behaviour. Since this study is attempting to identify factors which contribute to decision-making this overall discussion will focus on relevant concepts identified. The discussion comparing findings in Phase 1, 2 and 3 will be presented under the following broad themes:

- Ethnic group – cultural similarities and differences
- Knowledge of sickle cell
- Importance of having children
- Impact of religion
- Attitude to sickle cell disease
- Decision-making in pregnancy

This will be followed by a brief discussion on:

- Reflection on theory
- Personal reflection on experience
- Implications for future practise
- Implications for society
- Limitations of study
- Suggestions for future research

9.1.1 Ethnic group: cultural and social similarities and differences

The two ethnic groups were similar in their level of identification with their cultural group, hence there were no statistically significant differences observed in respect of ethnic orientation and identity (Section 5.3.1.1); the Africans identified highly with being African whilst the Caribbeans identified highly with being Caribbean, this included those born and raised in the UK. This affirms Sowell’s (1994) argument that crossing continents does not necessarily alter one’s inherent cultural orientation; it can only modify it and then only to a certain degree.
The differences observed in the educational level of the Phase 1 and Phase 2 respondents (Sections 5.1.4 and 6.1.4) can be attributed to differences in the historical migration pattern of the two ethnic groups. A significant proportion of the early African migrants in the 1940s and 1950s were educational migrants, many on government scholarship seeking professional training with a view to returning to Africa on completion of their studies, and many did. However, a large proportion of those from the Caribbean during the same era were economic migrants, and although many were also seeking training and educational opportunities a significantly larger number of these migrants did not have the necessary educational qualifications to attain their dreams and many found themselves relegated to doing menial jobs. Unable to train or gain the skills they had hoped for made returning to the Caribbean difficult, and many remained and settled in the UK creating the second-, third- and fourth-generation Caribbean community. Many African nations gained independence from their European colonizers during the 1960s. However corruption, embezzlement and mismanagement led to increasing economic hardship in many of these Africa countries and the number of economic migrants from Africa increased. At this point in history immigration laws were being developed which made migration into the UK difficult and the number of economic migrants from Africa was never able to reach the proportion of the early economic migrants from the Caribbean.

The Caribbean respondents’ strong identification with their culture of origin was unexpected in view of many of these being second-, third- and possibly fourth-generation migrants. For example, in the examination of ethnicity it was anticipated that there would be a statistically significant difference in the Africans and Caribbeans in respect of language (Section 5.3.1.1), since the majority of Africans are first or second generation migrants and have a distinct language other than English, yet there was no statistical difference. A difference was observed among those born/migrated <15 years of age and those who migrated >15 years of age (Section 5.3.3.1). A difference was also observed between African Females and Caribbean Females (Section 5.3.4.1), African Females and African Males (Section 5.3.5.1). In these paired groups the Africans and the migrated >15 years of age had a higher mean score. Some of these findings are confounding, for example, the difference observed between African Females and African Males, some of these can form the basis for a future study.

It was anticipated that the Caribbean respondents would identify less strongly with their Caribbean cultural origin but this was not the case. I suggest this is due to the experiences of these communities in the UK. Where a host culture is flexible and allows for multiculturalism there will
be greater cultural flexibility and a willingness to assimilate and identify with the host culture, adopt its symbols, emulate its cultural practices and perceive it as a culture worth assimilating in order to achieve one’s personal goals and ambitions. Where there are no benefits to the adoption of the host culture or there is experience of rejection or hostility, migrated individuals will adhere to the comfort zone of their original culture. There will be no merit in relinquishing this when what is available has the potential to create emotional distress since one is unable to achieve a sense of belonging to the dominant culture. Since it is difficult for a person to exist in a cultural vacuum many will retain what is known and comfortable.

Racism and negative experiences will perpetuate the individual’s voluntary and involuntary adherence to the culture of origin. I suggest that this is the factor that has perpetuated an adherence to the culture of origin among second- third- and even fourth-generation African and Caribbean migrants and perhaps those in this current study, especially those of Caribbean origin. If these negative experiences within society are compounded by inequality due to ‘institutionalized racism’ (MacPherson 1999) there is less willingness to embrace the host culture, even where one is a member of that society by virtue of birthright.

Although both groups experienced racism and discrimination their response and the outcome for both groups had areas of difference because those with a better education from both the African and Caribbean group were able to surmount the difficulties posed. The less educated were at a greater disadvantage with less skills and opportunities to ‘overcome’ they often found themselves marginalized and increasingly relegated to the lower ranks of society; the sought-after opportunities soon dissipated and many dreams were left unattained (Phillips and Phillips 1998, Fenton 1999). The children, grandchildren and great grandchildren of the poorly educated African and Caribbean communities continue to feel the impact of discrimination into the twenty-first century, with poor educational achievements and high unemployment many continue to feel marginalized, disenfranchised and remain on the fringes of mainstream British society.

The Northern American example described by Tsai et al. (2000) of the Chinese migrants could be explained by the argument that apart from a small group of original native Americans, most of the population in all other racial, ethnic and cultural groups were immigrants and the American First Amendment has enabled the development of a collective ‘American dream’, which perpetuates the notion that all are equal irrespective of cultural group and that all American citizens have an equal opportunity to live the American dream of prosperity, provided individuals are willing to develop
the mind-set and contribute fully to the continuing development of that American dream, upholding the cultural values irrespective of the individuals cultural origin. New migrants are indoctrinated way of thinking from the moment of entry into USA and soon feel that there are opportunities to sharing in the values of the ‘American dream’.

The British environment is dissimilar. The majority indigenous and dominant population is white English and has been for many generations. All other cultures are ‘newcomers’ and are migrants ‘guests’ within the English society, therefore, there is an expectation that such migrants will assimilate an already-existing English culture. Unlike the North America experience, in the English society there are no unifying socio-cultural structures or First Amendment to create a multicultural identity, at least not one that is recognised by all its citizens and accepted by all cultures in the society. In my view the Race Relations Act (HMSO 1976) and its Amendment (HMSO 2000) is merely a conduit to enable punishment of those who break the law. I argue that it was not created for the purpose of unifying a society.

It is not surprising therefore that unification and multiculturalism is proving unattainable in the British context. I argue therefore that the Black African and Black Caribbean respondents in this study demonstrate that they are compelled to maintain their original culture since there is no unifying English / British socio-cultural systems. Therefore there are more social factors unifying the African and Caribbean cultural group than dividing them, this is social experience. This study has highlighted that in terms of differences in culture between Africans and Caribbeans each cultural group has maintained its culture of origin and this adherence to the original culture is observed in the attitudes, values and beliefs of each group.

### 9.1.2 Knowledge of sickle cell and attitude to testing

The hypothesis that Caribbeans will have better knowledge of sickle cell than Africans has not been substantiated in this study and the converse appears to be true, the African respondents had a statistically significant better knowledge than the Caribbean respondents in both Phase 1 and Phase 2 of the project (Sections 5.3.1.2 and 6.2.1.2). However both groups had good overall knowledge.

It is possible that the better knowledge among the Africans demonstrate differences in educational level of those recruited to the study. People who are better educated have greater access to health
information through being engaged in practises that expose them to a wider variety of general information. Attending educational events, reading educational materials, accessing knowledgeable individuals through discussions and conversations all contribute to the development of one’s ability to gain knowledge on a wide number of subjects.

Many Africans appear to wish to dissociate from the sickle cell gene probably because many fear the stigma associated with the gene in Africa. They are more likely to deny knowledge of the condition during face-to-face interaction with health professionals, hence the perception that few Africans have knowledge of sickle cell. An anonymous questionnaire may create less anxiety and reduce an individual’s reluctance to admit to knowing about sickle cell. Interestingly, in completing the questionnaire a number of African respondents advertently or inadvertently claim not to be a carrier of the sickle cell gene, but they later contradict themselves by unwittingly stating otherwise in another section of the questionnaire, thus demonstrating how strongly Africans feel about being associated with SCD.

Many people perceive that by admitting knowledge of sickle cell, and especially that they have the gene, society will expect them to take the necessary actions to avoid having an affected child, such as seeking testing for themselves and their partner, consequently choosing a partner who will not place them at-risk or deciding not to have children. For many Africans the last option will not be deemed viable. By denying knowledge or failing to act individuals perceive that they will not be considered negligent or be held accountable for having an affected child. Giving birth to a child with a genetic condition inadvertently will be perceived as just ‘bad luck’ and not the fault of the individual.

The finding of this study supports Eagly and Chaiken’s (1993) proposition that where there is a tension between two cognitions or a cognition and behaviour individuals will attempt to reduce the dissonance by denying knowledge, avoid obtaining further information that could potentially increase their knowledge and consequently the dissonance that has been created between ‘knowledge’ and ‘inaction’. I propose that denying knowledge of sickle cell is often a response to dissonance and an individual’s attempt to reduce it and maintain consonance, ‘what you don’t know about will not hurt you’. Avoidance of people, especially health professionals, situations, information and lack of attention to detail, feigning ignorance are some of the modes that individuals may use in an attempt to reduce cognitive dissonance.
One African Antenatal woman who was aware of her carrier status during a previous pregnancy that resulted in a child with sickle cell trait, failed to attend invitations for genetic counselling both in pregnancy and after the birth of her first child. When asked why she did not seek further information prior to the current pregnancy and how she felt her community would respond if she has a child with SCD stated, ‘they cannot blame me, it is not my fault, no it is not my fault, I did not know’.

Both cultural groups in Phase 2 had high overall knowledge scores and a cultural group difference was not observed in this phase. Although the pregnant women as a group were overall better educated than the non-pregnant women, educational ability does not appear to account for the lack of difference in Phase 2. I suggest this is because the pregnant women are all at-risk of having a child with sickle cell anaemia and would have received a leaflet giving detailed information about sickle cell and, secondly, all the women would have had counselling in the current or previous pregnancy. The counselling session and leaflet generally include basic facts about sickle cell, similar to those used for the construction of Section 1 of the questionnaire (See appendix 1).

The statistical difference observed comparing Phase 1 general public women and Phase 2 pregnant women was anticipated by virtue to the difference in exposure to the genetic information and differences in their personal circumstance, notably all the pregnant women are aware of their sickle cell trait carrier state and are at-risk of having a child with sickle cell anaemia, a large proportion of the non-pregnant women are untested and are not at-risk.

The lack of difference in basic knowledge of sickle cell among the pregnant women suggests effectiveness of health promotion and genetic counselling in particular. When a situation has the potential to have a direct impact on personal circumstances one is likely to absorb information conveyed and to remember the pertinent aspects. In the Phase 3 interviews two Caribbean Antenatal women stated that they attended fundraising events on a regular basis prior to becoming pregnant, but they did not relate this information to themselves and did not appreciate that it had any relevance for them. Despite frequent exposure to the information, they did not use it to make pre-marital or pre-pregnancy genetic decisions, including whether to attend for testing. This calls into question the benefit of untargeted awareness campaigns and the validity of the approaches used. To expose people to information is not enough to influence this behaviour.
Change is a complex issue and perhaps funds should be directed at seeking a better approach and targeting individuals and groups at a time and in a manner when individuals are more likely to feel the information is of relevance to them, for example, when planning a pregnancy or in primary care as soon as a pregnancy is confirmed by the general medical practitioner, as recommended by Thomas and Oni et al. (2005). It is possible that people will make use of such information only when it will have a direct impact on their current situation and no amount of ‘preaching’ by health care professionals will change that situation.

When an individual has been tested and is aware of their haemoglobin status before marriage at what point does one approach a prospective partner of the potential risk and advice them to get tested? Early in the relationship will appear too presumptuous, as if one is assuming that the relationship will develop to the point where one is planning a family. Later in the relationship, when deep emotions are involved, it is difficult to raise the issue since for many the perceived only option is termination of the relationship, or where one contemplates continuing the relationship, the prospect of prenatal diagnosis and termination of an affected fetus. Having to make such painful decisions forces some individuals to perhaps obfuscate their knowledge of sickle cell and this may account in part for Hill’s (1994) finding in the USA study of low-income women. To believe that ‘it has nothing to do with me’ I suggest is a more comfortable position which may enable some individuals to cope psychologically with the anxieties that such knowledge brings and helps relieve the associated dissonance of their experience.

Dickinson and Bhatt (1994) identified fatalism as a common response of Caribbean women to disease and illness. It is possible that had the researchers included Africans in their study they would have found a similar or greater degree of fatalism among Africans. Perhaps fatalism and religious belief accounts for the lack of response to sickle cell awareness campaigns; campaigns which are often initiated by well intentioned European and Europe-trained policy makers and health and allied professionals. A failure to address the cultural and psychological attitude to these issues fails to respect the views of those the campaigns are targeting and results in a waste of resources. Perhaps the time has come to genuinely engage the cultural community in the decision to develop such campaigns in order to ascertain that they are required, in what format and when, this is more likely to ensure their effectiveness. Recognising the high depth of some respondent’s religious conviction and the power which religion and religious leaders have in shaping attitude and response to such health information, there needs to be greater collaboration with such groups in order to gain access to and plan a strategy that is acceptable to those being served.
The constant demand for Black women and men to attend for pre-marital and pre-conceptual sickle cell testing fails to acknowledge the entrenched attitude to sickle cell and testing. Despite being advised to seek testing few African and Caribbean people attend voluntarily; what people say they will do and what they do can be contradictory, as highlighted by Shiloh (1996). By acknowledging that an awareness of one’s haemoglobin status creates social tensions and dissonance health care professionals will be better able to develop health promotion that is most suited to the needs of the population. With current developments in human genetics the time is rapidly approaching when society may agree to whole population DNA analysis and storage of the information, including any identified genetic mutation. Whether individuals will avail themselves of this information when planning to have children is debatable unless it is legally enforced, thus taking away human liberty.

I suggest anxiety about what to do with the information contributes to people’s failure to attend for testing for sickle cell, and affirms Lenaghan’s (1998) observation that people are fearful of who will have access to their genetic information. Although Lenaghan was referring to insurance companies, if one were to apply the same anxieties to the population at risk of sickle cell one may suggest that being aware of one’s carrier status may create similar anxieties in regards to terms the families of prospective suitors, especially where the suitor is from a traditional society. This would make choosing a partner based on one’s own pre-marital test result difficult socially and culturally.

It is difficult to know how many women and men who were aware of their Hb status deliberately concealed the information from their partners due to feelings of shame, stigma and or fear of rejection and other repercussions that may arise as a result of disclosure.

Recognising the powerlessness of women in many traditional societies, it is pertinent to ask, ‘at what point does a woman inform a prospective partner that she has sickle cell trait and advice that he should attend for testing?’ Secondly, where arranged marriages are common does the individual, especially the woman, not reduce their potential for securing a marriage partner especially when one considers Jegede’s (1998) assertion that the presence of a heritable condition is very stigmatizing and some African communities and families will go to great lengths to conceal such genetic information. In a study of families with and at-risk of cystic fibrosis and sickle cell in USA Duster and Beeson (2007) found that although carrier respondents appear to advocate partner testing many of them were in fact resistant to testing and those who were tested failed to communicate their carrier status to prospective partners. The resistance was often done covertly, for example, by failing to take action, such as contacting the testing centre to book an appointment.
Knowledge of a carrier state was often not integrated into subsequent decision-making; and this appears to be the case in the majority of cases in this current study.

Knowledge of sickle cell improves with exposure to the specialist information especially if it has been obtained following confirmation of the presence of the sickle cell gene. Hence those who have been tested had greater knowledge and scored higher in the general knowledge score compared to those who have not been tested. This was the case in comparing Phase 1 and Phase 2 women, all in the latter group had been counselled. In sickle cell testing services in the UK it is common practise to provide pre-test counselling in order to ensure that individuals are making an informed choice about being tested; as defined by Marteau (1995) an ‘informed choice’ is where an individual’s attitude for or against a test is reflected in the choice made about whether to be tested or decline the offer of being tested and these two aspects will not be contradictory. In terms of sickle cell testing an informed choice includes having considered the implications of being tested and found to have the sickle cell gene not just for the individual’s immediate situation but to their future prospects in terms of coupling, marriage and having children and whether they have considered the potential implications to their nuclear and extended family if an abnormal gene is identified.

Despite prior knowledge of a carrier state few respondents in this study attempted to select their partner based on their own test result (Table 7 and Table 21). The leading influence for not doing so is religion and the respondent’s inability to make decisions that appear pre-emptive and contradict their perception about intimate relationships, values, religious doctrines and beliefs.

Human beings and their behaviour is complex and although many health care professionals (Atkin and Ahmad 1998) argue that people will make what is deemed a ‘right decision’ in light of scientific knowledge few appear to do so. The majority make decisions that may appear irrational and contradictory. In response to life’s challenges decisions are often made based on ‘gut feelings’ and this may not reflect rationality or science. Among both the African and Caribbean respondents in this study emotions and a belief in a supernatural being (God) appear to have greater influence than scientific knowledge. The possibility of having a child with a genetic defect in some cases was accepted as the will of God, a will that is beyond human comprehension and that should not be questioned under any circumstance, as highlighted by some of the respondents in Phase 3. For the majority of the respondents ‘love’ for the other person is of more significance than the risk of having a child with a genetic defect which for many was not a reality that they were able to fully
comprehend, except for the few who have a child with the condition already or lived with a sibling or other close family member who was seriously affected by the condition. The notion of love overriding all obstacles voiced by many respondents reflects Duster and Beeson’s (2007) findings.

This finding I suggest further highlight a response to dissonance and Abelson’s (1959) concept of using elements to justify actions that are not congruent with one’s cognition. In order to justify knowingly maintaining an at risk relationship individuals will use elements such as ‘religion’ and ‘love’ to bolster their decision and relieve the dissonance between ‘I have sickle cell trait and should not have children with someone who also has sickle cell trait’ and ‘I am in a relationship with someone with sickle cell trait and therefore at-risk of having a child with sickle cell disease’. These opposing cognitions create dissonance and since reality has placed a constraint on their being able to take alternative action individuals will add consonant elements, in this case ‘religion’ and ‘love’ which prevent them from taking alternative action but helps reduce the dissonance. These bolstering elements reduce the importance of the dissonant cognition, which is the importance of the seriousness of having a child with sickle cell disease.

The idea of ‘being at-risk’ is an arbitrary concept for many respondents in Phase 3, who, although they acknowledged the risk chose to ignore the reality of it and to hope for what many of them called a ‘good’ outcome. Fatalism was evident in many of the respondents’ reaction when asked why they did not opt for PND or consider termination of an affected fetus. ‘What ever will be will be’, was a common response from many respondents. The stigmatization of those with the sickle cell gene and the negative attitude to it was expressed by several African respondents in Phase 3 and reflects the North American experience, an expression that was not observed among the Caribbean respondents.

During the 1970s African-Americans were targeted for mass screening and the identification of the sickle gene, even in the carrier state, led to labelling of Blacks as ‘potentially diseased’. This created shame, stigma and stereotyping of Blacks. A poor understanding of the condition contributed to extensive racial and institutional discrimination not only of those who had the disease but also those who were healthy carriers. For example, individuals with a carrier states were excluded from joining the armed forces or training as aviators (Tapper 1999, Anionwu and Atkin 2001) for fear that they could have a sickle cell crisis. There was a perception that the disease was catching thus posing a threat to communities and an individual’s co-workers. There was a lack
of education or awareness and affected individuals, communities and the general public was not prepared adequately for the outcome of the mass screening programme.

The poor management of mass screening in America resulted in Black people’s reluctance to be identified with the gene. Extensive government investment since the 1980s, in an attempt to redress this gross error in public health screening, has been of some benefit resulting in a marginal reduction in stigmatization, but four decades later it is still proving difficult to reverse the harm done by unwitting policy-makers. In a discussion on attitude and political aspects of sickle cell in North America Tapper (1999) alluded to the stigmatization that the use of the ‘disease’ discourse has had on African-Americans and Black populations worldwide. The label ‘disease’ given in the mid-twentieth century has resulted in many Black Americans wanting to dissociate themselves from the gene. This appears to have had a knock-on effect in Africa especially since the African environment appears to be fertile ground for the development of stigma in view of the already held attitude to any disease and illness. Many European and American researchers in the mid-twentieth century conducted sickle cell research in Africa and it is possible that they have influenced the local society’s response to the condition. Perhaps the associated stigma was perpetuated by these early researchers. A society where a belief in witchcraft and superstition is common creates a fertile ground for further development of myths, superstitions and a possible negative attitude to a disease that was previously unknown and poorly understood, but proven to be a major killer.

Many of the African respondents demonstrated a shared cultural perception of the nature of SCD, and memories of their African societies’ negative attitude to SCD is perpetuated, many continuing to believe in its association with the birth of malevolent children ‘ogbanje’ (reincarnate) as aptly described by Nzewi (2001) who propose that the symptoms described suggest that many of these children probably had sickle cell disease, a proposition that was originated by Edelstein (1986). Being a parent of a child considered to be an Ogbanje is stigmatizing and something which many parents and families will attempt to conceal, especially where the genetic aspect is poorly understood. But few Africans accept SCD as the explanation, including those who are well educated, and they continue to perpetuate the ogbanje myth, demonstrating further the deep roots of culture and how people will continue to support a cultural explanation for a given phenomena.

The stigmatizing nature of SCD as perceived by many Africans can be difficult for western health care professionals to appreciate fully, including western-trained health professionals of African origin. How is it possible for people to have such strong views and objection to a condition that is
hereditary and beyond an individual’s control? Oppenheim (2003) made a distinction between different levels of being, claiming that the surface level ‘opinion’ can be influenced by social trends and is therefore changeable, but the second level, ‘attitude’, tends to be deeper, formed during the formative years (enculturation) and is more difficult to change. Even after attempts have been made through educational activities, a deeply held attitude is likely to meet with resistance because it has become embedded in a person’s psyche. Individuals are often unaware of this attitude which is often unconscious.

In an attempt to minimize the stigma associated with SCD a few health care professionals in the UK and Africa suggest renaming the condition ‘sickle cell syndrome’, but others think that renaming the condition may create the perception that it is not particularly serious, and affected individuals when presenting in a hospital emergency room may be given ineffective treatment. Many African societies believe that the main goal of adulthood is marriage and procreation. It is not surprising therefore that such strong negative feeling towards disease and illness are evoked. Anything that disturbs this human purpose can be detrimental to the future prospects of marriage not only for the individual but their extended family and kin. Kinship ties in many traditional societies can make it difficult for an individual to conceal the presence of a genetic condition in the family, especially with the common practise of conducting extensive research a family’s history prior to a marital proposal. Attitude to disease and illness is envel oped in the strongly held value attached to marriage and procreation and the data in this study demonstrates statistical significance between Africans and Caribbeans in respect of reproduction and hence to disease and illness, including SCD.

The statistically significant difference observed between African Male and Caribbean Male respondents, with African Males having greater knowledge than the Caribbean Males (Section 5.3.7.1) is likely to be due to reasons similar to those proposed for the African and Caribbean respondents, notably differences in educational background and level of exposure and experience of sickle cell disease. Because fewer of the Caribbean Males have personal experience of living with someone with SCD they invariably have less knowledge of the disease.

Hughes and Sharrock (1997) argued that knowledge is a shared social construction and the willingness to acquire knowledge about a specific subject depends in part on the socio-cultural attitude to the subject matter. This suggests that knowledge of sickle cell is a shared social construction: an individual or group may be receptive or dismissive of the subject depending on the
social environment, collective social construction of the subject and their society’s attitude to the subject. Since disease and illness is perceived a taboo subject in many African societies the social construction ‘discourse’ of SCD may in part account for the Africans obfuscation of knowledge about the condition. Even when exposed to the information, individuals may be cognitively unreceptive and may deny having such knowledge in an attempt to distance themselves from the subject. It is possible that this may be more evident among women than men when one considers the powerlessness of some women, especially those from traditional families where admission of awareness of such information places the woman at a disadvantage.

The myths about sickle cell continue to be perpetuated and appear to be culturally specific and some of these were observed in all three phrases of the study. For example, a common myth among Africans especially but also observed among some Caribbeans, is the notion that people with sickle cell disease die by the age of 21 years (Section 5.3.1.2), even among the pregnant women (Section 6.2.1.2) 21 African Antenatal and 3 Caribbean Antenatal women believed this myth to be true. This belief is understandable in view of the natural history of sickle cell disease in many developing countries where even those who do not have sickle cell disease are more likely to die young as a result of poverty, malaria and common childhood ailments. When this is compounded with a chronic life-threatening ailment like sickle cell disease the chances of survival is further reduced, especially in rural villages (Konotey-Ahulu 1992, Akinyanju 1989 and Akinyanju and Anionwu 1989).

The emotional impact of coping with the challenges that SCD poses can be challenging for many parents and families. To have surmounted these successfully for twenty-one years and then for the child to die subsequently when the rewards of parenthood are about to be realized, is something few parents would wish to experience. Among the African community there is a rational explanation for this misconception. SCD is associated with high mortality in Africa, as much as 80% of children born with SCD die before aged five years (Akinyanju 1989, Adekile et al. 1992, Juwah et al. 2004, Serjeant 2005). Many of the respondents in this study may not be aware of this statistic especially as the majority of these children die undiagnosed. Those with SCD who are relatively well, who are less severely affected or have better standards of living and can gain access to adequate health care are less prone to death from the clinical complications described in Diagram 5, therefore they are more likely to survive into adulthood. However, the long-term clinical pathology of SCD such as organ damage will begin to manifest in late childhood and the chances of death increase. In developed countries the median survival of those with sickle cell
anaemia (HbSS) is estimated to be 42 years in males and 48 years in females (Platt et al. 1994). This is considerably less in Africa, where the majority dies in childhood and of those who survive this period a significant proportion die in early adulthood, including those living in urban areas.

Lack of adequate nutrition, clean water or access to affordable health care makes living with this potentially fatal and unpredictable condition difficult and the death toll is high, even among middle-class affluent families. As observed by several clinicians and authors adults with sickle cell disease is a rarity in many African villages (Adekile et al. 1992, Konotey-Ahulu 1992, Embury et al. 1994, Akinyanju 1989, Serjeant and Serjeant 2001, Juwah et al. 2004, Serjeant 2005); the chances of dying from a myriad of associated complications means it is unlikely that many in these environments will survive into adulthood. It is not surprising therefore that many believe that people with SCD die during childhood and certainly by early adulthood. One African Male Partner whose brother had died the year before the interview stated, ‘(he) was forty and still died, the sickle cell was difficult for (a) long time before he came over to England, by the time (when) he came here it was managed very well, but he still died… he was about forty! Our belief then is that if you are twenty-one years old that means you have passed the age of dying from sickle cell, he shouldn't have died again!’ Although there has been extensive education to dispel the myth that the sickle gene is found only in Black people this belief has remained and was demonstrated in this study. A proportion of the overall population believed that the inheritance of the sickle gene is determined by one’s colour (Section 5.3.1.2). Many people find it difficult to understand that although some of our human characteristics have racial specificity, like the colour of our skin, the majority of our characteristics are not racially specific and the environment plays a significant part even in the way a condition is manifest in an individual. The human body is not an exact science and the human society is a melting-pot of individuals who have intermarried for many centuries.

Another common myth among many Africans is a perception that those who are educated (Section 5.3.1.2) is less likely to have the sickle cell gene in their family, because some believe that the condition is infectious and therefore contactable. A larger proportion, who know the condition to be genetic believe that educated people by virtue of their intellect should recognize the need for pre-conceptual testing and where the result indicate sickle cell trait should pre-select their partner to avoid the risk of having a child with sickle cell anaemia.

It was not surprising that this finding was most striking among those who migrated to the UK >15 years of age, noting that the majority of this latter group are African respondents. And it supports
the common notion advocated by a significant proportion of Africans, including many health care professionals that where two individuals carry the sickle cell gene they should not have children together (Section 5.3.1.3 and Graph 6). This attitude was observed in one Caribbean Antenatal only and this was an individual who has two children with SCD already and married to an African. It is likely that the personal experience of having children with SCD and frequent interaction with her husband’s culture and cultural group may have influenced this individual’s attitude.

It appears that when a situation becomes personal the reality of making such pre-marital or pre-conceptual choices is of greater importance but the decisions made do not necessarily fit with what may have been voiced by an individual, and decisions often contradict beliefs and values. This was highlighted by Shiloh (1996) and Duster and Beeson (2007). It is often the same individuals who perceive that educated people should know better that when placed in such a dilemma themselves are less likely to make what is deemed an anticipated or appropriate genetic or pre-pregnancy choice that will reduce their risk of having an affected child.

Interestingly, the fact that 24 (18%) of the African Antenatal women reported that they chose their partners before marriage or before starting a family suggest that some of the women had the power to make such choices (Table 21). What was not explored is at what point in their relationships did the women make their choices, since they remained at-risk of having a child with sickle cell anaemia? Was the choice relating to sickle risk, or choice in respect to not having an arranged marriage and selecting their partners not taking account of the risk of sickle cell? In these cases the prospective partner’s haemoglobin genotype is unknown before marriage.

Did all the women understand the question? I suspect the issue of choice was misunderstood by some respondents. If this is not the case then it suggests that despite having known their risk status prior to selecting their partners the women did not utilize the information to reduce their risk, and if this is the case why? On examination of the individual women’s partners’ questionnaires it became apparent that the majority of the women’s partners stated that they were not aware of their haemoglobin type prior to ‘starting a family’ and this suggests that they were not aware of their being at-risk if they have children with the woman they were at the time courting, hence it was confounding that these women stated that they selected their partners purposefully. Many of the women ignored the information which is akin to Hill’s (1994) finding of obfuscation of knowledge among low-income African-American women in USA.
In the current study, was the information not shared because of the women’s fear of losing a prospective partner if they disclose the information pre marital? This will require further exploration in a future study because it will have major implications for future policy-making. The current trend in the NHS strongly advocates pre-conceptual testing and major campaigns to promote this among African and Caribbean high-risk communities are imminent. An awareness of the way in which people use such genetic information, especially preconception, is crucial.

Screening has evidently brought dilemmas which individuals attempt to deal with often at a time least suited to dealing with the information. Many well-meaning health and allied professionals advocate pre-conceptual testing, but there is evidence that people armed with the result do not necessarily utilize it in the way anticipated by policy-makers, as demonstrated in this and other studies (Duster and Beeson 2007). It has been demonstrated in this study that knowledge is not an adequate explanation for genetic decision-making in relation to premarital or pre-conceptual choices in both the African and Caribbean group of respondents, especially the African, where one would have anticipated a more deliberate choice to avoid having a child with SCD since the social ramifications of having one appear somewhat bleak, as outlined by several respondents in Phase 3.

Although a few respondents made a conscious decision to purposefully select their partner before marriage or before conceiving the majority did not. Secondly, a greater proportion of the Africans agreed that individuals should share information about their carrier state with a prospective partner prior to having children (Graph 10) though evidently few of these respondents did. Six African Females indicated that they would have purposefully selected their partners if they had known that they have sickle cell trait but evidence from this study suggest that perhaps they probably would not, since of sixteen African Females who were tested and knew their carrier status none chose their partners purposefully. This is similar to Duster and Beeson’s (2007) findings: 20 African-American mothers of children with sickle cell disease knew their carrier status pre conceptually yet they did not use this information to prevent having a child with SCD. I suggest this finding is due to denial and a reluctance to acknowledge the implications of the presence of the gene or deal with having to make a decision as to what to do with the information, a common response to an anxiety provoking occurrence.

The study demonstrated the anxiety over disclosure of such information and its potential consequences may be contributing to limiting individuals’ decision to share or not to share such sensitive information. What is the likely outcome, how often would an individual be prepared to
terminate an at-risk relationship especially in a society where one in four are carriers and one in sixteen couples are at potential risk? Recognizing the stigma associated with being a carrier of a ‘defective’ gene in the African community is it likely that individuals will share such information? The choice not to have children is probably not an option for the majority of Africans and Caribbeans, especially the Africans, in view of the cultural imperative that every individual must strive for parenthood irrespective of personal choice.

Shiloh (1996) reporting on a study by Evers-Kiebooms on genetically determined Down’s syndrome. The researchers noted that 66% of those identified through family studies said they would subject themselves to genetic testing if it were available, in order to know if they carry the gene, but when it did become available only 11% of the same group agreed to be tested. What people say they will do and what they eventually do can be contradictory and appear irrational. It should be noted that in some cultures an admission of one’s genetic status may make an individual, especially a woman, less marriageable and this will have major social ramifications. In view of these findings perhaps greater emphasis should be placed on use of genetic screening as early as possible post-conception or advocating better access to pre-implantation diagnosis for at-risk couples where the technology is applicable. It was not surprising that in the current study men appear to feel more opposed to having a child with a genetic disease and feel the condition to be serious and a potential burden. This reflects the findings of other researchers including Beeson et al. (1985), Sorenson et al. (1986), Marteau (1995) and Duster and Beeson (2007).

The cultural difference in attitude towards the idea of two people with sickle cell trait not having children together as observed in Phase 1 (Graph 6) can be explained by differences in social experiences within the respective cultural environment and in the context of differences in health care in the two environments of origin. The majority of the Caribbean respondents are born in the UK and would be aware of the adequacy of health care in the UK via the NHS, even those who grew up in the Caribbean where health care is often paid for at point of access or through an affordable health insurance scheme individuals would expect a service that is accessible and for the average citizen affordable. Conversely many Africans are fully aware of the inaccessibility of health services in many African countries and even where one can afford to pay for services a lack of resources in some areas makes health care inaccessible, especially in rural areas where specialist knowledge may be scarce. Moreover many Africans are aware of the high fatality associated with living with SCD in Africa.
It was not surprising that the African Males were the largest group who ‘strongly agreed’ that two people with sickle cell trait should not have children together and this perhaps reflect the group’s perception that SCD is a severe disease that places a heavy burden on many families (Section 5.3.1.3 and Table 12), whilst Caribbean Females were least opposed to two people with sickle cell trait having children together. Many traditional cultures are male-dominated and patriarchal, including the majority of African communities, and society’s expectation is that the male is the provider for the family and has responsibility for its sustenance. This is enculturated into boys from childhood and reinforced through life associations and experiences within their culture. The male’s desire and ability to beget healthy children and provide adequately for his family some would suggest is intrinsically biological and instinctive, others would suggest nurturing and social structuring has a greater influence. Irrespective of which argument one supports, in many traditional African, and in many respects also in Caribbean families, this ability of the male to provide determines the level of respect that will be afforded the individual.

Anything that potentially jeopardizes or calls into question the man’s ability to beget healthy children in order to continue the family line and to provide adequately for his family I suggest will have a negative impact on the male’s ego and his sense of self-worth. Many African respondents in the Phase 3 interview raised this as an important issue, and it would account for the African Male being the largest group who ‘strongly agree’ that two people with sickle cell trait should not have children together (Graph 6). I suggest this construct has a close association with attitude to the importance of having children.

Although paternalism appears less strong among the Caribbean community where women appear to have greater autonomy in relationships and in the family, it was interesting to still note that of those who ‘agree’ with the statement Caribbean Males account for the largest group, again reflecting the male dominance and the intrinsic desire to have healthy children and provide adequately for the family. This gender difference I suggest demonstrates the responsibility and pressure placed on the Black male, in both ethnic groups, to ensure continued genetic stability of their community by producing healthy children and later securing their future through care and protection from elements which may disrupt their future ability to maintain future generations and is in accord with some of Welsing’s (1991) theory on race, colour and the Black male. The lack of difference to the issue of two people with sickle cell trait having children together among the pregnant women was surprising and can only be accounted for by the psychological distress which such a view would cause to those who are evidently in an at-risk situation already.
All the respondents in Phase 2 are pregnant and at-risk of having an affected child when data was being collected, I suggest that for them to echo the common cultural opinion about whether at-risk individuals should have children together or not suggest that they themselves have made what may be regarded as a ‘wrong’ choice which would force the women to confront their current predicament in a way that would probably be too painful for them to deal with emotionally and psychologically; the situation already exists and in most cases would be difficult to alter at a point in time when a woman needs the support of a partner emotionally and in terms of resources.

The stigma associated with SCD for the Caribbean population I suggest impacts on individual personal ego rather than having the same devastating social ramifications as it does for some African communities. Many African respondents alluded to the impact of stigma in the Phase 3 interviews, noting that the presence of the gene has a major impact not only on the affected individual but on members of their nuclear and extended family many of whom may experience rejection by prospective marital suitors. Hence attempts to conceal the presence of the gene. Interestingly, of the African respondents who were not in opposition to two at-risk people having children together the support for such a notion was often stated in a contradictory manner and often has religious connotations. These individuals feel God is in control of human destiny and whatever happens, happens for a reason yet they feel it is important for two such individuals not to marry each other and it was not uncommon in the Phase 3 interview to note the dilemma faced by these individuals as they sway between their cultural values and the pull of their religious values and convictions. The religious dimension will be discussed in greater depth later.

In comparing pregnant and non-pregnant women the differences in knowledge were not altogether unexpected (Section 7.2.1). The majority of the pregnant women in the current study would have been given written information about sickle cell trait, and by virtue of being at-risk would have had genetic counselling in the current or previous pregnancy. However, the healthy carrier state of sickle cell trait was still poorly understood even among some of the pregnant women. The women perceived that they were potentially less healthy than those without sickle cell trait. This is a worrying finding among the pregnant women, especially, and calls into question the adequacy of the genetic information that they were given. This lack of understanding about a healthy carrier states is similar to Marteau et al.’s (1992) observation in a pilot study of people tested for Tay Sachs disease comparing those with a normal result and those with a carrier states. Those with a carrier state were told that they have a healthy carrier state yet they assumed that their health status will be at-risk in future because of their carrier state.
A second misunderstanding is that sickle cell trait can change into sickle cell disease later in life (Section 7.2.1) and although a larger proportion of the non pregnant women believed this, again it is worrying that some of the pregnant women also believed this to be the case. It could be suggested that this lack of understanding may be attributed to language barriers among those whose first language is not English. This may occur among Africans, but how does one account for this finding among some of the Caribbean respondents since they all speak English? I suggest this call into question the adequacy of the information given to the pregnant women and perhaps a failure to check their full understanding.

A number of the African Antenatal women, when identified as being carriers, confirmed that they had difficulties trying to persuade their partners to attend for testing. This idea that people with sickle cell trait are less healthy will probably account for some of the men’s reluctance, since they are aware of their fitness it would seem pointless to have an unnecessary blood test just to confirm what they already know. In the Phase 3 interview a number of the African men were reported as claiming to be ‘OK’. Since they are not unwell and are physically strong they assume it is not possible for them to have the sickle gene.

Few lay people understand the concept of ‘healthy carrier’ and the nature of a ‘recessive’ genetic condition. The idea that one has ‘abnormal’ haemoglobin yet one is well contradicts many people’s concept of having a ‘positive’ result for a serious illness, and to be told that one is ‘healthy’ is beyond comprehension. This reflects the general lack of understanding of genetics, which prevails even among many health care professionals, as was highlighted by Marteau et al. (1992), Richards (1996) and Emery and Hayflick (2001). It also demonstrates the level of work required for educating people if they are to utilize the opportunities offered by new genetic technologies.

### 9.1.3 Importance of having children

Both the African and Caribbean cultural groups demonstrated that it is important to have children however there was a high statistical difference between the Africans and the Caribbeans (p=0.000) where the Africans had a higher mean score (Section 5.3.1.3 and Table 9). Statistical difference was also observed in the African Males and Caribbean Males where more of the African Males feel it is important. I suggest these findings are a reflection of the attitude to procreation. Whilst the
African and Caribbeans both feel it is important, the Africans of both gender experience greater pressure to have children. Caribbean Males value children but the majority does not experience the family and societal pressures that the African Males are subjected to. It is possible for a Caribbean Male to choose not to have children, something that is an anathema in the ‘interdependent’ African society. The importance of maintaining the family line is reiterated to the African child from early childhood and the interdependence of the African community ensures compliance of the majority of its members. Every child is indoctrinated during the early years of enculturation; the deep primary level of unspoken cultural norm (Helman 2001) is embedded into the individual’s psyche. Those who choose not to adhere to the rules of society are likely to be persistently ridiculed, ostracized and even excommunicated by kith, kin and the wider community. The naturally childless will be pitied but the selective childless will be viewed as foolish at best and insane at worst. The latter is likely to eventually conform to cultural expectations and have children. However this discrepancy in personal preference, not to have children, and society’s pressure to procreate will create dissonance and such individuals will use justification elements to help relieve the dissonance with the intention of returning to a state of equilibrium.

This is often not the case in the more westernized and ‘independent’ Caribbean societies of Britain where individual preference not to have children is acceptable. This aspect is further highlighted in the qualitative interview discussions where the Caribbean Females who are in a relationship with an African Male all recognized and reiterated the mantra that ‘childlessness is worthlessness’. They had come to recognize that childlessness is not an option, irrespective of their personal preference, if they expect to remain secure in their relationship with their African partner and be accepted by their in-laws and his extended family. As highlighted by Madu (1994), in most African cultures marriage is perceived as an undertaking to which all adults must subscribe and bachelorhood is seen as an aberration, but, more importantly childlessness is a state that is condoned even less and procreation even without marriage is considered a more acceptable state than childlessness. In view of this it is not surprising that there are differences between the African Male and Caribbean Male.

I suggest that the pressure exerted by society accounts for the Africans overt desire to have children and was amply illustrated in this study. Despite numerous literature searches no studies were found that examined this aspect of the Caribbean culture and it would be useful to do further studies in this area, comparing differing cultures and in different cultural settings, but especially comparing Caribbeans living in the Caribbean and first- second- and third-generation Caribbeans living in the UK. This finding is in support of Atkinson’s (2004) assertion that enculturation, which is the
learning that takes place in one’s indigenous culture, can be so powerful that the values, beliefs and practices absorbed by the individual can be difficult to eradicate and are often not perceived consciously by the individual (Helman 2001). This supports the theory that early enculturation ensures individual conformity to the group’s values, beliefs and socio-cultural practices, ensuring continuation of the group’s basic philosophies and values. As highlighted by (Sowell 1994), ‘cultures are not erased by crossing a political border, or even an ocean, nor do they necessarily disappear in later generations which adopt the language, dress and outward life style of a country’. This will account for the highly statistically significant difference observed between those born/migrated <15 years of age and those migrated >15 years of age (Table 11) and is related to the cultural pressure to have children that was discussed earlier.

Gender differences were also observed where more men than women felt it is important (Section 5.3.2.1) to have children; however I suspect the African Male is the major cause of this gender difference. As stated earlier the Caribbean respondents interviewed and demonstrated in the Phase 1 questionnaires felt that, although it is important to have children, however, the decision should be a wholly personal one and should be of little or no concern to the extended family, friends or wider community. All the Caribbean respondents acknowledged that in the Caribbean culture it is acceptable to choose not to have children without fear of hostility, overt or covert criticism, rejection or being ostracized by their family or cultural group. As noted by Lips (2003) ‘Attitudes towards childbearing vary across cultures and time periods, of course, but a common persistent theme is the notion that a woman who does not have children has missed out on the core aspect of being a woman’. For the average Caribbean close family and friends may express disappointment that the individual made such a decision but there is acceptance of the individual’s right to choose and the individual would not experience any anxiety about making such a decision. This attitude in the Caribbean culture further highlights the cultural emancipation of people from the Caribbean: the freedom to make choices that seem comfortable with one as an individual or as a close nuclear family. This reflects western values. This individualized western decision-making adopted by the Caribbean group I suggest demonstrates the greater western cultural orientation and the adoption of what Kashima et al. (1992) describe as an independent societal attitude to decision-making, i.e. individualistic, a state of being that feels comfortable and right for the decision-maker and to operate in a converse manner or make decisions that do not reflect this mode of being would create dissonance.
For many Black Caribbeans the original Black African cultural value relating to child bearing have long dissipated, giving way to the blend of a unique cultural tapestry, which includes Euro, Anglo, Afro, Creole, Asia values. To make decisions which focus on the individual’s preference will not be uncomfortable since the biggest influence is the Anglo cultural tradition, which advocates independence and individualistic decision-making. In contrast, data from the study demonstrated that all the African respondents including those who felt they personally did not want children recognized the cultural ramifications of making such a choice and the socio-cultural problems they would encounter not only from their immediate family but from the wider African society, where it is deemed ‘unnatural’, ‘unacceptable’ and ‘untenable’ to deliberately choose not to have children. Even those who felt they did not wish to have children many felt compelled to adhere to the cultural norm for fear of the possible ramifications of choosing what is discordant with the larger cultural group. This affirms the overwhelming evidence from other researchers including Maclean (1978), Madu (1994) and Lips (2003).

The cultural lens through which the African respondents view the world appears to be less responsive to modification than the Caribbean respondents’ cultural lens. There appears to be greater societal control over the individual’s thinking in the African culture probably due to greater interdependence within that culture. Even those who are highly educated maintain the cultural values and adhere to cultural expectations often irrespective of the impact it will have on them personally, provided it fits with the cultural expectations. Hence a medical doctor interviewed in Phase 3 felt compelled to have children even though this was not her personal desire.

The social transmission of a cultural response to having children is amply demonstrated and the findings of this study show the power of culture and give credence to the assertion that enculturation, which is the process of primary learning which takes place within the family and cultural group, serves to instill certain values, beliefs and ways of viewing the world and ensures conformity to the group’s norms (Durham 1991, Helman 2001, Collier 2004). The interdependence of many traditional African groups in terms of social and economic stability makes it difficult for individuals to reject many of the cultural norms for fear of rejection by the wider society. The power which many Black parents and parents from other non-western societies exert over their adult children is often perceived as remarkable by western observers. This is often irrespective of the degree of education, monetary wealth and social status of the individuals and can be said to be true for many African and, to a lesser extent, Caribbean families.
An African choosing not to have children will be considered at best peculiar or deviant and at worst insane, a person not to be trusted, taken seriously and perhaps not to be associated with unless absolutely necessary. Some of the respondents in Phase 3 alluded to this in describing the cultural response to the idea of choosing not to have children. Such individuals and couples will experience covert criticism, some hostility mistrust, ridicule and even name-calling, such as being called a ‘witch’ or ‘wizard’. A high level of education, financial and social status does not absolve individuals from the responsibilities of participating in parenting. The notion of a ‘career’ woman or man is anathema to the average African and is regarded an alien concept even where individuals attain the pre-requisite to be members of a higher echelon of society it is not sufficient compensation for childlessness. Where barrenness is as a result of infertility there maybe a degree of empathy and the offering of extended family or friend’s child or children to live with the individual or couple in order to relieve the emotional pain that it is assumed such individuals will be suffering for their lack of ability to conceive and bear a child. Such empathy however is unlikely to be extended to those who consciously choose not to have children they will be viewed with suspicion.

It has been established that within any given population a proportion of heterosexual women and couples are unable to have children, Lips (2003) estimate 5 to 7 per cent of women in some African countries. As in other communities the cause of infertility is often unknown and it is therefore unfortunate that such individuals and couples in the African community are subjected to social isolation and ridicule. In most cases it is assumed that the female is the cause of a couple’s childlessness and is potentially at-risk of being ousted from the marital to make way for another woman in her partner’s life. Quite a number of the African Male, African Female and African Antenatal respondents describe this cultural phenomenon as do Caribbean women who are in a relationship with African men, further demonstrating the depth of the cultural attitude to procreation and actions taken by the African community to deal with it. The plight of the barren woman is a contradiction in terms of the tolerance of many African communities and the interdependence of these societies.

It appears that many of the African at-risk women and couples were in a catch 22; whilst it is not culturally acceptable to choose not to have children it is also not acceptable to have unhealthy children because of the social and economic ramifications. The idea of choosing to marry but not to have children because of a genetic risk as proposed by Richards (1996) may be possible to a certain degree in the western society but is highly unlikely in the African community. I suggest an
individual may make choices about selection of a partner to reduce their risk but it is highly unlikely that an African man or woman will choose not to have children, even if there is risk of having child with SCD. The fear of being perceived as barren and rejected by society is greater than the concerns of having a child with SCD disease and many of the African respondents voiced the opinion that even if they were to have a child with SCD it is better than not having a child at all, as demonstrated by one African Antenatal woman interviewed, ‘… as a woman or family (when) you have got a child people will know that you’re not barren, you can produce only that you’re not lucky enough to have a healthy child’. Although the prospect of having a sickly child is not acceptable to many Africans the fear of being perceived as barren causes greater anxiety. These two cognitions create anxiety and dissonance and the respondent above utilizes a consonant element to justify risking having a child with SCD; that is the unacceptable state of being perceived as barren.

The often negative attitude to having children with a disease or illness I suggest affects African women more than African men since culturally women are often held responsible for producing a ‘sickly’ child. Irrespective of explanations about recessive genetic inheritance and the man’s contribution to the child’s inheritance, the woman is still more likely to be rejected by her in-laws or even ousted from her marital home. In many cases the man’s family will not accept their son’s genetic contribution to the child’s illness preferring to find another partner for their son. In any culture marital separation is an emotive subject and even more so in traditional societies like Africa where divorce is generally unacceptable and men are favoured. Women often find it difficult to find another partner when ‘rejected’ for producing ‘sickly’ children.

These issues create a social problem that is difficult to reconcile and one which places individuals especially women, at an unfair disadvantage within the society. Barren men and women may be labelled as ‘witches’ or ‘wizards’ and be accused of evil practises such as using their ‘womb’ or ‘manhood’ for performing money-making rituals. However the price to pay for such ill-gotten wealth is his or her fertility, which many perceive as justice according to the law of Karma. This cultural belief was highlighted by some of the African respondents.

This issue of labelling was mentioned by a number of both male and female African respondents from diverse African countries, including Nigeria, Ghana and Zambia. The continued belief in witchcraft and wizardry is highly cultural and a few from the Caribbean still maintain a strong belief in witchcraft, possibly remnants of their African ancestral heritage. Conversely a greater
proportion of educated as well as uneducated Africans continue to perpetuate this belief, including many professionals. The belief in the power of good and evil and religion remains strong in many African and Caribbean communities and appear to have significant influence in the respondents’ response, this religious aspect will be discussed further later in the discussion about the impact of religion. This was amply demonstrated in the Phase 3 interviews.

Western policy-makers and health care professionals who are unaware of the depth of the cultural response to procreation and barrenness may fail to appreciate the degree that some couples would go in order to have children. Even choosing to have a child with sickle cell anaemia is perceived as better than not having children at all. The continuing demand for infertility treatment beyond a level considered viable by western medical practitioners may baffle health practitioners and medical advice to cease pursuit of parenthood may be ignored by infertile African men and women as they pursue the strong cultural demand for ‘parenthood at any cost’.

It was surprising that of the Africans those who were born in the UK/ migrated <15 years of age demonstrated similar values to those who migrated > 15 years of age, further demonstrating the depth of culture despite crossing continents. Especially where the host culture does not lend itself to incorporating other cultural values and practises the adherence to the comfort zone of one’s original culture become perpetuated and the host culture has limited impact on the individual or community. It was not surprising that the African Males demonstrated the greatest conviction that it is important to have children more than Caribbean Males, but it was surprising that this desire is also greater than that of the African Women, where I had anticipated that because of the social ramifications of being barren African Females would express stronger sentiments towards having children than African Males. In an attempt to understand this unexpected phenomena one need to examine the psyche of the African male and the pressure placed on him to maintain the family line. Although he will not fear being expelled from his home, his plight is probably graver than that of the barren African female. For many men to be unable to impregnate a woman is a social stigma which has a great effect on the male ego and in a traditional society where it is unacceptable to be childless there is great pressure to produce. It is not uncommon for barren men to seek the assistance of a brother or other male member of the family who may be approached by elders in the family to help impregnate the man’s wife in order to conceal the man’s impotence. This becomes a family secret to which all those concerned swears to maintain secrecy, some of the African respondents in Phase 3 described this cultural phenomenon. It can create problems in a genetic screening service, for example, in the national neonatal sickle cell screening programme where a
child’s haemoglobin type fails to match that of the parents, invariably questions arise with regard to paternity and can create social complications, especially if the extramarital arrangement was not made known to the woman’s partner and the child’s putative father.

In most traditional and patriarchal societies maintaining the family lineage rests solely with the male and more so in societies where one’s status in society is dependent on the ability to produce sons such as that observed in the majority of African and Asian cultures. Inability to beget a son who will continue the family line is serious (Maclean 1978) but inability to produce children at all creates greater anxiety, shame and tremendous fear not only for the affected individual but for their nuclear and extended family whose members may also feel the reverberations. This is even more crucial in communities where arranged marriage or pre-marital fact finding is practised and distant relatives may experience difficulty securing a partner even where their own fertility has not been tested or proven. Hence in some African communities it is acceptable and often preferred for a woman to be pregnant prior to the man’s family seeking her family’s consent for a marriage. Without this some traditional families would not allow a marriage to proceed. This practise is common even among those who purport to be highly religious.

It was interesting but not surprising to note the highly significant statistical difference in attitude to procreation between pregnant and non-pregnant women with more of the pregnant women feeling that is important to have children (Section 7.4.6). The pregnant and non-pregnant African women felt it is important to have children and the difference observed between the African Antenatal and African Females, with the African Antenatal women having a greater conviction than the general public African Females was unexpected in view of their common cultural background. Perhaps differences in their current situation accounts for this. Evidently being pregnant in it self affirms ones attitude to having children and I argue that it would be psychologically difficult for a pregnant women to say that it is not important to have children by virtue of their current physical state.

Secondly, I suggest the age difference of the two groups probably contributes to the difference observed: the younger women would probably feel this conviction more strongly than the older women. The latter having lived longer may feel less compelled to adhere to a cultural way of thinking and developed the confidence to challenge cultural norms and values. This is supported by the finding of a statistical difference where the African Antenatal women scored higher in the Powerful Others domain of the Multi-dimension Health Locus of Control than the African Females (Section 7.2.4). The African Antenatal women believed that other people had a greater influence
on their ability to remain healthy and this is probably reflective of their general belief about other life situations, where there is perhaps a tendency to feel powerless despite the overall better education of the pregnant women. An example of this was demonstrated in Phase 3 where one African Antenatal woman stated that she did not want to have children but felt compelled to do so as a result of pressure from her family and society. This affirms other researchers’ findings that education or moving to another culture does not necessarily alter one’s cultural mindset. In addition I suggest that life experiences and the maturity that goes with age probably does; as one gets older perhaps one feel better able to challenge pre determined cultural values.

9.1.4 Attitude to sickle cell disease

It was proposed by several authors (Dickinson and Bhatt 1994, Marteau and Senior 1998, Petrie et al. 1998, Henley and Schott 1999) that culture plays a significant role in attitude to disease and illness. The data in this study provides further support for this assertion.

Many African communities remain highly patriarchal and men are often the main family providers not only for the nuclear but for the extended family, especially family who remain in the country of origin, ‘back home’, many of whom depend on their relatives living in the more affluent west to provide for their basic subsistence. It was not surprising that Males perceived SCD as a serious condition not only because of its health impact, but I suggest because of the social and economic ramifications for the family bread winner and their nuclear and extended family. Carrying the burden of family welfare is a major responsibility and the severity of the disease will probably appear greater than reality, especially for males who do not participate in family health care management, and I suggest this is the majority of men in many societies. Females are often the main care-giver in the family (Thorogood 1989), so their experience and ability to deal with the challenges of disease and illness is often better developed compared to males who are more likely to be recipients of health-care, even in the home. I suggest that this accounts for men’s perception of the severity of disease and the difference compared to the women.

Many Caribbean communities are matriarchal. Those who migrated from the Caribbean especially first generation migrants, many continue to maintain ties with ‘back home’ and are depended upon to maintain nuclear and extended families, especially elderly parents ‘back home’. Many first-
generation Caribbean migrants’ perception of the severity of SCD is likely to be derived from their memory of the impact of SCD in their country of origin. However, the healthcare system in the Caribbean appears better developed and care is readily available. Although cost is also an issue it is not as incapacitating as that witnessed in many African countries. It is worth noting that the world-renowned sickle cell research and clinical management specialist centre funded by the English Medical Research Council (MRC) was based in Jamaica for over thirty years and continues to flourish even today without the MRC funding. I suggest that many of the surrounding islands are likely to have benefited from the research findings of the centre, and likely to have had some direct association with it, further promoting knowledge and awareness of SCD.

The majority of the Caribbean respondents felt able to share information about their genetic status with family members and friends, few of the African respondents felt able to do so and those who did was with immediate family members only. There was a level of secrecy (Section 8.3.2) among some of the African respondents that reflects a cultural attitude to sickle cell disease and to disease and illness generally. The stigmatizing nature of the illness became very evident in the response of many of the African respondents (Section 8.3.2.2). The Africans belief in the mystical cause of disease and illness as described by Jegede (1998) and others was highlighted by the African respondents in the current study and the cultural reluctance to accept disease and illness fits with the commonly held belief that such events are as a result of the machination of evil forces, especially witchcraft invoked by one’s enemies. The perception of the burden of sickle cell disease and the social ramifications has a major influence on the attitude, as demonstrated in Phase 1 and 2, and reiterated by respondents in the Phase 3 interviews. This finding is related to the perception that SCD is a severe condition. The primary reason for this is the consequence of observing the physical suffering endured by affected individuals, but more importantly the perception that the disease places a heavy burden on the family. It was not surprising that more of the Africans perceive that SCD is serious and poses a heavy burden on the individual and their immediate and extended family. The highly significant statistical difference relating to burden of illness observed among the African and Caribbean respondents (Section 5.3.1.3 and Table 9) and Males compared to Females where more of the Male respondents perceive SCD to be a severe disease (Section 5.3.2.1) was not surprising in view of the social experiences of these groups. A similar difference was observed where those who migrated to the UK >15 years of age perceived that the condition is a severe disease and a burden compared to those born/migrated <15 years of age (Table 11). It should be noted that those of African origin make up 71% of those migrated >15 years of age and this would have influenced the difference observed in this category. It was noted however that
there was no gender difference between the Caribbean Female and Caribbean Male. The African Female particularly recognizes the potential impact of having a child with sickle cell anaemia and how this can destabilize her position in the marital home as well as its impact on the family in terms of economic sustainability.

The difference observed between the African Male and Caribbean Male probably relates to the African Males greater exposure and socio-cultural experiences of SCD which is similar to the differences observed between all the African and all the Caribbean in Phase 1, noting that the prevalence of the sickle cell gene and the number of potential at-risk couples is greater among Africans (Table 2), hence the African respondents are more likely to experience sickle cell in their immediate and extended family and among friends.

In many African societies hereditary diseases are particularly stigmatizing and individuals known to have these conditions may be ostracized by mainstream society in terms of marriage. The exclusion may include other members of the nuclear and extended family (Jegede 1998), making it difficult for individuals to find marital partners. Petrie (1998) argued that culture influences attitude to disease and illness and ‘health-related behaviour or coping responses are heavily influenced by the patient’s own beliefs and representation of an illness’. I therefore suggest that the African respondents in this study are demonstrating a long held view and attitude that SCD is burdensome, severe and stigmatizing.

Although Tapper (1999) suggests that the 'disease' discourse, applied to the naming of sickle cell by James Herrick in 1910, contributed to the development and persistence of stigmatization of the condition in North America I argue that this is not a factor influencing African communities. The long-held attitude of Africans to disease and illness, and particularly to SCD, probably dates back many centuries, is perpetuated by a strong belief in the supernatural, especially witchcraft (Konotey-Ahulu 1992, Kondor 1993, Jegede 1998, Nzewi 2001). These beliefs emerged in Africa long before James Herrick’s coined the phrase sickle cell disease.

Although disease and illness is stigmatizing in the Caribbean among the respondents in the current study this has not emerged as a particularly relevant issue in relation to SCD. This is perhaps a reflection of the Caribbean respondents’ western attitude to SCD, demonstrating the impact of being second- and third-generation migrants in the UK. Perhaps if the study was replicated in the
Caribbean among indigenous residents of the Caribbean stigma associated with disease and illness and SCD in particular may emerge as a relevant issue.

As stated earlier, the desire to have children and the pressure to do so is very overwhelming in many Black communities but I suggest more so in the African than the Caribbean communities in the UK. Choosing not to have children may be a viable proposition in many Caribbean communities but would rarely be considered in many African communities (Maclean 1978, Basden in Madu 1994 and Lips 2003). The increased risk of having a child with SCD is compounded by the pressure to have children, pressures emanating from family, friends, close community and the wider society. The need to avoid the social, financial and emotional burden associated with having a chronically sick child increases the burden placed on individuals originating from the African community.

In many developing countries and among the less educated in developed countries women are blamed for producing a ‘sickly’ child, this includes any form of disability including genetic conditions, and that is irrespective of the man’s contribution to the child’s genotype. Those who have observed the impact of SCD in a developing country will have a perception that the condition is serious, debilitating and potentially poses a heavy burden on the individual and family resources. Those migrated >15 years of age are more likely to be in this category, whilst those born/ migrated <15 years of age would have observed health and social care facilities that provide adequately for individuals and their families enabling them to cope and live resourcefully with the condition. Therefore, this difference in perception between these two groups is not surprising and should be anticipated in light of previous arguments relating to health and social experiences.

In response to the attitude statement ‘I feel that having a child with sickle cell disease can be a blessing in a family’ a higher proportion of the African Male and African Female ‘strongly disagreed’ with the statement (Graph 7). Although Africans demonstrated a greater level of religious belief I suggest that the perceived level of burden of SCD led to the African respondents’ perception that having a child with SCD is not a blessing for the family, whilst conversely a greater proportion of the Caribbean respondents ‘agree’ or ‘neither agree or disagree’ with the statement. This again highlights the depth of feeling among Africans that having a child with a chronic debilitating disease is potentially difficult, recognizing that the SCD discourse is one that is associated with many negative connotations within the African society, especially because of its
social and economic impact, but more importantly the high rate of handicap it causes and a mortality rate of 80% in some parts of west and central Africa.

The gender difference in respect of attitude to genetic illness supports the findings of other researchers, such as Beeson and Golbus-Mitchell (1985), Sorenson et al. (1986), Marteau (1995) and Duster and Beeson (2007). The current study demonstrated that men perceive SCD to be a serious condition that will place a heavy burden on the family’s capacity to cope and since most African communities are patriarchal men are likely to be more anxious about having a child who will place a burden on their ability to cope emotionally and reduce their ability to provide adequately for their family, especially financially. This would account for the difference observed between Africans and Caribbeans in Phase 1 and Phase 2, where the majority of the Africans believe that having a child with sickle cell disease will cause financial hardship for the family (Section 5.3.1.3 and Graph 8) and the African Antenatal more than the Caribbean Antenatal (Section 6.2.1.4).

Many of the African respondents refer to the issue of burden in the Phase 3 interviews (Section 8.3.2.2). It was interesting to note that there was no statistical difference observed in the Phase 2 women’s perception that SCD is severe and a burden and this I suggest is likely to be due to a collective psychological response to being at-risk of having a child with sickle cell anaemia, better knowledge of the condition as a result of genetic counselling and an awareness of the adequacy of services available in the UK. The African Antenatal and Caribbean Antenatal women are in the same predicament of being at-risk and this appears to have influenced their collective knowledge and attitude as a unified group, hence the lack of statistical difference observed. This suggest that being pregnant and at-risk of having a child with sickle cell anaemia appears to have influenced both groups’ attitude and caused a convergence of attitudes.

I suggest that the other influencing factor is genetic counselling, all these women would have received counselling during the current or previous pregnancy, attempts would have been made to address myths and misconceptions, detailed information would have been given about the disease, its biology, genetics, pathology, clinical and health manifestation and services available to individuals and their families. In comparing the Phase 1 and Phase 2 women the statistical significant difference in knowledge (Section 5.3.1.2 and Section 6.2.1.2) helps to support this argument. Fear of the unknown often creates greater anxiety than reality; hence the lack of
difference in the African Antenatal and Caribbean Antenatal women could be due to genetic counselling by specialist nurses as occurs in most units in the UK. This affirms Clarke’s (1991), assertion that the use of specialist sickle cell nurses who provide clinical care to children and adults with sickle cell disease as well as provide specialist genetic counselling services to women and couples at-risk is of proven benefit. The nurses’ in-depth clinical involvement with patients with the condition makes them better able to provide at-risk women and couples with a realistic view of the disease, allay their anxieties and fears and direct them to sources of further information and support whilst they are attempting to make a decision about an at-risk pregnancy And since they have access to families, this includes putting the women and couples in contact with those who have been through a similar experience.

The majority of the women and couples in Phase 3 reported that they found the genetic counselling service of benefit, whilst a few felt they were being coerced into making a decision that did not fit with their own personal values. One African Antenatal and one Caribbean Antenatal interviewed felt they were being coerced into making a decision to have prenatal diagnosis. However both women were sufficiently articulate and felt able to resist this and to make a decision that is consonant with their own values, beliefs and preferences, as described by Marteau (1995). Within any given therapeutic relationship where there are two or more players, each brings into the interaction some of their cultural values and beliefs, and in as much as professional education and training attempts to influence the professionals’ ability to maintain their objectivity and serve the client’s best interest individual prejudices and values invariably filter through. Being non-directive is a concept and practise that many feel is unattainable and some have even questioned the validity of such an approach (Shiloh 1996). Evidently in a few cases the cultural attitude of the counsellor has filtered through, hence the counsellee’s perception that they were being coerced into a decision that conflicts with their own values. There is a fine line between supporting the client through the decision-making process and coercion, but irrespective of the professionals' view of the session what is of more important is how the recipient feels. An experienced and skilled professional will be able to assess the degree of support the client is seeking and tailor the counselling session accordingly. This issue will be discussed further in implications for future practise.

A deviation from the practise of employing specialist clinicians to do genetic counselling would result in the loss of the evident benefit of using such personnel. Secondly, the majority of specialist nurses in this field are of minority ethnic origin and more than 90% are of African or Caribbean origin. I suggest since all these respondents are of African or Caribbean origin many may feel able
to identify with these counsellors and feel that the counsellor will understand, identify with and respect their cultural views, attitudes and beliefs; perhaps Anionwu’s (1996) argument to ethnically match counsellors and clients has some degree of merit. Only those who agreed to participate in the study were able to express their opinion of genetic counselling services and the majority of these were those who did access services. It would have been interesting to obtain a more robust view of those who did not access services to note whether avoidance of service providers and the genetic information they provided is demonstration of a possible response to the anxiety that being told they have a genetic condition has evoked. In an attempt to reduce the dissonance which knowledge and the need to act and the failure to act brings, individuals may fail to attend for counselling thus using avoidance as a tactic for reducing dissonance as described by Eagly and Chaiken (1993). I propose that many of those who obfuscate knowledge of sickle cell and fail to attend an invitation for counselling, except those who have prior knowledge, is an attempt to avoid the possible psychological impact of the information.

For many women, especially African women, the fear that having a child with sickle cell disease could break their marital home is a reflection of the level of burden that they feel the disease can exert on their family (Section 8.3.2.2). This is reflected in the graphic difference observed in respect of prevention, where 19 African Antenatal and 1 Caribbean Antenatal strongly agreed that science should be used to prevent the birth of children with sickle cell disease (Section 6.2.1.4). This is in keeping with the belief that such children cause financial hardship for the family: 9 of the African Antenatal and 1 Caribbean Antenatal woman strongly agreed with this view. This reflects the ethnic differences also observed in Phase 1.

The implications of caring for a child with a chronic life-long disease in an environment where health services are paid for at point of contact and dependent on one’s ability to pay threatens many families’ social and economic stability. Hence the view that prevention is a better option if possible, even among those who are highly religious, and opposed to PND and termination of affected pregnancies. The idea of prevention seems a more acceptable option particularly with regard to pre-marital selection, despite many of the respondents’ failure to utilize this option, even when they are already aware of their own haemoglobin type preconception.

Dryden in Green and Statham (1996) noted that degree of burden caused by SCD disease influenced parents’ decision-making, but the opposite was found in Alkuraya and Kilani’s (2001) study of Islamic Saudi families who were also at-risk of having a child with SCD. The latter
researcher reported that the burden of disease did not appear to influence the decision to have PND or termination of an affected pregnancy, religion did. The current study did not demonstrate whether this was the case since this aspect was not measured empirically, but the qualitative data suggest that the Africans perceive the condition as being burdensome compared to the Caribbean respondents but this did not appear to influence many of the respondents’ decision because many still rejected PND.

The Phase 3 interview demonstrated that personal experience of living with someone with sickle cell disease played an important role in influencing women and their partner’s attitude to being at-risk of having a child with SCD and the options taken to prevent occurrence. The women who have a child already with SCD were more likely to opt for prenatal diagnosis either in order to prepare for the birth of another sick child or in order to avoid having another child with the disease because they feel unable to cope with the additional physical, emotional and financial burden that another child with SCD would bring. This reflects Dryden in Green and Statham’s (1996) observation that degree of burden influenced decision-making in relation to an at-risk pregnancy.

I suggest the depth of the Islamic religion and a belief that Allah has supreme authority in what he gives you, including a child with SCD accounts in part for the lack of indifference to disease burden in Alkuraya and Kilani’s (2001) study. Whilst many respondents in this current study stated that they were highly religious when faced with the prospect and reality of having another child with SCD one seriously contemplated termination if the fetus is diagnosed with SCD following prenatal diagnosis. Many of the women expressed anguish at the prospect of making such a heart-rending decision especially as it conflicts with their religious values. Dorticos-Balea et al. (1997) reported a similar finding in their study of couples at-risk of having a child with SCD. They noted that those who already have a child with SCD were more likely to opt for PND and termination of an affected fetus. Interestingly, of those who did not have a child with the disease already but opted for prenatal diagnosis the majority did so in order to prepare for the birth of a sick child, which reflects Green and Statham (1996) and the HGC’s (2006) assertion.

An examination of the way in which people use genetic information is crucial since few of the respondents in the current study who knew their carrier status selected their partners purposefully pre conception. Of those who responded to the question about choosing their partner based on their own Hb result none of the sixteen African Females in Phase 1 with a known carrier state which included those with sickle as well as other haemoglobin carrier states: (HbAC, Hb Aβthal) chose
their partner based on their Hb genotype (Table 7). Similarly, of the 13 Caribbean Females with a carrier state none chose their partner based on their Hb genotype, but 1 Caribbean with normal haemoglobin chose her partner purposefully but did not make it clear the reason for this, despite not being at-risk. 7 African Males and 1 Caribbean Male chose their partners pre marriage or pre conception. Interestingly of the women who knew their sickle cell trait status (Table 21) 14 of the African Antenatal and one Caribbean Antenatal claimed to have chosen their partners pre-conception, yet they still committed themselves to an at-risk relationship.

This finding confirms the complexity of human behaviour, which is often beyond logic or science. Availing one with information does not necessarily lead to a predictable response, which is contrary to Atkin and Ahmad’s (1998) argument that if you provide people with sufficient information before conception it will reduce the number of babies born with SCD. The current study has demonstrated that this is not the case, some of those who had exposure to the information through attending awareness-raising events failed to relate the information to themselves and assumed that it has nothing to do with them but with other people (Section 8.3.1). The aim of such health campaigns is to increase the number of those who attend for testing, affording greater pre-marital and pre-conception choices. But this has not been the outcome in many of the African and Caribbean communities. Of those who knew of their carrier status, often as a result of opportunistic testing, such as pre-surgery, the majority did not use the information to select a non-carrier partner or PND in order to prevent the birth of a child with SCD.

The findings of this study raise the question: what will it take to impact on the consciousness of Africans and Caribbeans and encourage greater awareness and testing before marriage and conception? Perhaps health-care providers need to acknowledge that people will not always act in the way anticipated and decision-making in respect of disease and illness is a complex issue. Anxieties about sickle cell is such that four African Males and one Caribbean Female with normal haemoglobin selected their partners pre conception, the reason given by one African Male is the wish to avoid bringing the sickle cell gene into his family, so as to avoid the future ramifications. However, the individual is perhaps underestimating the rapid advances in human genetics and the future possibility of being able to eradicate the faulty gene through gene therapy, a utopian perception perhaps? The other respondents did not indicate their reasons for purposefully selecting their partners despite having normal haemoglobin themselves. This avoidance of the sickle cell gene demonstrates the depth of feeling towards SCD and its associated stigma especially in Africa.
9.1.5 Decision-making in pregnancy

The main focus of this study was to find out whether culture and other social issues played a part in influencing African and Caribbean women and couples decisions about a pregnancy at-risk of producing a child with sickle cell anaemia. In order to examine this specific issue it was necessary to commence with an examination of culture and attitude to a number of social factors that impinge on attitude to procreation, disease and illness and to sickle cell disease specifically. Secondly it was necessary to examine whether the pregnant women reflect their cultural group or whether pregnancy has an impact in shaping their attitude and response to being at-risk. Having examined these aspects it was then possible to explore issues and factors influencing decisions about a current at-risk pregnancy.

It is particularly poignant that although there were some differences in the Phase 1 population’s attitude to sickle cell disease and their perception there was minimal difference in the pregnant population. In knowledge of sickle cell both the African Antenatal and Caribbean Antenatal women had good basic knowledge and there was no statistically significant difference observed in attitude to procreation and all four attitude variables, the group appeared homogenous and even ethnicity had little or no impact. This suggests that the collective experience of being at-risk of having a child with SCD played a part in polarizing this group of Black women.

The BMA (1998) have said rightly that genetic testing places people in painful dilemmas, and raises many social and emotional complexities for which many are ill prepared. Being faced with the prospect of having a child with a potentially fatal disease like sickle cell anaemia has created a dilemma that many of our parents and grandparents never had to deal with. Now that society has opened a Pandora’s Box many men and women find themselves confronted with having to make decisions about an issue that was previously left to nature. Since implementation of antenatal screening for sickle cell in the late 1970s many people are now questioning the benefits of knowing that they are at-risk when more than likely they feel compelled to do nothing with the knowledge.

In an assessment of attitude to being at-risk, to prenatal diagnosis and possible termination of an affected fetus there were many similarities between the African and Caribbean at-risk women and their partners. The main differences observed were to do with the conflicts which their cultural attitude to SCD poses with religion, compounding the dilemma and creating additional
complexities when faced with making a decision about an at-risk pregnancy. It was very evident that few of the respondents would advocate termination of an affected fetus except for those who already have a child or children with SCD, those who lived with a severely affected sibling and those with a perception that the condition is very serious. But the majority of the respondents were opposed to the idea of termination for a number of reasons, the major one being their religious conviction.

Although many of the African respondents perceived that having a child with SCD would pose a burden on the family, few advocated PND and contemplation of terminating an affected pregnancy, except some of the African Males. A number of factors appear to be influencing the decisions about what to do with an at-risk pregnancy. The African Male in this study appear less willing to have a child with SCD, one African Male Partner in defence of having coerced his partner into having PND and termination of a previously affected fetus stated ‘it’s just we didn’t want to have a baby with sickle cell, zero tolerance, I just don’t want it the fact that this is sickle cell that’s it’. Secondly the idea that having a child with SCD could be a blessing in the family seems preposterous to many African Females but more so to the African Males (Graph 7), where more of the latter ‘strongly disagree’ with this view. This was contrary to Durosinmi et al.’s (1995) findings that Nigerian (African) females were more opposed to having a child with SCD than the Nigerian males. I suggest this difference in findings is probably because Durosinmi et al.’s population all reside in Nigeria, the epicenter of SCD, and many of the women will have a full appreciation of the potential social ramifications of a woman producing ‘sickly’ children. No woman would relish the possible consequences, which often include abandonment or being ousted from her marital home. The African women in the UK will have some awareness of some of the protective systems in the UK, including access to health and social support and government-provided services.

The majority of the respondents in Phase 3 advocate prenatal diagnosis (PND). However the risk of miscarriage was the major deterrent for both the men and women, where even a 1% risk of miscarriage is considered morally unacceptable. The reason for this is that the majority would contemplate PND not for the purpose of preventing the birth of a child with SCD but in order to prepare for the birth of a potentially sick child. Although many of the African Male Partners and African Antenatal women expressed anguish at the prospect of having a child with SCD the majority still felt they would not consider termination. This was bemusing in view of the cultural attitude to SCD. When asked about possible termination of an affected fetus one African Antenatal woman reflecting on her partner’s belief stated, ‘we just don’t do that where I come from’.
demonstrating that in their view of their African culture it would be unacceptable to terminate a pregnancy irrespective of the presence or absence of a genetic condition. Many respondents alluded to their anxiety of the risk of miscarriage and rejection of possible termination of an affected child; one African Male Partner stated, ‘I wouldn’t like that, even if you talk to me again that would be the last thing I would say, that’s my child, that’s my child, no I wouldn’t take my child’s life’.

The major factor influencing a decision to have prenatal diagnosis was past experience of having a child or children with SCD or living with a sibling who is severely affected or died as a result of complications of the disease. An African Antenatal respondent who has one child with SCD stated, ‘If the baby has got sickle cell I have to terminate it, I don't think it is right because I don't like abortion but I don't have a choice you know, because I don't want to have another child with sickle cell’. The dilemma and anguish in the decision-making is evident in some of the respondents’ comments, including the comments of those who opted for PND, some of whom expressed strong emotions about their witnessing the impact of the disease in their families and a reluctance to go through the experience their parents went through or having to cope with another child with SCD and the difficulties this would pose for their family.

Those who advocated termination of an affected pregnancy were predominantly those who have had extreme experiences of observing the pain and anguish which having a sibling with SCD had on their parents and the rest of the family. This is a similar finding to Dorticos-Balea et al.’s (1997) study of Cuban couples at-risk of having a child with SCD. In the current study a Caribbean Antenatal woman with two children with SCD already felt the family would not be able to cope with another child with SCD and despite strong religious convictions, she felt compelled to consider termination should the fetus be found to have SCD following PND. Fortunately the fetus was unaffected.

In an opposing finding to the above Duster and Beeson (2007) noted that having an affected close family member often meant that individuals are less likely to accept PND or consider termination since doing so calls into question their loyalty to the affected member of the family, seeming to imply that that person’s existence is of limited or no value. The current study did not appear to demonstrate this and none of the at-risk respondents alluded to this. The most compelling reason for rejecting PND and possible termination is religion 99% of the antenatal women and their partners in the present study practise a religion. One African Male Partner stated, ‘As a human being you're supposed to accept what you are given especially pregnancy, it's a gift from God’.
Many of the respondents echoed this sentiment and feel compelled to accept whatever God gives them as a precious gift. This reflects the findings of other researchers and authors, including Alkuraya and Kilani (2001), Weatherall (1991) and Hill (1994b).

Marteau (1995) asserts that the seriousness of the genetic condition is a good ‘predictor’ for acceptance or rejection of PND. Perhaps the at-risk population in this study perceived that SCD is not serious enough to warrant termination of an affected fetus, except for a few respondents who felt otherwise. The Africans in particular perceive that the condition is serious, but there is conflict between perception of the seriousness of the disease and the moral, ethical and religious conviction that it is wrong to end a life, creating dissonance. Many of the respondents appear to be anti-abortion, which creates an irreconcilable conflict over which many expressed great anxiety. In the case example illustrated earlier the respondent experienced a great deal of dissonance whilst attempting to reconcile her desire not to have another child with SCD, not being able to deal with another child with SCD and her religious conviction that it is a ‘sin’ to terminate a pregnancy. In order to relieve the dissonance she used her not being able to ‘cope’ with another child with SCD as a justification for considering terminating an affected fetus. By adding the consonant element ‘coping’, she has been able to change the amount of value she had placed on her religious conviction that it is wrong to ‘kill an unborn child’ thereby changing the importance of her religious conviction in order to reduce the dissonance which her actions would evoke if the pregnancy had been found to be affected and she had opted for termination.

A number of authors suggest that more women accept PND if it is provided early enough and at least before the twelfth week of pregnancy (Petrou et al. 1992, Nuenschwander and Modell et al. 1997, Modell et al. 2000, Thomas and Oni et al. 2005). However, I suggest that unless the issue of miscarriage can be eliminated the majority of African and Caribbean women and their partners will not consider accepting PND especially since the most common reason for their wishing for the test is to prepare for an affected child and not termination of an affected fetus. Many policy-makers will question the benefits of offering PND to this group and may suggest that it is a waste of resources if termination of an affected fetus is not considered the logical outcome of PND. As highlighted by the HGC, ‘(health professionals) …felt that invasive diagnostic procedures such as amniocentesis should be carried out only where the woman would consider a termination of pregnancy in the case of a positive diagnosis’ (HGC 2006: 33).
This opposition to termination of an affected fetus by the majority of the African respondents demonstrates a contradiction in terms of a strong desire for a ‘normal’ healthy child and the often negative cultural attitude to disease and illness, to SCD in particular and to disability generally. Again this demonstrates the complexity of human nature and the difficulty of attempting to reconcile two or three often divergent cognitions cultural expectations, social values and religious beliefs. A socio-cultural response to SCD in many African communities is to avoid having a child with the disease whilst religion states that God gives and it is the human condition to accept whatever God gives. There is a contradiction highlighted by unbelievers, they ask ‘if your God is a loving God why would he place you in this predicament?’ As Thakur (1981) stated, religion is in the ‘sphere of faith and not rationality’ and many believers will claim that God never promised a problem-free life. This conception of religion enabled many of the respondents to cope with their predicament and a belief that irrespective of the outcome God will provide them with the capacity to cope with any and all eventuality, including dealing effectively with a health limited or disabled child.

One African Male Partner, who grew up with a sibling with SCD who died the year before the interviews at the age of 41 years and he has a toddler who also has SCD, in an attempt to deal with the situation he stated, ‘If I am going to follow religion I wouldn't have made the decision to have the pregnancy tested or consider abortion. If you permitted your religion to get in the way it's a really hard decision to make’, demonstrating the conflict that religion creates in a situation where one feels compelled to make a decision about an issue that will have a major life-long impact on the family and the affected individual themselves. Evidently the respondent has extensive experience of living with someone with SCD during his own childhood and as a father of an affected child, he felt compelled to ignore religion and make a decision that fits with his own and family’s needs. Interestingly a similar decision was made by a Caribbean Antenatal respondent who already had two children with SCD even though she is highly religious she felt compelled to opt for PND and consider terminating an affected fetus. This suggests that when faced with the reality of the situation individuals may have to make decisions that conflict with their religion or personal values.

In a study of attitude to reproductive choice of parents of children with cystic fibrosis Henneman et al. (2001) found that religion had a greater influence on intention to use PND than the clinical severity of the disease. I suggest in this current study that first-hand knowledge and experience of the clinical severity of SCD is a major factor that overrides religion for some at-risk couples.
Religion appears to be the cord holding many of the respondents together and enabling them to cope with their situation. A belief that things will be ‘OK’, that their God will not fail them was voiced by many of both the African and Caribbean respondents in Phase 3. Many felt it would be morally unacceptable for them to consider termination of an affected fetus, ‘their child’, therefore it was pointless having PND. One of the respondents appear to be bargaining with God and said that if the child has SCD God should not ‘allow it to come’ into the world. Secondly many of the respondents were hopeful as they contemplate what the child could become in future.

I propose that the use of consonant elements such as religion and the prospect of what the child could become in future was useful justification for refusing PND for many of the respondents in Phase 3 and enabled them to reduce the high level of anxiety created between a number of cognitions, the wish not to have an affected child, society’s demand for them to have children and religious values which is opposed to termination of pregnancy. Of the small number of respondents who considered PND with a view to termination of an affected fetus, some based their decision on the unwanted prospect of having child who will place a heavy burden on the family but more importantly a child that may die prematurely. Again the addition of consonant elements, such as ‘burden’ and ‘potential premature death of an affected child’ act as justification for selecting PND and possible termination of an affected pregnancy, since the choice creates tensions and dissonance with moral and religious values and beliefs.

Evidently making a decision about an affected pregnancy is emotionally traumatic as demonstrated by one Caribbean Antenatal woman who had PND and was cogitating about whether to continue or terminate the pregnancy. All the respondents experienced turmoil in the decision-making, and this again reinforces the BMA’s (1998) view that ‘the ability to access new knowledge (genetic information) not only brings affected individuals more choices but also raises new and often painful dilemmas’. For many people the prospect of making what they consider a wrong decision creates a great deal of anxiety and few people are trained or adequately prepared for genetic decision-making.

Despite overall differences in attitude to sickle cell disease and the distress of the prospect of having an affected child, the pregnancy outcome for both the African and Caribbean women and couples were not very dissimilar. The number interviewed was small, however, and it is not possible to make many inferences from the qualitative findings. Nonetheless the data has provided
some insight into the decision-making process, strategies adopted and factors influencing these respondents when attempting to make such life-changing decisions.

Apart from expected gender differences in the Powerful Others domain of the Multi Dimension Health Locus of control (Section 5.3.2.2), where more Males than Females and more African Males than African Females perceived that Powerful Others have some control over their ability to remain healthy overall, the African and Caribbeans scored highly in the Internal health locus of control domain. This gender difference probably illustrates that women, especially educated women, are likely to feel they have control over their health decision-making when confronted by a health care professional. The ability to have control over one’s fertility and decisions relating to an at-risk pregnancy is complex. However, it appears that the majority of the Caribbean Antenatal respondents have greater control over these issues than the African Antenatal respondents in this study.

### 9.1.6 Impact of religion

A high proportion of the African and Caribbean respondents have a religious affiliation and many practise a religion often or sometimes. A statistical difference was observed where more of the Africans (92%) practised a religion than the Caribbeans (70%). The findings of this study contribute to the body of evidence that a significantly large proportion of Africans and Caribbeans practise a religion and the majority practise Christianity. This is a similar finding to Madu (1994), Beit-Hallahmi and Argyle (1997), Jegede (1998) and Henley and Schott (1999). Read (2001) claimed that the practise of a religious faith is one of the major components of a peoples’ culture and since culture influences attitude and behaviour it was not unexpected that religion appears to be a major social factor influencing the decision-making of a significant proportion of the respondents in this study not only decisions about an at-risk pregnancy but in respect of procreation and childbearing.

Those who were born or migrated <15 years of age and who have not been fully indoctrinated into having a religious affiliation would have had exposure through social encounters with kith and kin who would make a concerted effort to persuade and cajole non-believers into the religious doctrine and values of the family or pervading community in order to, as they perceive it, to save the individual’s soul and promote their future salvation. Those who are suffering hardship, persecution,
social isolation, lack of progress, ill health and other social ailments will soon believe that perhaps the promise of a God that can offer hope, peace, healing and future progress is an attractive proposition worth trying after all there is nothing to lose. The promise of God as an all-round provider and one to give salvation is widely and frequently broadcast, especially on minority ethnic radio and satellite television stations, which are growing incredibly, and the message is further reinforced by family and friends. It appears that it is almost impossible not to embrace religion within the minority ethnic African and Caribbean community.

Some authors argue that life crisis, social and health problems entice many individuals to religion. They see it as a possible route for the relief of their pain, anxieties and social distress. Karl Marx stated, ‘religion is the sigh of the oppressed creature, the sentiment of a heartless world and the soul of soulless conditions. It is the opium of the people’. He argued that it is used to relieve the pain and misery of oppression (Haralambos and Holborn 1991).

Is it possible that the social pressures of living within the British society contribute to this high level of religion among the African and Caribbean respondents in the current study? I suggest not. Several authors have provided overwhelming evidence that there is a high level of religious practise in the majority of people living in Black African and Black Caribbean countries (Kondor 1993, Madu 1994, Beit-Hallahmi and Argyle 1997, Jegede 1998, Frazer in Jegede 1998, Henley and Schott 1999, Pulis and Szwed 1999) and across all social classes, the rich as well as the poor, the well educated as well as the illiterate. The highly educated appear to practise religion as fervently as the less well educated. A visit to any Black-led church on a Sunday morning or late Friday night in the UK and many African or Caribbean countries or viewing of religious channels on satellite television will provide ample evidence for this long-standing phenomenon. In view of this I suggest that culture is the major factor that influences the practise of religion and not oppression, economic or social deprivation, unless one considers global oppression as a valid aspect worth investigating. I also argue that those who originate from an ‘interdependent’ society, as described by Kashima et al. (1992), are more likely than those from an ‘independent’ society to conform to the rules, values and beliefs of their family and cultural group and this probably accounts for the marginally higher level of religion among the African respondents, including the highly educated, compared to the Caribbean respondents.

Religion appears to have had a major impact on the attitudes and beliefs of the respondents in this study. Much decision-making was influenced by religious convictions, for example, attitude to
procreation, whether to have prenatal diagnosis or consider possible termination of an affected pregnancy. As Thakur (1981) asserts, religion is rooted in experience and commands deep personal commitment to certain beliefs and attitudes, this is amply demonstrated in the attitude and response of the respondents in Phase 3, where many alluded to the fact that their faith and religious belief is influencing their decisions in respect of being at-risk of having a child with SCD and their rejection of PND or the prospect of terminating an affected pregnancy. Yet it is specific interpretations of religious belief that are contributing most significantly to the high level of dissonance experienced by many of the African at-risk women and couples as they attempt to reconcile the emotional inconsistencies created by socio-cultural pressures to have children, the unpredictability of the possible clinical severity of SCD in an individual, the society’s stigmatization of those who have a ‘sickly’ child and the need to avoid committing the ‘sin’ of ending a life by terminating an affected fetus.

A Caribbean Antenatal respondent who already had two children with SCD is a good example of how individuals bargain with God and have a religious conviction that the outcome would be well. ‘When they told us about two weeks after she was born [first child] that she had sickle cell, I think my husband and I we didn’t talk we were blaming each other in a way for having a child with SCA. Then I went on to have another child in that one, actually, I moved and went to another hospital and then they offered me the testing. But being a Christian, I was hoping, I believed in God for a change in this pregnancy and I turned down the prenatal diagnosis’. That child was also born with SCD. During the study she opted for PND with a view to termination if the third pregnancy was affected but it was not. The interview demonstrated the high level of dissonance which many at-risk women and couples experience and the strategies they use to reduce the anxieties evoked.

Although Petrou et al. (1992) did not identify religion as a factor influencing those attending for prenatal diagnosis (PND) it appeared to have had a major influence in the decision-making of the respondents in the current study. In major cities in the UK the majority of women at risk of having a child with SCD would be seen by a specialist genetic nurse counsellor in the first instance and only those who opt for PND would be referred to a tertiary fetal medicine unit, hence it is unlikely Petrou et al. (1992) would have seen such women and couples since they have already rejected PND on religious grounds. Specialist sickle cell centres are better able to provide such data and the findings of this study affirm that religion plays a pivotal role in the decisions made by Africans and Caribbeans at-risk of having a child with SCD. The reason for the low uptake of PND among women and at-risk couples is also the unpredictable nature of SCD a situation alluded to by
Dortico-Balea et al. (1997). SCD ranges from a clinically mild, moderate to severe disease (Embury et al. 1994, Serjeant and Serjeant 2001, Steinberg et al. 2001) and clinicians cannot inform parents unequivocally whether the condition will manifest in their child as clinically mild, moderate or severe.

As stated by Green and Statham (1996) where a condition is known to be severe 93% of women opt for PND compared to 29% where the prognosis is unknown or uncertain. The respondents in this study reflect this and their cogitating about whether to have PND or not as well as what to do with an affected pregnancy shows the difficulties encountered. I propose that the unpredictability of the severity of SCD is a major contributor to the high level of anxiety experienced by at risk women and couples. The HGC (2006) asserted that in the majority of cases women will terminate an affected pregnancy where a fetus is diagnosed with a serious genetic condition. However, if the women do not even attend for PND they do not reach that point in the decision-making. One Caribbean Antenatal woman who had an affected fetus diagnosed through PND cogitated and agonized about having a termination: ‘I definitely know that I don’t want to put myself through that [termination] because now that I know that the child can be quite well you just don’t know what to expect. I am willing to take that chance now as opposed to what I think would have been a lot easier before to just get rid of it’. Despite this statement the respondent continued to cogitate over the decision right through the remainder of the interview and I propose that this in part because of the realization that the clinical prognosis of SCD is so unpredictable.

The effect of gender and power was evident in the study where one African Antenatal respondent felt she was coerced by her partner into having PND and subsequent termination of an affected fetus in a previous pregnancy. This demonstrates the powerlessness of many women, not only in the African context but, I suggest, globally. This was interesting in view of the gender difference observed in the Multi Dimension Health Locus of Control where more Males than Females (Section 5.3.2.2) and more African Males than African Females (Section 5.3.5.3) perceived that Powerful Others have greater control over their ability to remain healthy. One would have anticipated that this would be reflected in the African Antenatal women having power over the decisions relating to outcome of an at-risk pregnancy. Evidently in this social context this was not the case. I suggest having control over one’s own health differs from having control over decisions that have a potential to impact on the couple and entire family and in this case the decision-making may be relinquished to the more powerful partner in the relationship, more likely the man.
The majority of the Caribbean Antenatal respondents in Phase 3 made it very clear that the decision about procreation, PND and possible termination of an affected pregnancy lies with them and despite their partner’s contribution to the decision-making they themselves have the power to determine what to do about the pregnancy. This was not evident in the African Antenatal women’s response, the majority of these, including those who were highly educated, felt compelled to adhere to cultural expectations and norms both in terms of procreation as well as making a decision about an at-risk pregnancy. An African Antenatal medical doctor who did not want to have children when interviewed was pregnant with a second at-risk pregnancy and felt she was coerced into changing her attitude to having children in order to maintain her marriage. Other women felt compelled to obey their partner’s desire not to have a child with SCD and made decisions that conflict with their own values. For example, one African Antenatal who had terminated a previously affected pregnancy stated, ‘It was a very hard decision to make, because being pregnant for about five months you see that child as human. So we quarreled a lot. We had a tough time of deciding what to do being our first child... I didn't want to terminate it, having gone through five months, I did not want to abort it no, no, no...I would have kept it because I’m a Pentecostal Christian, my bible didn’t tell me it’s OK to have abortion, my religion is against abortion, it wasn’t my decision to have the abortion’. The respondent demonstrated the powerlessness which some women felt in the decision-making and during the interview the respondent was evidently very emotionally traumatized by that previous experience especially as she had to go through PND in a second current pregnancy, again against her will, she stated that the decision to have PND in both pregnancies were made by her husband as was the decision to terminate the last affected pregnancy.

The effect of having made a decision which is opposed to ones preference creates even greater anxiety and dissonance. Similar to Festinger and Carlsmith’s (1959) argument that where an individual has been compelled to act against their personal belief without sufficient justification they can only perform the act by altering their original belief and convincing themselves that their belief required modification in the first place. An African Antenatal woman who had terminated a previously affected pregnancy attempted to justify acting against her belief by stating: ‘It was my husband he told me it's not proper to keep this child. For him the child will suffer in years to come, with problems he would have medication and all that. For him the child will suffer in years to come, with problems he would have medication and all that. The child would not be able to make it to adulthood, maybe even get married or something, it would have a tough time. I guess he could be right eh’.
By modifying her belief and adopting the idea that perhaps her husband is right the respondent was able to reduce the anxiety and come to terms with the decision to terminate the affected pregnancy.

Another African Antenatal respondent stated, ‘he [husband] said don’t worry everything will be OK just let’s go there [for PND] if they say the baby is SS, don’t think because you are four months pregnant, morning sickness and all that, just forget about it we [will] terminate it and try again’.

Both of these women demonstrate the power which African Males have in the marital relationship and sometimes the women’s powerlessness in the decision-making. This was not found among the Caribbean women where it is evident that such decisions are made by the women primarily and perhaps with some input from their partners.
9.2 Reflection on theoretical models

Adhering to the principles of Interpretive Phenomenology the respondents own words were used to convey their thoughts and attitude to specific issues relating to the subject and an attempt was made to interpret the meaning conveyed in their statements; where there were any uncertainty, ambiguity or risk of misinterpretation individuals were contacted by phone for clarification.

The original hypothesis was that:

- Caribbeans would have better knowledge of sickle cell disease (SCD) than Africans

that

- there would be culturally specific differences in attitude to SCD between African and Caribbeans

and that these

- culturally specific difference in attitude would influence decisions about a pregnancy at-risk of producing a child with sickle cell anaemia

In addition I propose that

- cognitive dissonance is a factor affecting decision making in respect of accessing genetic information, attending voluntarily for testing and acting on the tests result, procreation and use of genetic support services

During collection of Phase 3 interview data it became evident that the sociological paradigm that I had intended to apply to the interpretation of the data would not be sufficient to address the psychological issues that were emerging from the data. Following a period of reflection I had to consider a revision of the literature search and attempt to integrate sociological and psychological paradigms; it became apparent that to examine the sociological (cultural) aspect, whilst failing to examine the psychological (cognitive) aspect would be a serious error that could potentially create a major weakness of the study. The psychological aspect examined how some individuals reconciled what appeared to be irreconcilable cognitions, these being a cultural demand for people to have children, society’s demand for people to avoid having a disabled child that can potentially become a long-term burden to society, moral and religious beliefs that promote the sanctity of life and are opposed to abortion and the at-risk couples decisions and behaviour (rejection of prenatal
diagnosis and or termination of an affected pregnancy) that is not congruent with the other cognitions. The sociological framework focusing on culture was not sufficient for addressing the psychological tensions that were emerging from the interview data and the needs to explore this aspect became apparent later in the life-time of the project, hence the application of cognitive dissonance theory post hoc, which helped to explain how some of the interviewees dealt with incompatible cognitions.

The findings of this study have demonstrated that the first hypothesis was not substantiated; there is overall good knowledge of sickle cell among both the African and the Caribbean Male and Female respondents however the African respondents had a marginally better knowledge than the Caribbean; the pregnant population had overall better knowledge however there was no difference between the African Antenatal and Caribbean Antenatal women which suggests that education and genetic counselling has had an influence on the women but more significantly the data confirmed that being pregnant appeared to have caused a convergence in the attitude of the two ethnic groups. Many of the statistically significant differences observed in the Phase 1 general population were not observed in the Phase 2 pregnant women.

The original hypothesis was formed as a result of clinical experience and the findings of this study suggests there are other factors which may account for the Africans obfuscation of knowledge of sickle cell in clinical practise and I suggest this is stigma and a wish of the Africans to dissociate from the genetic condition or knowledge of it for fear of being labeled, especially in the context of being in an antenatal at-risk situation. Having to acknowledge one’s knowledge of the sickle cell gene in ones family is to admit that one was aware of its potential implications. The question which may arise is, ‘if you were aware of the gene why did you not attempt to avoid being in a potential risk situation?’ This would be a difficult question for many individuals to respond to, since for many they have dismissed the subject (denial perhaps) from their mind, refused to find out more information in order to take the necessary steps to avoid having a child with sickle cell disease in future. In some instances this denial in itself is a psychologically response to dissonance and omission to act can be a demonstration of ‘choice’ and a dissonance reducing or eliminating strategy. This is in keeping with Eagly and Chaiken’s (1993) assertion that where dissonance is present perceivers do not only seek to reduce it they also attempt to avoid information that might result in further increments in its magnitude; avoidance of situations or persons that may increase the dissonance is a common phenomena. Inattention to detail given, defensive modes of behaviour and feigning misunderstanding or ignorance are common responses to dissonance and can account
for the response of some of these participants, their failure to attend for testing prior to marriage or procreation is an example of a response to dissonance and these are used as attempts to prevent the ‘cognition’ from becoming fully established. Obfuscation is a common response to cognitive dissonance.

Other researchers demonstrated a reluctance to seek genetic counselling in a subsequent pregnancy following the birth of a previously affected child with SCD (Hill 1994a, 1994b, Dorticos-Balea et al.’s 1997); the first study was conducted in North America (USA) and the other in West Africa (Nigeria). Evidently the issue of avoidance in making a decision is a common phenomenon perhaps more common than anticipated and possibly crosses ethnic boundaries. In this current study one Caribbean Antenatal with one child with SCD failed to act in a second pregnancy and had a second child with SCD however in a third pregnancy, during the life-time of this study, she opted for PND with a view to termination if the pregnancy is affected, it later transpired that it was not.

The Eurocentric western assumption that offering knowledge and information would promote action and individual’s would be more likely to seek testing and make informed premarital and preconception choices (Atkin and Ahmad 1998) is failing to acknowledge the importance of a cultural attitude to disease and illness, and especially SCD and to the factors affecting genetic decision-making, which include a psychological response to a sociological phenomena. The idea of choice assumes that individuals have the capacity to make those choices. I suggest that for some communities the notion of individualistic decision-making and the ability to make choices that are preemptive is not within the reach of many from traditional cultures, the authority to make choices lie not with the individual but with perhaps their extended family and in some instances the dictates of the wider society. A society which advocates the importance of having children even where there is a risk of having unhealthy children, whilst being opposed to disability places individuals in a dilemma when it comes to making life-changing decisions. Society’s unrealistic demands add to an individual’s emotional burden and create greater anxiety than many expectant women and their partners feel able to deal with socially, morally and psychologically.

Cognitive dissonance theory has contributed to an understanding of decision making and is relevant in this current study, in respect of: having a blood test in order to identify if you have sickle cell trait, selecting a future partner, deciding whether to have children or not, whether to opt for prenatal diagnosis and subsequent termination of an affected pregnancy. The tensions that can arise in all these situations is dependent on the amount of value that individuals place on each of
these issues, as highlighted by Cooper (2007) where two or more issues or objects are of a high value and they are related to each other any cognitive dissonance between them will create greater tensions. There is evidence in the current study that the two cultural groups, Africans and Caribbeans, place a relatively high value on having children and having healthy children, however there are differences in the level of value placed by the Africans and the Caribbeans at the macro and micro level, hence the level of dissonance that will result if there is dissonance between these aspects will differ at a cultural level. As suggested by Festinger (1957) the more important or valuable the cognition elements the greater the magnitude of dissonance. Hence, if having children is of great importance and highly valued and it is of relevance and related to the cognition that having a disabled child knowingly is unacceptable to society the level of dissonance experienced will be high and individuals and couples will attempt to reduce the dissonance, using a variety of dissonance reducing or eliminating strategies such as feigning ignorance, avoidance of information that will add to the dissonance, playing down the importance of the dissonant elements, adding consonant elements and other modes that will help reduce the dissonance.

For example a Caribbean antenatal stated, ‘I think it didn’t matter [being at risk of having a child with sickle cell anaemia] because sort of personally we knew the risk is there but it’s not 100%. The way it works out it could be or couldn’t. I mean my whole family are carriers but my parents, with seven children obviously you never know which one could get it, but none of them have it; I don’t think it mattered then. I suggest that although the respondent was fully aware of the possibility of having a child with sickle cell anaemia by adding the consonant element, ‘my parents with seven children…none of them have it [sickle cell disease]’, this helped her reduce any dissonance that may occur between the cognition, ‘I want a health child’ and ‘I am at-risk of having a child with sickle cell disease’ and ‘I chose not to take any action to avoid having a child with sickle cell disease’. However, it is quite possible that this individual did not feel any anxiety about these opposing cognitions and her decision not to have prenatal diagnosis or consider termination of an affected child are not inconsistent and she is perfectly comfortable with these inconsistencies. Perhaps the participant perceives it a moral imperative not to seek to have a ‘a perfect child’ and this moral view eliminates any dissonance she may have felt.

Subjecting one self to testing requires a mind set of wanting to act on the information, the few who voluntarily attended for testing pre marital had made a conscious decision with the intention of avoiding having a child with SCD, evidently quite a number who were aware that they carried the sickle gene did not attempt to get their partners tested pre marital or pre conception, since doing so
would entail having to make a decision to act on the outcome of the test which presumably will be to avoid being in an at-risk relationship. Hill (1994a) highlighted that the obfuscation of knowledge could be the women’s avoidance of having to make a decision, especially for the low income women who may feel that motherhood is probably the only avenue which validates them in society, to have some power and control over their fertility and consequently their lives raises their value in a society that often devalues them and their contribution; this current study appears to support this argument. I propose that obfuscation of knowledge, avoidance of information, persons and situations that increase dissonance are partially viable strategies adopted by many individuals to help them eliminate or reduce the dissonance created by the reality of being in an at-risk relationship. Society’s demand for individuals to produce healthy children and being at-risk of producing an unhealthy child are irreconcilable and creates a dilemma for many women and their partners.

Many theories about attitude and choice fail to acknowledge that culturally some individuals and communities feels unable to avail themselves of the choices on offer in western society and to do so would place the individual in a state of dissonance especially where there is inability to use the information to make true choices, i.e. avoidance of producing a sickly child. Individuals may fail to recognize that they are in a state of dissonance or responding to this psychological state but their observable actions confirms this, for example, similar to the findings of Duster and Beeson (2007) individuals may fail to book an appointment for testing, or as seen in this current study fail to attend for a counselling appointment, failing to seek information about sickle cell even when one is aware of the presence of the gene in the despite having more than thirty specialist Centres in the UK, frequent national awareness campaigns and ardent attempts by health care professionals to convey the genetic information to the population. I propose that the lack of response to awareness campaigns is not that the information is being misunderstood or not penetrating but individuals are making a conscious decision to avoid the information or take action based on its content, a conscious rejection of information is choice.

The ‘freedom’ to choose whether to have a child with sickle cell disease has created complexities for many women and couples. It is not uncommon for women and couples to ask the genetic counsellor what they would do were they in their predicament, some will actively seek to delegate the decision making to the health professional, this I suggest is also a display of dissonance and an attempt to reduce its effect, by relegating decision making to others absolves some of the responsibility and accountability which accompanies free-will. As indicated in dissonance theory

373
where there is high-decision freedom dissonance can occur between attitude and behaviour however where there is low-decision freedom, lack of control or responsibility for ones behaviour or choice, inability to choose eliminates dissonance. The need to seek justification elements will only be relevant where there is freedom in the decision making. Where a couple have been given total freedom to choose what to do about the at-risk pregnancy, they will perceive that they will be held accountable for the outcome, if their attitude and behaviour do not match the level of dissonance will be high and they will seek to reduce it. Others use bolsters to justify their actions, for example, religion, one respondent stated, ‘from what I believe, from a religious point of view, God is responsible for everything. Doctors could say your child’s gonna have sickle cell but it's God who really, really knows’. In this instance any dissonance that may arise as a result of choosing not have prenatal diagnosis or contemplate termination of an affected pregnancy will be reduced or eliminated since the individual will perceive that their choice was based on what God would want them to do, their freedom to choose in essence has been removed and since inability to choose eliminates dissonance the individual will no longer experience dissonance.

As proposed by Eiser and van der Plight (1988) individuals are likely to alter their attitude if they feel they will be held personally accountable for any negative outcome that arises from their behaviour or actions; they are conscious of the inferences that others may draw from their observable behaviour. In order to avoid public criticism individuals may change their attitude in order to avoid this, by for example adhering to cultural rules and norms irrespective of personal preference and this was amply demonstrated in this current study.

As indicated in the data some of the respondents were aware of their haemoglobin carrier status prior to selecting their partner and some prior to having children, but failed to inform their partner of their haemoglobin status, some were aware that they were in an at-risk relationship yet minimized the importance of this knowledge. Some of these individuals stated that the issue was unimportant yet agonized about whether to have prenatal diagnosis or not. In order to avoid public criticism some individuals dismissed knowledge of the importance of the information, whilst others feigned ignorance, this I suggest is an attempt to avoid personal responsibility. Having knowingly engaged in an at-risk relationship they will be aware of being held personally accountable for their choices and a public response that may suggest that they have acted irresponsibly. As discussed in the literature review Marteau (1995) reported that a policy-maker claimed it is self-indulgent for parents to knowingly bring into the world a child with a birth defect and choosing not to terminate an affected pregnancy is social negligence and fails to take into account the best interest of society
and a collective moral responsibility. Individuals in this study are making decision whilst being aware of the wider society’s opinion to having a child with a disability.

It could be argued that being able to choose is not always an acceptable state that all individuals welcome and inaction or even failing to consider options in terms of whether to attend for testing or not maybe for some a more comfortable state of being, especially since it eliminates having to deal with the possible associated dissonance. Not knowing what the options are maybe less anxiety provoking especially for those who feel their religious convictions would not allow them to make the choices that would reduce their risk, for example, one African Antenatal stated, ‘...what you don’t know you don’t know, when you begin to question the unknown you are bound to get into trouble so for me to question what is in my tummy whether it has sickle cell or not is just creating more problems for myself’. This I suggest is a response to dissonance, the cognition that ‘I am at-risk of having a child with sickle cell anaemia’ and ‘society does not accept a disabled child readily and will prefer I do not have one’ and the behaviour, ‘I have not chosen to avoid having a child with sickle cell anaemia’. As implied in dissonance theory an individual will attempt to justify their behaviour by adding consonant elements, in this respondent’s case, the avoidance of getting into trouble by questioning what is in her tummy and avoidance of having to make a subsidiary decision if the fetus is diagnosed with sickle cell disease.

As Zimmern et al. (2001) stated genetics has brought new complexities and dilemmas which few members of society are prepared for, I suggest that if that is the opinion about those in western societies many of those in the developing world are even less prepared for the possible impact of the new genetics and the challenges it will create. The social impact of the new genetics is under researched especially in respect of African and other minority ethnic communities.

The second hypothesis that there would be culturally specific differences in the attitude of Africans and Caribbean respondents, that Caribbeans would have better knowledge of SCD than the Africans, this was substantiated but the Africans had marginally better knowledge than the Caribbeans in Phase 1 but less so in Phase 2; the Africans and Caribbeans were divergent in their attitude to SCD however these differences did not influence decisions about the outcome of an at-risk pregnancy. Few of those who were at-risk opted for prenatal diagnosis with a view to termination of an affected fetus; this was surprising among the African women especially since it contradicts their attitude towards having a child with a disability; the religious aspect has been the greater bolster used in this regard and helped many of these respondents to reduce dissonance.
Many reasons for individuals opting or not opting for prenatal diagnosis (PND) were demonstrated in this current study and affirms the findings of other researchers (Anionwu et al. 1988, Petrou et al. 1992, Marteau 1995, Modell et al. 1997, Dorticos-Balea et al. 1997, Duster and Beeson 2007), for example:

- Perceived severity of the genetic disorder
- Perceived burden of the disease
- Growing up with a sibling or other significant person with the genetic disease
- Having a previous child with the disease
- Religion
- Disapproval of termination of pregnancy

In the current study, age of migration emerged as a new concept that was of research significance: those who were born in the UK or migrated at a young age (<15 years of age) and those who migrated at an older age (>15 years of age) demonstrated unanticipated attitudinal differences, and this finding supported the original hypothesis that in a convoluted way culture does have a major influence on attitude but it was dependent on where individuals received their primary cultural orientation and the degree of exposure to their culture of origin. I propose that if more of the Caribbean respondents in this study were, similar to the African respondents, by being first generation migrants more similarities may be observed in attitude to procreation and attitude to SCD. Age of migration will need further exploration in future studies relating not only to sickle cell but to attitude, health, disease and illness. This study has demonstrated that cultural orientation contributes significantly to attitude to sickle cell disease (SCD).

In line with Tapper’s (1999) theory that the ‘disease’ discourse applied to the historical naming of SCD in the western world has contributed to the stigmatization of those with the gene appears to have had reverberations which has affected not only African Americans but Blacks through out the world and especially those in Africa and the Diaspora, where the attitude to disease and illness is already influenced by a strong preponderance to mysticism and a belief that supernatural forces are responsible for disease and illness, such environments create fertile ground for the development of a negative attitude to SCD. In view of this the differences in attitude noted in Phase 1 were not unexpected and were reinforced in the phase 3 interviews; the convergence noted in Phase 2 is likely to be as a result of health promotion and education of the at-risk women and their partners which illustrates the effectiveness of education and counselling interventions. Following genetic
and health counselling there appears to be an attitude change whereby there is a less negative attitude to SCD even among Africans and a strengthening of the majority of the at-risk respondents’ belief that they would be able to cope with a disabled child, especially if it is the first child with SCD born to the family. This was not the case for one of the two pregnant women who already had a child with SCD, whilst one had PND in order to prepare for a potentially sick child the other who had two children already had PND in order to terminate an affected fetus and this latter finding supports other authors’ observations (Petrou et al.’s 1992, Green and Statham 1996, Shiloh 1996) that an already affected child influences decision-making about a subsequent at-risk pregnancy.

The findings of this current study appears to support Anionwu et al.’s (1988) and Modell et al.’s (1997) argument that as few as 25% of Black women at-risk of having a child with SCD opt for PND, few at-risk women and couples in this current study opted for PND and the reasons varied the most poignant being fear of miscarriage since most of these women and their partners’ intention for considering this option is to prepare for a potentially sick child and not termination of an affected fetus, the second most important reason for rejection of PND is the rejection of termination of an affected pregnancy and the final most salient reason is religion. Therefore in two decades little has changed to influence the uptake of PND and as highlighted by Streetly et al. (1997) if this trend continues and with an increasing Black population in the UK invariably there will be a proportionate increase in the number of children born with SCD as witnessed in the increase from approximately two hundred and fifty births per year in 1987 to over three hundred per year in 2007. This will have implications for service provision not only in the UK but in other developed and developing countries worldwide.

The issues highlighted have demonstrated that there are culturally specific attitudes to SCD and these influences the outcome of at-risk pregnancies. Whilst a cultural attitude to SCD and social societal expectations play a pivotal role in influencing the Africans rejection of PND and termination of an affected pregnancy with religion adding additional and often unexpected complexities to the decision-making; the Caribbeans were more strongly influenced by a moral attitude to PND and termination and to a lesser degree religion. Although the outcome for both ethnic groups resulted in the same decisions they were made for different reasons but with a common thread of religion and morality.
Cognitive dissonance theory has also demonstrated that the sociological dimension of culture has a major impact on the psychological dimension of individual decision making. Examining one dimension whilst neglecting to examine the other would be a failure in this study since both dimensions have proven to be of important in the quest to understand attitude to disease, illness and to decision making in particular. Although cognitive dissonance theory was not useful for examining each ethnic group’s innate cultural values it was useful and helped illuminate the personal psychological response to cultural pressures and the tensions inherent in divergent cognitions encountered in genetic decision making. I propose that the application of this theory to the data analysis has added a useful insight which can be expanded in future studies of health, disease, illness and decision making especially when applied to differing ethnic groups.

The two ethnic groups in this study appear to have a significant number of differences in Phase 1, a few in Phase 2 and more culturally specific difference in Phase 3 but the similarities in the pregnant women in Phase 2 and the outcome of their at-risk pregnancies was unexpected and can only be accounted for by their shared situation of being at-risk of having a child with SCD and having been through the health care system in terms of genetic counselling. This illustrates that the health care system, sharing of knowledge and health information about the condition by those working within the health care environment has a major influence on decision making. Health care professionals are often the gate keepers to health information and decision-making and this begs the question of how non-directive genetic counsellors are when conveying information? I suggest that they probably were on the whole non-directive, hence the majority of the women and couples felt able to make decisions that fit with their personal or societal values and beliefs. The one respondent who felt she was being coerced into making a decision that is contrary to her own values was able to resist the perceived coercion and make decisions that she and her partner felt comfortable with.

I propose that a response to the dissonance created between differing cognitions is contributing to the beliefs, attitudes and actions of the African and Caribbean population examined, especially the African respondents who appeared to struggle with the pull between their society’s expectation that all men and women must have children, one must avoid having unhealthy children and religion which protects the sanctity of life. Although culture is important in shaping attitude to SCD, ethnicity is not the issue; the age of migration and the environment in which an individual has received their primary cultural orientation has proven to be of significance and how much one adheres to the cultural group values, beliefs and practices.
9.3 Implications for future practise

The findings of this study has highlighted that despite many years of awareness campaigns and efforts to get high risk groups to seek pre marital and pre conception testing for sickle cell disease with the intention of enabling individuals and couples to make informed decisions few avail themselves of the opportunity and many wait until they are expecting a child and offered testing routinely when booking for their confinement of pregnancy.

Greater effort need to be placed in targeting people at the time when they are likely to be more receptive to the information and perhaps this is when planning a pregnancy or as soon as possible when pregnancy is confirmed usually in primary care, this gives support to Thomas, Oni et al.’s (2005) argument that greater efforts should be directed at promoting screening in primary care and at a stage where individuals are likely to utilize the information. This is not suggesting that pre marital or preconception testing should be obsolete but that policies should be developed to enhance and sustain early pregnancy screening.

Preaching about pre conception screening fails to acknowledge that not all pregnancies are planned and secondly it fails to acknowledge the cultural and psychological implications of being found to have a carrier state especially for African men and women. Until the stigma associated with carrying the sickle cell gene is dispelled major campaigns will be of limited benefit, many individuals hear the health promotion message but few act on it and the reason for this are complex and require further exploration.

Health care professionals should be trained in how to help clients examine all the potential social ramifications when requesting testing for a genetic condition. The client’s choice must be handled with sensitivity irrespective of what that choice is. Practitioners must be sensitized to recognizing the myriad of responses encountered in a genetic counselling arena and support clients who are experiencing dissonance.

As stated earlier the majority of people in the two ethnic groups are highly religious and many attend a place of worship. In many instances the Imam, minister, pastor, prophet, reverend or religious leader is held in very high esteem and revered, their opinion is highly valued and respected especially in many Black led churches. Policy makers need to acknowledge the
complexity of peoples’ belief and its influence on their actions, it is therefore imperative that care providers work alongside reputable, trustworthy community group leaders in order to ascertain the way forward, in terms of dispelling myths, stigma and to determine what do the communities want and how should it be provided? It has been established that the Eurocentric mode of providing health promotion will not work for all ethnic groups within society and alternative approaches need to be developed with the full involvement of the communities that are being targeted.

I suggest the time has come when policy makers need to communicate and engage with the African and Caribbean communities effectively in order to determine the best approach for promoting choice about testing, to identify the optimum time and method of testing. The utopian expectation of policy makers is that with adequate awareness campaigns populations at greatest risk of sickle cell, notably Africans and Caribbeans, will respond by subjecting themselves to testing pre marital and pre conception, evidence from this study has demonstrated that few of the respondents availed themselves of the offer and the majority were not be identified until they are expecting a child or they were identified opportunistically perhaps pre surgery and even then this does not mean they will utilize the information to make genetic choices for parenting.

The current study to a certain degree has attempted to address Zimmern et al.’s (2001) suggestion that it is important to examine the possible impact of genetics on society rather than merely focusing on the impact of genetics to health and health services. I suggest this examination need to include an assessment of the impact of pre marital and pre conceptual testing and how it affects different social and ethnic groups. In addition there needs to be an acknowledgement of the cultural and psychological response to genetic information and health promotion.

Interestingly there remains a lack of understanding about the benign nature of sickle cell trait greater efforts need to be made to ensure that information is conveyed accurately to those who have been tested and especially to those with a healthy carrier state. Marteau et al. (1992) suggested a need for greater clarity in explaining the nature of genetic carrier states. Perhaps the time has come when alternative methods of conveying information need to be adopted, the heavy reliance on written material is rapidly becoming untenable in an era that is becoming increasingly reliant on visual imagery and health educators need to utilize other technologies that will make information easier to understand and retained and perhaps revisited to aid memory. For example, use of film clips on DVDs.
A few of the women interviewed in Phase 3 felt they were being coerced into making a decision about prenatal diagnosis and this was in conflict with their own values and choices. There is a fine line between supporting the client through a decision-making and coercion but irrespective of the professionals view of the session what is of more significance is how is the recipient feeling towards the counselling experience and a skilled professional will be able to assess the degree of support the client is seeking and tailor the counselling session accordingly. Training of those providing genetic counselling is crucial to further promote delivery of a therapeutic session that best meets the client’s needs, tailoring the degree of support required accordingly.

Professionals providing genetic and other services must be in tune with their own cultural view of a phenomenon and recognize what their own prejudices are before they can be better able to prevent these from influencing the therapeutic relationship with their client and in order to meet the client’s best interest. A failure to recognize and acknowledge this basic self awareness is fertile ground for ones inability to listen to and respect the clients own values and beliefs.
9.4 Implications for society

The stigma associated with sickle cell disease especially among Africans has to date been difficult to eradicate but it is imperative that attempts be made to do so. Stigma contributes significantly to a lack of willingness to seek information about SCD, premarital and preconception genetic testing and thus limits individuals’ ability to make informed decisions even where that decisions is to take no further action or seek testing. Although people have a right to choose not to know something about a subject it will be difficult to ascertain who wants and who does not want information without providing the information in the first instance. I suggest therefore that irrespective of what choice is made ultimately people should be given the opportunity to access information if and when they want it, but education is crucial in order to enable people to decide whether to seek the information or not. The number of babies born with SCD in sub-Saharan Africa and the level of care and resources they require especially in the current economic climate of many African countries I suggest are not sustainable. The psychological and emotional burden of the vast number of deaths of children with SCD for parents, families and communities is I suggest immeasurable, especially since it is not uncommon for families of all social classes to experience repeated infant deaths as a consequence of SCD.

Governments must be involved in the process of demystifying and eliminating the stigma of SCD if health promotion efforts are to achieve the objective of enabling people to make an informed choice. Involving religious leaders is the potential key for reducing the stigma associated with SCD and promoting the engagement of African and Caribbean communities. Meeting people and communities at their point of need is essential rather than taking a paternalistic view and adopting methods that is likely to render the health promotion message ineffective.

As stated in a well known Chinese Proverb from an anonymous source:

Go to the people, live among them, start with what they know, build on what they have, but of the best leaders when their task is done, the people will remark we have done it ourselves (Anonymous)

If this strategy is adopted there will emerge an approach that will be less anxiety provoking for the population that the health promotion is targeting.
9.5 Limitations of Study

A number of methodological limitations need to be acknowledged. In determining ethnic grouping, there were logistical problems in defining what constitutes ‘Africaness’ or ‘Caribbeaness’, this is relevant when attempting to measure attitude and identifying whether there are any statistical differences between two cultural groups. Ethnic identity does not necessarily constitute cultural identity and this is supported by findings of the study and age of migration proved to be a more pertinent variable in assessing cultural orientation and attitude, more so than ethnicity.

It would have been useful to examine the sociological and psychological paradigms in tandem from the commencement of the project I believe this would have yielded far richer data and provided a better map of the terrain. Although the application of cognitive dissonance theory post hoc was useful it would have been more illuminating to have considered applying the theory during the project development stage, this may have influenced the research methodology, development of the questionnaire and the interview scheduled. I had underestimated the relevance of the psychological dimension at commencement of the project otherwise it would have been better incorporated from the outset, the focus on the sociological whilst ignoring the psychological and individualistic aspect would have been a major weakness of the study.

A great deal of effort was made to recruit a minimum of sixty three respondents for each of the Phase 1 and Phase 2 groups so as to maintain validity and conduct a robust statistical analysis, however the required number was not obtained for the Caribbean Males (n=59) and Caribbean Antenatal women (n=41). In view of this a conservative approach was adopted and only issues that were highly significant were considered for analysis and consequently reported. Convenience sampling using educational conferences, websites and other similar avenues influenced the caliber of respondents recruited to the study and may have inadvertently biased the sample, albeit to a small degree, since a better educated population tend to attend such educational events and being more confident are more likely to agree to participate in research which requires filling in a questionnaire written in English only.

In Phase 1 of the study there were few opportunities for people living outside London to participate in the study and only those able to visit the Every Generation website or those who read The Voice newspaper, (a weekly publication aimed at the Black community nationally) where the project was advertised had access to the research. In order to obtain a large enough sample fifteen Black
community voluntary organizations and support groups in London were solicited and they assisted
in the recruitment of subjects. In Phase 2 of the project all subjects were from one of eight
specialist units. It is possible that living in a Cosmopolitan city influences attitude, especially
because of the multi-cultural, multi-ethnic mix of London’s population. In view of this the findings
may not reflect the attitude of Africans and Caribbeans living outside London or Africans and
Caribbeans in the wider Diaspora.

In view of the difficulty experienced in obtaining sufficient number of participants for Phase 2 it
was not possible to purposefully select a cross Section of participants that would reflect a variety of
biographical and social backgrounds for inclusion in the Phase 3 interview. A convenience sample
was used in both Phase 2 and Phase 3, any woman or couple identified as being at-risk of having a
child with sickle cell anaemia (Hb SS) was invited to participate in Phase 3 until the desired
number of approximately ten of each cultural group of women was obtained. Sadly the number of
Caribbean Male obtained was wholly insufficient and inferences could not be made, the qualitative
data merely described one respondent’s view in the Phase 3 interview. This sampling method
meant that there was no control over the variables that may potentially make comparisons more
difficult, for example, social class, educational level, age, marital status, whether the family already
have a child with sickle cell disease and other factors that may influence attitude to sickle cell
disease. In order to measure these variables in more depth a larger sample would be required and
by virtue of number at-risk at any given time in the UK this may prove difficult to obtain. Perhaps
a multi centre international study would be required to obtain this level of data collection.

In an attempt to obtain unbiased data about culture the study was accessible to those whose first
language is not English or those who are unable to speak English or read English competently they
were offered an interpreter or reader if required. But in order to give consent and agree to
participate in the study an individual would need to understand what they were being asked to
participate in perhaps an interpreter at that early stage could have increased the potential for these
individuals to consider participation.

The offer of a reader was accepted on one occasion by a Caribbean Antenatal respondent whilst
completing the Phase 2 questionnaire and an interpreter was used once by an African Antenatal
during the Phase 3 interview. It was not possible to assess literacy in Phase 1 and in most cases the
Phase 2 respondents; secondly the degree to which such respondents understood the questions in
the questionnaire and their response may or may not be a true representation of their attitude to the
statements in the questionnaire, especially in the few inflected questions. Secondly it was not possible to control how the candidates were approached and asked to participate, it is possible that those who were unable to speak English fluently were not asked to participate because of the difficulty of having to explain the project to them in the first place, especially following what may have been an already difficult genetic counselling session.

A convenience sample was used for Phase 1, 2 and 3 of the project, since no attempt was made to select on the basis of equal representation of the population it is not possible to make major inferences based on the small number participating especially in Phase 3 of the project. Those sampled is a mere reflection of those who were highly motivated, could be persuaded and or were willing to participate therefore the data does not attempt to claim to be representative of the wider African and Caribbean community.

Due to ethical constraints the researcher was unable to approach potential participants directly for Phase 2 and 3 of the project and had to rely on the specialist practitioners to assist with recruitment. In view of this it is difficult to ascertain how many of the pregnant women genuinely refused to participate and how many were not asked to participate because busy practitioners conducting a clinic forgot to bring the project to the attention of the potential participants.

In view of this it is not impossible to provide an accurate overall response rate for Phase 2 of the project i.e. the percentage of women who agreed to participate out of the total number of eligible pregnant women with sickle cell trait booked at the eight participating units.
9.6 Suggestions for future research

- In light of rapid advances in the new genetics it will be useful to apply cognitive dissonance theory to this field of medicine and examine genetics and genetic decision making focusing specifically on sociological (cultural) and psychological (individual attitudes and beliefs) aspects and whether these two paradigms have any interaction, how and to what degree they interact.

- Findings from this current study have demonstrated that few people of African and Caribbean origin voluntarily seek testing for sickle cell, so an in-depth study to examine peoples’ reasons for failing to make enquiries about sickle cell or seeking testing will be useful to enable development of appropriate health promotion strategies to meet the needs of these communities.

- A Caribbean Antenatal woman expressed feelings of worthlessness for producing two children with sickle cell anaemia in the past and being pregnant again and at-risk of producing another child with SCD. It would be useful to examine this aspect of an emotional response to being at risk of having a child with SCD or any other genetic disease, comparing different ethnic groups and conditions.

- Experience and expressions made by several women in the Phase 3 interviews suggest that a significant proportion of pregnant women are not aware that they are being tested for haemoglobinopathies and certainly are not made aware of the potential social implications or the fact that they have a choice whether to be tested or not. A survey needs to be conducted to assess how many women are making a truly informed choice about testing, and the reasons for their choices for or against testing.

- It will be useful to replicate Marteau et al.’s (1992) study and examine the degree to which people with sickle cell trait perceive that they are less healthy or will be less healthy in future when compared to those with normal haemoglobin (HbAA), and also whether they believe that their carrier status can change into a disease state later in life.
• It will be useful to examine how much impact having a child with SCD already has on decision-making in a future pregnancy. By comparing those with a child with SCD with those who are at-risk for the first time; and perhaps comparing the attitude of at-risk couples, who are carriers, with those who have SCD themselves.

• It will be useful to conduct a postnatal interview on all the at-risk women and couples that were interviewed in Phase 3 and declined PND to find out the outcome of the pregnancy and their reaction to their newborn baby’s result, including those born with normal (HbAA), carrier (HbAS) or disease (HbSS) states.
9.7 Personal Reflection

Having many years clinical experience of working with African communities I have come to recognize the difficulty in eliciting sensitive health information from many African communities especially those who share the same tribal group and language as myself (Yoruba speaking group of Southern Nigeria). Being from the same tribal group has advantages and disadvantages. In a community that is highly secretive about personal information, especially health information, despite assurances of confidentiality, I had rightly anticipated that many Nigerian participants may be reluctant to participate in the project, especially the face-to-face interviews. This reluctance became evident when a number of African women were willing to complete the Phase 2 questionnaires anonymously but unwilling to be interviewed for Phase 3 of the project.

Conversely other members of the tribal group were receptive to a researcher that shared their cultural background, some of the respondents interviewed, especially the women, seemed less suspicious and insecure perhaps because they perceive that a researcher who shares their ethnic group will be more sensitive to their values and recognize the need to maintain confidentiality of their personal information. My experience was that a small number of the Nigerian community were receptive and demonstrated an eagerness and willingness to assist in the research since they regarded the exercise as assisting and contributing to the professional progress of a ‘sister’.

I am conscious that the African respondents interviewed may have felt compelled to respond in a culturally predictable way to my questioning, they may have assumed that I would subscribe to a cultural attitude to procreation, child bearing, disease and illness. The response of these individuals may therefore not reflect their genuine attitude to the issue but a portrayal of their expectation that as an African woman I would expect a culturally conditioned response, thus safeguarding the ‘public image’ of themselves. As highlighted by Gaes, Kalle and Tedeschi (1978) where a person is asked to make a statement about an issue and they experience dissonance in cognitions there is a greater likelihood of attitude change if the statement was made in public however the degree of attitude change decreases if the statement was made anonymously.

Shavers-Hornaday et al. (1997) in a review of literature to identify factors contributing to African-Americans under-representation in medical research identified the community’s distrust of medical institutions and researchers as a major contributor; due to the Black community’s negative
experiences of abuse by unethical researcher by the research community, examples of such practices are fully illustrated in Sims (1989), King (1992) and Gamble (1993) and ‘alienation of minority (ethnic) health professionals’ also played a part. The unethical Tuskegee Syphilis Project of 1932 – 1972 was described by Tapper (1999) and Duster and Beeson (2007) as one of the many contributory events that led to wide spread mistrust of researchers by African–Americans in USA. It is unclear whether Black communities in the UK have had similar experiences of unethical research directed at the Black community specifically, no reports were found of such practises.

Sadly a significant proportion of the Africans approached for the current study were hesitant about participating even in Phase 1 of the study, when approached they agree to take part, however many failed to return the completed questionnaire and it took a lot more effort to chase up unreturned booklets. It is possible that a reluctance to participate is because of the length of the questionnaire which took thirty to forty minutes to complete, literacy and language barriers may also contribute in some cases and others may be due to an unwillingness to disclose their blood test result. When questioned by one of the research site supporters who is of Caribbean origin one Nigerian antenatal respondent reported that she was unwilling to participate because the lead researcher (myself) is Yoruba and may know and associate with people from her community and her personal information may be deliberately or inadvertently disclosed to other members of the community. This anxiety was not dissipated by an assurance of confidentiality on the part of the on site collaborator.

A few respondents gave conflicting answers, which suggest there was either a genuine misunderstanding of a question or a lack of trust that the information will not be treated as confidential. For example, one Antenatal Female in response to the question about testing in the questionnaire ticked ‘yes’ she has been tested, however, later in the questionnaire in response to the question about her haemoglobin type she ticked normal (Hb AA). Inclusion in phase 2 however is dependent on laboratory confirmation that the pregnant woman has sickle cell trait only those with a confirmed HbAS result are referred to the specialist sickle cell centre and become eligible to participate in the project. The possible explanations that can be offered for this inconsistency are, the woman was wrongly informed of her result or she was correctly informed but misunderstood the result or she unknowingly ticked the Hb AA box instead of Hb AS or she deliberately ticked the wrong box because she did not wish to disclose her result. This discrepancy in reporting was corrected by checking the result with the specialist centre and discussing the result with the pregnant woman prior to correcting the questionnaire. It is difficult to estimate how frequently this
discrepancy occurred in the Phase 1 group since respondents were recruited from the general population and inclusion is not dependent on being a carrier of the sickle gene, however I suspect it is minimal since respondents could use a fictitious name if they wish.

A few women when asked their partners result ticked ‘I don’t know’, however, later in the questionnaire they stated that they were told they were at-risk of having a child with sickle cell anaemia but declined offer of prenatal diagnosis, which suggest that they knew their partner’s blood test result or they would not have been aware of being at-risk. There was greater willingness among the Caribbean to participate in the project and many expressed great pride in supporting an African sister and celebrating her pursuance of academic excellence, a significant proportion of those approached were willing to disclose information about their test results and there was less inconsistency in their response. Those who were reluctant to participate were primarily those who felt the questionnaire was cumbersome and felt unable to spare the time or energy to complete it, a large proportion of Caribbean men were in this category which made it a more arduous task to recruit this group. The difference in attitude to participation among the Africans and Caribbean I suggest is a further reflection of the two ethnic group’s attitude to disease and illness and being comfortable to share information with an unknown individual, especially where that individual may or may not know others from within ones community.

It is difficult to know how much illiteracy or a poor understanding of English influenced the response of some of the respondents, this is difficult to determine in Phase 1 and Phase 2. However there were two African and one Caribbean respondent who were not very fluent in English and in one case (African Female) an interpreter was used effectively. Secondly it is difficult to know whether in an attempt to support the researcher some respondents may have inadvertently given responses that conflict with their true feelings, giving rise to the ‘Hawthorn effect’, whereby the respondents say what they think I want to hear, it is difficult to assess.

Wrightson and Wardle’s (1997) argument that in collectivist (interdependent) societies there is a strong inclination towards social cohesion and individuals, such as those from Africa and Asia, may respond to things in a way that conflicts with their own belief or preferred option. It is difficult to know whether this state of being has inadvertently affected the responses of respondents in this study, especially during the phase 3 interviews.
I acknowledge that I share many similarities with some and in some cases with all members of the study population, especially the Phase 2 and Phase 3 respondents, for example, Blackness, cultural group, gender, social class, educational background, religious practise, cultural values and attitudes these may have inadvertently impacted on the respondents reaction to the study and their responses especially in the Phase 3 face-to-face interviews.

During the Phase 3 interviews I often felt a sense of presence in the women and couples experience as they grappled with the decisions about whether to have PND and in on case whether to terminate and affected pregnancy. Because of my many years experience as a specialist genetic counsellor I believe I was able to remain impartial and desist from taking on the role of a genetic counsellor in my interaction with the counsellee’s, despite my remaining empathetic towards them and their often painful and anxiety provoking predicament. There were occasions that I shared myself with the participants during the interview and this enabled the development of a relationship of equals and I believe that this allowed richer data to emerge because the interviewees were able to recognize that they were respected, their contribution was appreciated and they were trusted with my own personal information. A similar observation was noted by Oakley (1981) in her study of motherhood.
References


National Sickle cell and Thalassaemia Screening Programme (2002). Screening Policy - newborn screening programme policy. www-phm.umds.ac.uk/haemscreening


Appendix 1 – Phase 1 and 2 questionnaire

Appendix 2 – Phase 3 questionnaire

Appendix 3 – Phase 3 Interview schedule

Appendix 4 – Example of an interview transcript

Appendix 5 – Literature search strategy

Appendix 6 – Qualitative data analysis coding and selection
APPENDIX 1

Title of Project:
Sickle Cell Genetic Decision Making in African and African-Caribbean Men and Women of Childbearing Age

Person Doing Project:
Ms Lola Oni, Nurse Manager
Brent Sickle Cell & Thalassaemia Centre
Tel: 020 8357 7115
Email: lo@sickle-thalassaemia.org

and PhD Student
European Institute of Health and Medical Sciences
University of Surrey
Tel: 01483 686717
Email: l.oni@surrey.ac.uk

Group ID: 

Participant ID Number: 

Please return the completed questionnaire by:

African Version
Please indicate the most convenient time to phone you on this number, just in case we need to contact you to check any information on the questionnaire.

<table>
<thead>
<tr>
<th>DAY(s) OF THE WEEK</th>
<th>TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Your opinion is very important for this project even if you do not speak or cannot read English. An interpreter or reader can be arranged to visit you at the clinic or at home if you prefer, and will explain the questions to you. Please indicate if you need an interpreter or reader and also indicate what language you speak and understand well.

Interpreter/Reader Required (please tick one box):  YES ☐ NO ☐

<table>
<thead>
<tr>
<th>LANGUAGE YOU SPEAK WELL AND PREFER TO USE</th>
</tr>
</thead>
<tbody>
<tr>
<td>........................................................................................................................................</td>
</tr>
</tbody>
</table>
### SECTION - 1

**Questions 1 - 21** If you believe the statement to be true or false please tick either the True or False box (tick one box only per question). You must answer ALL 21 questions with a tick for each and every one indicating true or false.

If you have not heard of or feel you are not able to answer any questions on sickle cell please put a tick here □ then go to section 3 on page 8 and answer questions 40 - 64.

PLEASE DO THE QUESTIONNAIRE ON YOUR OWN. DO NOT ASK ANYONE ELSE FOR AN ANSWER EVEN IF YOU ARE NOT SURE OF THE ANSWER.

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
14. People with sickle cell disease often die by 21 years of age

15. If in a couple both have sickle cell trait any of their children can inherit normal red blood cells and not have sickle cell

16. People with sickle cell disease are not sick any more than people who do not have sickle cell disease.

17. If in a couple both have sickle cell trait any of their children can inherit sickle cell trait

18. Sickle cell can affect White people

19. Having sickle cell disease does not affect a child's intelligence

20. People with sickle cell disease cannot have children

21. If in a couple both have sickle cell trait any of their children can inherit sickle cell anaemia (disease)
SECTION - 2

Questions 22 - 37 - please Tick one box to indicate whether you strongly agree, disagree, neither agree nor disagree, agree or strongly agree. For example question 23 if you disagree you will mark it like this:

23. If in a couple both have sickle cell trait I think they should not have children together

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>X</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

22. I believe that Sickle cell disease is not a serious condition:

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

23. If in a couple both have sickle cell trait I think they should not have children together

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

24. I think Science should **NOT** be used to prevent the birth of children with sickle cell disease

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

25. I think Women/Couples should have the right to choose whether to have a child with sickle cell disease or not

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
26. I feel that having a child with sickle cell disease can be a blessing in a family

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

27. If a couple are at-risk of having a child with sickle cell disease I feel they should consider adopting a child instead of having their own children

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

28. If a pregnancy is tested and the fetus is found to have sickle cell disease I feel the couple should continue the pregnancy and NOT have a termination (abortion)

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

29. If a couple are at-risk of having a child with sickle cell disease I think they should consider having a test tube baby using a donor egg or sperm

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

30. I believe that Science should be used to help prevent births that will result in a child with sickle cell disease

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
31. I think people should be tested automatically for sickle cell before they reach childbearing age (for example, during childhood, or in school)

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

32. I think people with sickle cell disease can achieve as much as any one else educationally

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

33. I think people should tell their partners their blood test result before having children

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

34. If a couple is at-risk of having a child with sickle cell disease I feel they should **not** consider having children together

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

35. I believe that having a child with sickle cell disease can cause financial hardship for the family

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

36. I feel it is very important for **ALL** healthy men and women to have children

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
37. If a couple is at-risk of having a child with sickle cell disease when the woman is pregnant I feel they should test the pregnancy to see if the fetus has the disease.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

38. Do you know anyone with sickle cell disease?
(please tick one box only)
Yes □ No □

39. If you do know someone with sickle cell disease was the person:
(Please tick as many boxes as applies to you or say whom on the dotted line)

A member of your family who lived or still lives with you □
A friend or neighbour who lived or still lives with you □
A person that never lived with you □
Other (please specify) .........................................................
..........................................................................................
..........................................................................................
..........................................................................................
..........................................................................................
SECTION - 3

Questions 40 - 64 are about you. It is important that you answer the questions as accurately as possible. Remember only the researcher and her assistant will have each individual participant's information and will put them together to form a whole. The final project will not contain your personal details or individual opinion.

40. What is your ethnic background

(please tick one box only)

- Black African
- Black African-Caribbean
- Mixed African and African-Caribbean
- Not Known

(Please specify country of origin of both of your parents and your four grandparents)

Your mother  ..........................................................
Your father  .........................................................
Your mother's mother ..............................................
Your mother's father ..............................................
Your father's mother ..............................................
Your father's father ..............................................

41. Are you: (please tick one box only)

Female  
Male  

42. Are you: (please tick one box only or specify)

Married  
Single  
Living with partner  

8
Living with parents with your partner  
Living with parents without your partner  
Other (please specify)  ........................................
...........................................................................................................
...........................................................................................................
...........................................................................................................
43. What is your age group? (please tick one box only)
   18 - 24  
   25 - 30  
   31 - 40  
   41 - 45  
   46 and above  
44. What educational qualifications do you have? (please tick all those that apply)
   None  
   School leaving certificate CSE  
   GCE / GCSE  
   A Level  
   Diploma  
   Higher National Diploma (HND)  
   Degree  
   Postgraduate degree  
   Other (please specify)  ........................................
...........................................................................................................
...........................................................................................................
45. Are you in paid employment? *(Please tick one box only)*

- Paid Employment
- Unemployed
- Full time Home maker
- Full time student
(Please specify Subject: ........................................)
Other (please specify) ........................................

46. What is your work/job title?
*(Even if you are not working at the moment state your last job title or profession)*

47. Do you practice a religious faith?

- Yes
- No
- Sometimes
*(If your answer is NO to question 47 please go to question 51)*

48. If you answered yes or sometimes to question 47 what is your religion?
*(If you practice one religion please tick one box only but if you practice more than one religion tick as many boxes as applies to you)*

- Christian
  - Anglican
  - Roman Catholic
  - Baptist
Methodist
- Seventh Day Adventist
Pentecostal
Cherubim & Seraphim (C&S)
Celestial
Other Christian (Please specify)

Muslim
Jehovah's Witness
Rastafarian
Other religion (Please specify)

49. How often do you go to the mosque, church, temple or your place of worship?

At least once a day
At least once a week
At least once a month
About once in 3 - 6 Months
About once in 7 - 12 Months
Less than once a year
Attend festivals only e.g. Christmas
50. Apart from going to your place of worship what other religious activities do you do *(please tick as many as may apply)*

- None
- Reading Holy book (e.g. Bible, Quoran)
- Praying
- Fasting
- Other (Please specify)

51. At what age did you come to the UK? *(Please tick one box only. If you do not live in the UK specify the country you live in)*

- Not living in UK
- Which country do you live in *(Please specify)*
- Born and still living in the UK
- Came before or at age 15 Years
- Came after age 15 Years

52. Have you been tested for sickle cell?

- Yes
- No

53. If you have given birth or fathered a child, were you tested before starting a family?

- Yes
- No
54. Has your partner been tested for sickle cell?

Yes  
No  
I don't know

55. If your partner has been tested what is his or her test result.

(Please tick one box only)

The usual haemoglobin (HbAA)  
Sickle cell trait (Hb AS)  
Haemoglobin C Trait (HbAC)  
Beta thalassaemia trait (HbAβThal)  
He / she was not told the result  
He / she did not tell me the result  
Other type of result (please specify)

…………………………………………………………………………………………
…………………………………………………………………………………………

56. If you have not been tested for sickle cell please say why you have not been tested:

(please state all the reasons that apply to you)

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

If you have not been tested please go on to number 64.
57. If you have been tested when were you tested?  
(Please tick one box only)

- As a young baby or child
- As teenager / adult when I was pregnant
- When my partner was pregnant
- As teenager / adult not related to pregnancy
- Other (Please specify)

58. What was your blood test result?  (please tick one box only)

- The usual haemoglobin (HbAA)
- Sickle cell trait (Hb AS)
- Haemoglobin C Trait (HbAC)
- Beta thalassaemia trait (HbAβThal)
- I was not given or told the result
- I cannot remember the result
- Other type of result (please specify result)

59. If you were given the test result how did you get the result?  
(please tick only one box)

- Through the post by letter or sent a result card
- Face- to- face explanation / counselling
60. If you were given a face-to-face explanation / counselling who did the session? (Please tick all boxes that apply)

- GP
- Doctor at the hospital
- Nurse at GP Surgery
- Midwife
- Genetic/specialist Nurse at hospital
- Specialist nurse at Centre
- Social worker
- Not sure/cannot remember
- Other (please specify who)

61. If you were given a face-to-face explanation/counselling did you find the session(s) Reassuring or Not reassuring? (Please tick next to the person (s) who did the session (s))

- GP Reassuring
- Doctor at the hospital Reassuring
- Nurse at GP Surgery Reassuring
- Midwife Reassuring
- Genetic / specialist Nurse at hospital Reassuring
- Specialist nurse at Centre Reassuring
- Social worker
- Not sure/cannot remember
- Other comments

(please write any other comments about the session (s) below)

...........................................................................................................
...........................................................................................................
...........................................................................................................
...........................................................................................................
.............................................................................................................
62. If you were given a face-to-face explanation / counselling did you find the session(s) **Useful or Not useful** (Please tick next to the person(s) who did the session(s))

<table>
<thead>
<tr>
<th></th>
<th>Useful</th>
<th>Not useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor at the hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse at GP Surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midwife</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic / specialist Nurse at hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist nurse at Centre</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other comments (please write any other comments about the session(s) below)

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

63. If you knew your test result before starting a family did you choose your partner based on your own test result?

- Yes
- No
- I did not know my test result

If you did know your test result before starting a family please explain why you chose or did not choose your partner based on your own test result:

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
64. If you have any comments or anything you want to add please write these below and if necessary continue on a separate piece of paper:

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
APPENDIX 1

SECTION 4
Multidimensional Health Locus of Control

Listed below are a series of statements concerning the ways in which people think about their health. Read each item carefully, and indicate how far you agree with it, using the scale on the right hand side.

YOU NEED TO ANSWER ALL QUESTIONS NUMBERED 1 - 18

Tick ONE of the boxes against each question as follows:

SD   MD      D        A    MA     SA

1 - Strongly Disagree (SD)  4 - Slightly Agree (A)
2 - Moderately Disagree (MD)  5 - Moderately Agree (MA)
3 - Slightly Disagree (D)  6 - Strongly Agree (SA)

Remember, there are no right or wrong answers

1  If I become ill, I have the power to make myself well again
   1 2 3 4 5 6

2  Often I feel that no matter what I do, if I am going to get ill, I will get ill.  1 2 3 4 5 6

3  If I see an excellent doctor regularly, I am less likely to have health problems.  1 2 3 4 5 6

4  It seems that my health is greatly influenced by accidental happenings.  1 2 3 4 5 6

5  I can only maintain my health by consulting health professionals.  1 2 3 4 5 6

6  I am directly responsible for my health.  1 2 3 4 5 6

7  Other people play a big part in whether I stay healthy or become ill.  1 2 3 4 5 6

8  Whatever goes wrong with my health is my own fault.  1 2 3 4 5 6
9 When I am sick, I just have to let nature run its course
1 2 3 4 5 6

10 Health professionals keep me healthy.
1 2 3 4 5 6

11 When I stay healthy, I'm just plain lucky.
1 2 3 4 5 6

12 My physical well-being depends on how well I take care of myself.
1 2 3 4 5 6

13 When I feel ill, I know it is because I have not been taking care of myself properly
1 2 3 4 5 6

14 The type of care I receive from other people is what is responsible for how well I recover from an illness.
1 2 3 4 5 6

15 Even when I take care of myself, it's easy to get sick.
1 2 3 4 5 6

16 When I become ill, it's a matter of fate.
1 2 3 4 5 6

17 I can pretty much stay healthy by taking good care of myself.
1 2 3 4 5 6

18 Following doctor's orders to the letter is the best way for me to stay healthy.
1 2 3 4 5 6

PLEASE CHECK TO MAKE SURE THAT YOU HAVE ANSWERED ALL 18 QUESTIONS?
SECTION 5
GENERAL ETHNICITY QUESTIONNAIRE

Tick ONE of the boxes against each question as follows:

1 - Strongly Disagree 2 - Disagree
3 - Neither Agree or Disagree 4 - Agree
5 - Strongly Agree

1. I was raised in a way that was Caribbean
2. When I was growing up, I was exposed to Caribbean Culture
3. Now I am exposed to Caribbean culture
4. Compared to how much I negatively criticize other cultures I criticize Caribbean culture less
5. I am embarrassed / ashamed of Caribbean culture
6. I am proud of Caribbean culture
7. Caribbean culture has had a positive impact on my life
8. I believe that my children should read, write and speak English
9. I have a strong belief that my children should have Caribbean/black origin names only
10. I go to social gatherings where people are English or non-Caribbean
11. I am familiar with Caribbean cultural practices and customs
12. I relate to my partner in a way that is Caribbean
13. I admire people who are Caribbean / Caribbean-British
14. I would prefer to live in an area where there are large numbers of Caribbean people

15. I listen to Caribbean music

16. I go to Caribbean parties and join in Caribbean dancing

17. I engage in Caribbean forms of recreation

18. I celebrate my country's / Islands independence day

19. At home I eat Caribbean food

20. At restaurants I eat Caribbean food

21. When I was a child the majority of my friends were Caribbean

22. Now the majority of my friends are Caribbean

23. I wish to be seen and accepted as Caribbean by my Caribbean friends

24. The people I date (or my partner if in a permanent relationship is) are Caribbean

25. Overall I am Caribbean

Tick ONE of the boxes against each question as follows:

1 - Very Much  2 - Much  3 - Somewhat  4 - A Little  5 - Not at all

26. How much do you speak your Caribbean language/dialect at home (e.g. Patua, French)
27. How much do you speak your Caribbean language/dialect at school or at work 1 2 3 4 5
28. If you practice a religion how much do you use your Caribbean language/dialect to pray 1 2 3 4 5
29. How much do you speak your Caribbean language/dialect with friends who speak the same language as you 1 2 3 4 5
30. How much do you listen to a Caribbean/black radio station 1 2 3 4 5
31. How much do you view TV/ films/ video that are of Caribbean/ Black origin 1 2 3 4 5
32. How much literature of Caribbean origin do you read 1 2 3 4 5
33. How fluently do you speak your Caribbean language/dialect 1 2 3 4 5
34. How fluently do you read literature written in your Caribbean language/dialect 1 2 3 4 5
35. How fluently do you write your Caribbean language/dialect 1 2 3 4 5
36. How fluently do you understand your Caribbean language/dialect 1 2 3 4 5
37. Are you bilingual or multilingual (please tick YES or NO) YES □ NO □
If YES, please list all the languages you speak
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

Please double check that you have answered all the questions and provided a telephone number on page 1

Thank you
Thank you for taking the time to complete this questionnaire
Please put it in the stamped addressed envelope provided
and post to:

Ms Lola Oni, Ph.D. Student
5th Floor, Institute of Health and Medical Sciences
Duke of Kent Building
University of Surrey
Stag Hill
Guildford Surrey GU2 7TE

If you need to ask any questions about the questionnaire or the project you can contact me or my research assistant Tanya Dasgupta on Telephone: 020 8357 7115. If we are not available leave a message and we will get back to you.

You can also contact me at the University on 01483 686717.
Genetic decision making in African and African-Caribbean men and women of childbearing age

(Phase 3)

**Please complete this top section**

Date: 

Full Name: 

Telephone / Mobile Number: 

Thank you for agreeing to take part in the project and being interviewed. Please be assured that all the information you give will be strictly confidential and your personal details will not be shared with anyone other than my research assistant who will also treat all information as strictly confidential.

Lola Oni (Nurse Director / Researcher)

---

**This part is for office use only:**

Group ID: 

Participant ID Number: 

Phase 3/ (Personal ID: )
Questions 1 - 18 are about you and your present pregnancy. **It is important that you** answer the questions to reflect your true opinion and feelings. Remember only the researcher and her assistant will have each participant's information and will put them together to form a whole. The final project will not contain your personal details or individual opinion.

Date: 

Group ID: 

1. How many weeks pregnant were you when you came for your first antenatal booking appointment (*Please tick one box only or specify)*?

   - Less than 10 weeks 
   - 11 - 15 weeks 
   - 16 - 20 weeks 
   - Above 20 weeks 
   - Not sure / cannot remember 
   - Other (please specify) .........................

2. How long were you trying before becoming pregnant:

   - Less than six months 
   - Less than one year 
   - 1 - 2 years 
   - More than 2 years 

3. Were you referred or treated for infertility?

   - Yes 
   - No 

Phase 3/ (Personal ID: )
4. How many pregnancies have you had in the past that resulted in:
(Please specify the number in each case)?

- Live birth ........................................
- Miscarriage ....................................
- Termination (due to medical reason) ................................
- Termination (due to social reason) ................................
- Still birth .....................................

5. Did you know that you were at-risk of having a child with sickle cell anaemia before this present pregnancy?

- Yes □
- No □

6. If you answered yes to question 5, were you planning to have the pregnancy tested before birth?

- Yes □
- No □
- Not decided □

7. If you were not planning to have the pregnancy tested before birth what are your reasons? (Please specify as many reasons as applies to you)

......................................................................................................................
......................................................................................................................
......................................................................................................................
......................................................................................................................
......................................................................................................................
......................................................................................................................

8. If you had planned to have the pregnancy tested before birth what are your reasons? (Please specify as many reasons as applies to you)

......................................................................................................................
......................................................................................................................
......................................................................................................................
......................................................................................................................
......................................................................................................................

3
Phase 3/ (Personal ID: )
9. Do you have any children of your own already (these relate to children you have given birth to or in the case of a man that you have fathered)?

   Yes ☐
   No ☐

   (If your answer is no please go to question 76 and answer questions 76 - 80)

10. Have your own children been tested for sickle cell. If your answer is YES please write test result for each child in the boxes provided and state year child was born. If any have not been tested write NO in the relevant box and indicate whether child is a boy or girl
   (For example AA, AS, SS, or NO + year born + boy/ girl)

   1st Child
   Year Born........... Boy ☐  Girl ☐

   2nd Child
   Year Born........... Boy ☐  Girl ☐

   3rd Child
   Year Born........... Boy ☐  Girl ☐

   4th Child
   Year Born........... Boy ☐  Girl ☐

   5th Child
   Year Born........... Boy ☐  Girl ☐

   6th Child
   Year Born........... Boy ☐  Girl ☐

   If you have more than six children please list the others below, plus their test result and the year of birth of each child:

   ……………………………………………………………………………………………………………………………
   ……………………………………………………………………………………………………………………………
   ……………………………………………………………………………………………………………………………
   ……………………………………………………………………………………………………………………………
11. Do you have any step or adopted or permanently fostered children **living with you**? If **YES** have any of them been tested and what is their test result. If you are not sure just indicate year of birth and whether child is a boy or a girl.

<table>
<thead>
<tr>
<th>1st Child</th>
<th>2nd Child</th>
<th>3rd Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Year Born</td>
<td>Year Born</td>
<td>Year Born</td>
</tr>
<tr>
<td>Boy ☐</td>
<td>Girl ☐</td>
<td>Boy ☐</td>
</tr>
<tr>
<td>Boy ☐</td>
<td>Girl ☐</td>
<td>Boy ☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4th Child</th>
<th>5th Child</th>
<th>6th Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Year Born</td>
<td>Year Born</td>
<td>Year Born</td>
</tr>
<tr>
<td>Boy ☐</td>
<td>Girl ☐</td>
<td>Boy ☐</td>
</tr>
<tr>
<td>Boy ☐</td>
<td>Girl ☐</td>
<td>Boy ☐</td>
</tr>
</tbody>
</table>

If you have more than six step adopted and permanently fostered children please list the others below, plus their test result and the year of birth of each child:

……………………………………………………………………………………………………………………………………
……………………………………………………………………………………………………………………………………
……………………………………………………………………………………………………………………………………
……………………………………………………………………………………………………………………………………

12. After this present pregnancy are you planning to have more children?

   Yes ☐
   No ☐
   Not yet decided ☐

13. If your answer is **yes**, what influenced your decision?

   *(Please specify as many reasons as applies to you)*

   ………………………………………………………………………………………………………………………………………
   ………………………………………………………………………………………………………………………………………

14. If your answer is **no or undecided**, what influenced your decision?

   *(Please specify as many reasons as applies to you)*

   ………………………………………………………………………………………………………………………………………
   ………………………………………………………………………………………………………………………………………
15. When you found out about you and your partner’s test result, apart from a doctor or nurse, did you ask anyone for advice or support, for example, a friend, your pastor?

Yes ☐

No ☐

16. If you answered **yes** to question 15 whom did you talk to and what was your reason for talking to that person or persons? (*Please specify*)

................................................................................................................................................................................................
................................................................................................................................................................................................
................................................................................................................................................................................................

17. If you answered **no** to question 15 what was your reason for not talking to anyone else about the result? (*Please specify*)

................................................................................................................................................................................................
................................................................................................................................................................................................
................................................................................................................................................................................................

18. If you have any comments or anything you want to add please write these below and if necessary continue on a separate sheet of paper:

................................................................................................................................................................................................
................................................................................................................................................................................................

Thank you for taking the time to complete this questionnaire
Please put it in the stamped addressed envelope provided and post to:

Ms Lola Oni, Ph.D. Student
Institute of Health and Medical Sciences
Duke of Kent Building
University of Surrey
Stag Hill
Guilford Surrey GU2 2TE

If you need to ask any questions about the questionnaire or the project you can contact me on Mondays at Telephone: 020 8961 9005. If I am not available please ask to speak to my research colleague Emma Lawrence. You can also contact me at the University on 01483 686717. If I am not available leave a message and I will get back to you.
Qualitative Interview Schedule

1. Your partner’s blood test result has confirmed that you are at risk of having a child with sickle cell anaemia, how did you feel when you were first told of this risk? *(to examine emotional response to knowing he/she / they are at-risk)*

2. What was your experience of the genetic counselling session (s) that you had? *(to assess level of directive or non-directiveness of counselling received)*

3. Do you feel it is important for a woman (man) to have children irrespective of any social or health problems that she (he) may have or may pass on to their children? *(to examine maternal/ paternal drive)*

4. What do you think influences a woman's (man's) desire to have children? *(to examine maternal / paternal drive)*

5. If you knew that you would be at risk of having a child with sickle cell anaemia before getting married would you still want a child? *(to examine maternal / paternal drive)*

6. If you knew that you would be at risk of having a child with sickle cell anaemia before getting pregnant would you still want to have a child? *(to examine maternal / paternal drive)*

7. What aspect of having a child with sickle cell anaemia worries you most? *(perception of disease)*

8. What positive or negative things do you see to having a child with sickle cell anaemia? *(perception of disease and level of burden)*

9. Would you consider having the pregnancy tested before birth (Prenatal diagnosis) and what are the reasons for your decision? *(attitude to PND)* Also explore gestational issues in relation to decisions about PND.

10. Who do you think should decide whether one should have prenatal diagnosis or not and why? *(Locus of control/ self efficacy)*

11. If you do have prenatal diagnosis would you consider terminating an affected pregnancy? *(attitude to TOP)*

12. What and who would influence your decision? *(attitude to TOP)*

13. Who would you talk to, to help you make a decision about continuing or terminating an affected pregnancy? *(support systems and utilization)*. Also explore decision making in respect of assistance of health professionals.

14. What effect do you feel having a child with sickle cell anaemia will or may have on your relationship with
   - your partner?
   - your other children?
   - your in-laws
   - extended family?
   - wider community?
 *(impact on close relationships and cultural values)*

15. Are you planning to have more children and what is going to influence your decision? *(effect of disease in family size)*
MB: I'm from Nigeria, I'm married in the last 18 months and now I'm pregnant again, my husband is a sickle cell carrier and I also is a sickle cell carrier. My first baby, she is sickle cell carrier also, and I'm pregnant at the moment and they say that this one's a sickle cell carrier also, so that's all about my family.

LO: So you already know that this pregnancy also hasn't got SS.

MB: No, no, it's a carrier also.

LO: That's good.

MB: I found out in the last two weeks (had prenatal diagnosis).

LO: Okay, that's fortunate.

MB: Yes.

LO: Did you know when you had your daughter, that you were a carrier?

MB: I know that I'm a carrier, that I'm AS but I didn't know that my husband could be a carrier because he is a strong man, very strong even when we went to the hospital for counselling, they said to him you are a carrier, she said, "I'm sorry sir you're a carrier", he said "No, I can't be, I cannot, I haven't fallen sick at anytime". She said you know most men say they are fine, they are OK, she then said, "You're a carrier. I'm sorry. You just have to calm down, see the test yourself, look at it, if you're not sure, we can take it again and do it again". Then he said "Okay, I'm a carrier. What does that mean, what do I have to do?" She said "You are both at risk 'cause now your family is at risk, every pregnancy you have a chance of fifty-fifty, so each time you are pregnant you can get AA, SS or anything. So the only thing you can do now, you are five months pregnant and you don't know what this one is carrying you have to go to a place in the City and go and test the baby. If he's AS, SS, or anything, it's up to you. 'cause you are four, five months pregnant now. If you want to remove it (abort an affected pregnancy) fine, if you want to leave it it's up to you. When we got there, we did the test and everything is fine the result told us we are lucky this one is AS.

LO: So you didn't know with your daughter?

MB: No, I didn't know. I know that she, I'm thinking that she may be AS.

LO: So when you were pregnant with her, didn't they ask you to come for a test?

MB: No, no, no, no.

LO: They didn't?

MB: No, no I just decided not to do anything because then my husband said that he is AA.

LO: Okay, he said he is AA?

MB: Yes, he said "I'm OK I don't want to go through any stress, I'm AA", but this time I said "no you just have to do the test because once you have the baby at least I'll know if you are AA and your wife is AS it's OK, so I told him he just has to come down it's compulsory.

LO: So with your first daughter, he kept saying he is AA?

MB: Yes he said "I am AA, I'm OK, I haven't fallen sick at any time, I am strong, so, it's you that has it you fall sick all the time, you're always tired maybe because of your sickle cell you have one S, but for me I'm OK". He was so surprised that he said "ahhh me I'm AS?"

LO: I am used to hearing this all the time from men (both laugh)

MB: He just said "ohh no. no. no it can't be, I just have to go there and see the result myself", he rang and asked "can I have the result please, are you sure this is my result, can we check it again, it doesn't cost anything to do it again and send it down", but she explained there is no mistake even if we do it again there is no mistake it is your blood, then he said "OK".
LO: So when you were first told that you were at risk, how did you feel, what was your response to the information?
MB: That umm, hmmmm (a Nigerian way of depicting anguish or a deep response) because once you are in a relationship for the past eight years and have a baby, because I have been planning a family since four years ago, being together so long, all of a sudden someone said you're at risk having a baby with SCD nobody is going to have a baby with SCD. You know to be with them is very hard and she said you are having a sickle cell I said “Oh God”, you know at home (in Nigeria) once you are AS and he is AS you can't be together.
LO: Is that what you feel?
MB: That's what I feel, this can break my home, it can bring a lot of things into my family. But my husband understands that this is a civilized country, we are not in Nigeria and we are not in Africa. But here, if you’re having a child with SCD, the woman at the hospital told us, she's from Africa also, she told us that over here there is no problem that you people should split, she said some people split, some women say “please don't tell my husband that I am AS, because I know him very well, it will bring a lot of problems into my family”, but in my situation my husband said “OK, when you go to the hospital and they say this baby is SS you have to terminate it, we'll try again, there is no problem with that”. Before this pregnancy, I had two pregnancies and I had miscarriage with them. He said if this one is SS, you can't deal with SS, you cannot, it's difficult to deal with them and at the end they can die off any time then it's going to pain you that if I had known from the start I could have abort this baby. So I said OK 'cause even the other day when he came home I was upstairs in my room and I was crying, he was downstairs watching TV, then he came to look for me and I said I'm okay, he just came upstairs, then he said “ahh you are crying because of the result, the woman said I am AS also, I too feel bad but don’t worry everything will be OK just let’s go there (for the prenatal diagnosis) if they say the baby is SS, don’t think because you are four months pregnant, morning sickness and all that, just forget about it we terminate it and try again. So once my husband had encouraged me and I have a very good friend a family friend and I explained to her since we share everything together, she said “OK, don’t cry once your husband is OK with it, you are OK if this baby's SS, I will follow you if your husband cannot go with you to terminate it, then you try again, there's no problem in that, just be praying that when you have the result the baby will be OK. Your baby will be OK, and now when you want to have another one they say at eight weeks you have the test to see if the baby SS”. My husband said don’t worry even if this one is SS if you decide not to terminate it well it’s our baby God gave us we will have it, we will have it, we will face our problem, so I said “OK fine”.
LO: That's brilliant, that's brilliant. When you went for the genetic counselling did you find that useful or not?
MB: Yeah, yeah, yeah, yeah, it's very, very useful, it is. Without them (the specialist nurse counsellor) you cannot even get anything because the programme is very, very OK.
LO: Did you feel that there was any pressure for you to have the test or not to have the test or what did you find?
MB: I didn't feel bad about it, once they said you are AS and your husband is AS this is family, this is family and these children they look up to you, if your child has SS throughout all their life you just have to look after him or her, because even when you go to work or go any where, you will think “Oh my baby”, you'll be scared because she's not healthy or he's not healthy. You'd be scared. The (sickle cell) programme is very, very OK for me.
LO: So did you know people with SCD in Nigeria?
MB: No, I didn't know, I'm not sure but like my senior sister, she had almost four children and it’s only one, only one is surviving only one is living with them the others they are all… I think, I even explained to her last time that maybe you are having a problem of sickle cell.
LO: And what do you mean by that?
MB: Maybe your husband is AS and you too are AS and you are producing SS, SS very time. Because I spoke to a woman at the hospital (prenatal diagnosis unit) she dais I am please to tell you that your baby is AS you are very lucky, you are very, very lucky, she's even happy because I'm already four months pregnant, she said she would feel bad, this woman is four months, she said “I don’t want you to have to abort this baby, I am very happy for you”. But my sister she had four children, four pregnancies but only one surviving.
LO: Did she give birth to other three?
MB: She normally gave birth to them.
LO: And then they died when?
MB: Maybe died soon after birth, the other one, after maybe four-five months like that, so I think I told her last time that maybe, but she said you are in Europe that’s why you can really understand these things.
LO: ‘Cause about three or four months, that's commonly the age in Africa where babies with sickle cell die, but they may have died from other things of course.
MB: In Africa they can’t treat them very well. She said “you are in Europe that’s why you are OK, you know in Nigeria the problem with our men if they find out you have something like that know you have to part, but because you and your husband are in Europe and you have people around you to counsell you, then it’s up to you to decide what to do when you have a problem, they tell you, you can do this, you can do that, you have the chance to check your baby (prenatal diagnosis) in two months and all those things, but in Nigeria there is nothing like that”, so I said “yes that’s true”.
LO: So do you think she's frightened of bringing up the subject with her husband? What does she think will happen if she finds out that maybe she has sickle cell?
MB: I think she is because having had four children and you only have one who survived. My mother in Nigeria she had eleven pregnancies but we have only three of us who survived me, my sister, and my junior brother. So that is it. So I think …
LO: Of course there are other things that can cause children to die in Africa, especially with all the infections and everything.
MB: Yeah, yeah but when it is so common you think of that this, my husband said that yeah maybe that's the same thing that's going on with my sister, so I said I know
LO: It is likely because, you know, I go to Nigeria and I see quite a few that experience that. You find someone with six children and they only have one left and they always die between three months to six months, certainly by about a year. So that's not uncommon. Do you think it's important for a woman to have children?
MB: Yes.
LO: Why?
MB: Ahh (tone seemed surprised at question) without them, I don't think your life is complete.
LO: Why is that?
MB: You know, children ... I don't know how to explain. I believe that you have to have children. It's very important in your life you just have to go into it even if it is just one 'cause sometimes everybody will be out there playing and enjoying their children. It's good to have them because children, once you have your baby it's a part of you, even if someone says let your baby come and spend time with them, you miss them. So it's very important.
LO: But what makes it important?
MB: I don't know how to put it but for me, I think because ehh, ahh, it's very compulsory even important sort of. Even in Africa you know some people that don't have children, they'll be behave funny, even when you talk to them, they will be low it's because they don't have children.
LO: You feel that people who don't have children are irritable or something?
MB: Yeah, yeah, yeah. They have very, very irritable, they'll scream at you, they'll do things like that. Like my auntie she is almost fifty or something like that, she is very, very wicked everybody is scared of her even my mother will say “Ahh don't go to her don't go near her, if you do any little things she's going to smack you”, and yeah.
LO: That happens does it?.
MB: Yeah, she says “you know I don't have children if you behave funny your mother has warned you that I am wicked and I am so don't test me just leave me that's the way I am”.
LO: So she admits to that?
MB: Yes, for example my little girl she's just 18 months, any and everybody want her to come and play and stay with them. I can send her on errands she is useful, she will come and kiss me and things like that.
LO: What if you decided after you got married that you didn't want to have children? Do you think that is something that would be acceptable to your family and to your husband?
MB: (laughed) nobody would ever accept that from me
LO: Why do you think that is?
MB: Because we are expected to have children because Ahh even your mother said, "I gave birth to you, you have to give birth to a person, you have to have your own children." If you don't have children, people ask you "do you have problem with your family, is it your husband or you". Even if me or my husband decide not to have children people will say "what's wrong with you, are you mad?" In Africa they won’t accept that from anybody, maybe in white people but in black people, something like that, you can never tell people you don't want to have children they will say maybe you are insane or something is in you or you are possessed or something like that. They'll say “ahh this one is, just go away you don't know what you are talking about".
LO: So do you think it's just as important for a man to have children as well?
MB: Yeah. It's both. It's both because my husband, he's not around, but as soon as he comes in he asks “how's my baby”, and when he phones he talks to her, she says “Daddy, hello daddy”, he says “Hello baby girl, are you all right?”, that's it. When you see your baby and it looks like you and everybody comes and says your baby looks like you and you'll be happy, you feel proud, he says “oh I'm a man”, you can see something that has come out of you, it makes you feel “yes I am a man I can produce children that look like me, I am a man, and I'm okay (normal, healthy)".
LO: Do you think he would feel less of a man if he doesn't have children?
MB: Ahh, even people around that have children all their children will be calling you uncle and all those things, none of them would like come to your house because you don't have children. Even in Europe if you have children most of your friends their children will want to come to your house and spend time with your children when they are on holiday. But if you don't have children, they won't want to come, children want to be around other children like them.
LO: How do you think your family, your husband's family would feel if you didn't have children?
MB: Ahh as for me, my husband's mother, my mother-in-law she is OK she is fine but if you are with a man, even back in Africa, two years latest three years if you don't have children they will say please go and get another person, because we don't think this marriage is gonna work. Because she has spent almost three years with you and nothing has come out of the marriage, even people who got married after you they are already have children, maybe two, but you in three years... even the man will call you and say I can't go on with you anymore I cant go on I'm tired. Just stay in there, just say, I didn’t say you should pack out and if you know you can’t cope with me getting another woman then pack your things I am going to get another person, but if you want to stay, then stay I am still married to you but I will get another wife, that's how it is. But for my mother-in-law, my family, my husband's family they will say “ahh, what do you want us to do now?” You know how it is in African they will not talk to you, if you are a very nice person they will not discuss it with you (because they like you and want to be sensitive to your plight) they will prefer to call their son and say “what are you looking it, you can’t drive this woman away she is OK, she is nice, everybody loves her, but at least you can’t compromise that because she is nice, if she can’t bear you children, then just get another person if that one gets pregnant then we will know how to tell her (your first wife), that’s it.
LO: Okay. If you knew that you were at risk of having a child with SCA, would you have married your husband still? Would you still have continued and married each other?
MB: As I said earlier this is Europe they said OK you are AS and I am AS also, we can marry, we can stay together but once you get pregnant you must come down (for prenatal diagnosis) it's OK. Because if I said, “I don't want you because you're AS, I want to go and marry another person”, what about that other person?
LO: Hmm, when you meet somebody else they may be AS as well.
MB: So you're just going out, going out, going out, and you are wasting your time. So it's better you plan your life with that person like the woman (specialist nurse) said I can have my baby I can have even four five without even terminating, it's chance.
LO: Yeah, it's chance.
MB: It's chance.
LO: If you were back home and you knew you had AS, and say you were going out with your husband and he also has AS, do you think you would still continue and have children for him, if you were back home in Nigeria?.
MB: Yes, even if we were back home, we love each other at least we can still say this is my baby and she's OK and this (current pregnancy) is the second one and this one is OK. There is a God can, once you believe that my god will do this he is going to do it, if you believe, even this pregnancy before we even went to the hospital and had the test (PND) I said to my husband “this baby is OK, it’s going to be OK” I feel that the baby is going to be OK. We will go for the test but I know it’s going to be OK. I believe it’s going to be AA or AS and it’s going to be OK. It's to do with belief, if you believe that your God will do it, he will do it, don't doubt. I believe that even if I have four of them and I believe that they are all going to be OK, they will be OK. I am a Moslem and I always pray and everything, I didn’t pray for any SS or anything, so SS will not come to my family. If I am back home I will still carry on, yes, yes.
LO: Even before you got pregnant, do you think you would, if you knew you were at risk, you would still have carried on and have children anyway?
MB: Yes, 'cause I like having babies even when they are little, they make you happy. I can't imagine not to, having children is very important to me.
LO: Which aspect of having a child with sickle cell do you think would worry you the most, if any?
MB: When you hear that your husband is AS and you are AS that’s the annoying part of it everything will be down, you will be thinking...
LO: So when they told you that you were both AS and then you were at risk of having a child with SS, what part of having a child with SS do you think would worry you or frighten you?
MB: That’s SS, having SS you will think, that’s very, very dangerous, AS is OK.
LO: So what part of it worries you?
MB: Uhhh today you take them to the hospital, tomorrow they says they are sick, the doctor said their hands will be swelling maybe at about three months, their belly, all their bones, their blood is clot all those things, you’ll be scared anytime they can die, all those things, take them to the hospital almost every time, you won’t be able to do anything they’ll just keep you occupied, seeing to them almost twenty four hours, non, no, no. That’s terrible not the idea of having children, that’s terrible.
LO: Can you think of anything positive to having a child with SCA?
MB: No.
LO: No?
MB: Nothing.
LO: Nothing at all? So the only things you can think of are negative things?
MB: Yes.
LO: Why do you think you decided to have the pregnancy tested?
MB: Because my midwife told me that once I didn’t know my husband’s blood group I need to know that, then I said fine, then we found he is AS also and this pregnancy is at risk maybe SS its very, very dangerous, you go to the hospital and if the baby is SS you take it out, but it’s your choice nobody will force you for that, it’s your problem, so you have to face it, that’s all.
LO: Okay. Who do you think should decide whether you should have the pregnancy tested?
MB: It’s between the man and the woman.
MB: No, it’s between me and my husband we decided to have the test done. The doctor cannot say I should do it, the test is painful, you have to use a needle it’s painful at the end of the day if I have a miscarriage are you going to… no, no, no it's between me and my husband.
LO: When you were first told, did you discuss it with anybody else to seek their advice, for example your friends?
MB: No, no , no.
LO: None of your friends or ...
MB: No, after, I told my friend, she said OK when the test is done if the baby is SS and you have to terminate I will follow you if your husband is scared to go with you, but I’m sure you’ll be OK, don’t think of it and I said fine. The other lady (specialist nurse), a black woman, a very nice woman, she talked to us that we should make a decision that is best for our family, we shouldn’t let it disturb our family that won't split you apart just try and work things out among your family. The woman said “I think the test is best for you, we are in a good position, SS is not good, just go there, and if they say the test is SS I will call you and you can decide what you want to do if the baby is SS”.
LO: If you were to have a child with SCA how do you think it would have affected your relationship with your husband?
MB: Hmm, hmm, having those children, having them hmm is big problem, family around you, I don't know. My husband and I we have been together for a long time and I don’t want something like that to split us a part. But it’s not my fault and it’s not his fault, it’s not the baby’s fault either none of us we will see it as this is our problem, we would just have to face it.
LO: So you think in terms of your husband, you think he would understand and he would stick by you?
MB: Like last time he said it’s not your fault and it’s not my fault, this is biological we just have to face this, if you want to stay with me just accept this is my baby and I will take care of it, but to be on the safer side I don’t want to have SS baby, anytime you are pregnant we go for the test (PND) if the baby is SS we will stop it, and I said OK fine.
LO: If you were to have a child with SS, how do you think it would affect your relationship with your in-laws?
MB: You know Africans they will talk, they will look at the baby and say “look at the baby, the baby is not healthy, he is SS””. Nobody will like to accept the baby, they would say a lot of things about the baby “look at their baby it’s not healthy, look at its hands, look at its legs”. For me nobody prays for that, nobody as a mother.
LO: So do you think your husband’s family would accept the child?
MB: They would not, they’ll react funny, they will even ask their son to get another woman, but make sure you check that one very well to make sure that one is OK. No family in Africa will react normal or praise you for even having the child (described in Nigerian Yoruba language the derogatory things s that would be said to the woman who bears a child with SCA).
LO: If you do have a child with SCA even though you know both you and your husband have AS do you think they would blame you for having the child?
MB: You know in Africa everything is the blame will be on the woman, they will say she is not able to bear normal children, they will say why are you still together? They will call their son and say OK we know you people are having all these abnormal children go and have another woman just leave her alone. We can’t ask her to pack, she has children for us also but they are not normal children you can’t depend on them, they can pack off (die) at any time, they can die tomorrow
LO: For him to go and get another wife?
MB: Get another wife, just leave her alone, nobody will take care of those children for her, just let her take care of her children its her problem, just you go and find another person. The blame will be on that woman not the man.
LO: Even though both of them have AS and AS?
MB: Yeah, even though both of them have AS and AS, but the woman is the one that carry that blame because they are your children that’s how it is in Africa.
LO: What about the rest of society, like your friends and people in your neighborhood, how would they react to you having a child with SCD?
MB: They would look at you funny in any society if you see SS you know that this one is SS. Maybe their eyes is green, their heart in pain, their legs, all those things, you will look at them in a different way, if you see them among twenty children you will know this one is SS, he is different among those children.
LO: He is different?
MB: Yes, different, people will say it’s a pity this one is SS, you will know. Even in all society, even in school they will say this one is SS you don’t play with that one, don’t push her you know she’s not healthy, it’s like that.
LO: So you think they'll be rejected?
MB: No, they won't be rejected but they’ll caution other children not to push them (children with SCD) because they are fragile. But normal children you say to them if your school mate smack you, don’t come and complain to me smack her back but not SS you tell the other children not to smack her back you know she is not well don’t push her, don’t touch her, don’t smack her.
LO: So in terms of the society’s attitude to sickle cell, do you think we accept sickness, do we accept sickle cell in our society?
MB: Nobody wants that, nobody, but that situation when I say don’t push her, don’t smack her you are saying indirectly this thing is not normal, but once you have it there is nothing you can do about it, you just have to accept what God give us, just accept it the way God give us, we don’t want it but if God give us we accept it like that. That’s what I feel, OK fine SS baby. So nobody wants SS in his or her family, I don’t want it and when I see them I pity them, likewise if I have it in my family people around me will pity me.
LO: Does religion play any part in influencing people's decision about this?
MB: Yeah, if you have belief, even if you have SS if you have belief, it’s God that give this baby nothing will affect this baby, you tell God you gave this baby to me and know it is SS before you gave it to me it just has to live, because I’m a Moslem I believe. I told my husband this baby will be OK but he said if anything comes up (if the baby has SS) and you have not allowed us to have the test done in the first place, the then that’s when we will fight because now you see they say the baby has got SS.
LO: So when your daughter, and let's say it’s a son or another girl, when they grow up, 'cause they obviously have AS, what are you going to tell them about it when they come to choose a partner?
MB: Ahh well I don't want them to make the mistake that I made. I have to tell them you are AS, if you were AA you can have anybody you are OK, but you who are AS you cannot have an AS partner, I'll tell them my story and explain that it’s only because your daddy really understand because we love each other if not we may have parted and maybe we would even not have had you. Just choose AA.
LO: So they should choose somebody who is AA?
MB: Yes not to go through the stress that I went through, it’s not good that SS, just choose somebody who is AA, I'll keep everything on record so they know I am not lying.
LO: At what age do you think you would tell them about sickle cell?
MB: I think at about fifteen years or going to eighteen. I just have to tell them.
LO: Well thanks very much for giving me the time. I don't know if there's anything else you want to add in relation to how you think the attitude is to sickle cell, particularly in Nigeria, where you and I come from.
MB: You know in Nigeria it’s terrible they say you are having ‘abiku’ and all those things, but that’s back home that people say you are having abiku but now I don’t even think it’s abiku, I think something like that is rubbish.
LO: You'll probably find a lot of those children that people call abiku are children with SCD.
MB: SS, all those things but once they have them, this pregnancy you lose it, next one you lose it, then they say you are having abiku they take you to herbalist and with doctors, yes. They say you should go and buy a goat, buy all those things (for doing a sacrifice to appease the spirits), they are just eating your money for nothing. But if you sit and think about it get people to counsell you then you will know that there is nothing like that and you will be OK.
LO: Yes, we have a lot to learn in Africa.
MB: Yeah, in Europe they tell you these things, but in Africa nobody knows.
LO: Most of us don’t know what our sickle status is.
MB: Yeah, if you go there they give you wrong one (result) it’s like a friend of mine in Nigeria, she is AS also but they gave her an AA result until she fell sick and went to a big hospital with typhoid and they tested and told her she is AS. So I said “ahh you said you are AA before why are you AS again”, she said that’s what they told me now.
LO: They make a lot of mistakes in the laboratories in Nigeria.
MB: Yeah, they mix everything together, that’s why my husband was suspicious that maybe when they tested him here (in the UK) that maybe they made a mistake, but the woman (specialist nurse) told him no we don’t make those kind of mistakes here, but if you want I will take it again and you will see that it will be the same result. We are not in Africa they are doing very careful tests here they will not give you someone else’s result.
LO: But most Nigeria men will say that anyway, they will say (shared a brief discussion about Nigerian men’s attitude in their native Nigerian language, both laugh) You know me that is strong, I’ never sick and all that they say all these things because they just won’t accept that sickle cell trait is not an illness.
MB: Yes, yes.
LO: It's genetic, some of them feel perhaps it will affect their libido.
MB: Exactly, exactly.
LO: You try to explain to them that it doesn’t affect your sex life (both laugh)
MB: When they told my husband he said no it's impossible, impossible, how come, maybe there is a mistake some where, can I come now today you have to do it again, you know Nigerian men (both laugh)
LO: They never accept anything is different for them, well thanks very much.

END OF INTERVIEW
A comprehensive literature search was conducted for six months at commencement of the PhD, every six months thereafter an update search was conducted to search for any relevant new materials and to widen search to include concepts that were emerging during the course of the study.

1. **Search Terms**

   - Abortion / Termination of pregnancy / and genetics
   - Acculturation/ Enculturation
   - Antenatal
   - Attitude
   - Black Health
   - Black Women’s health
   - Counselling
   - Culture/ Cultural/ Cultural Theory/ Culture Health and Illness
   - Cross Cultural
   - Disease / Illness
   - Education / Health Promotion
   - Ethnicity
   - Ethnicity and Health
   - Feminism / Women's Health/ Gender
   - Gender / and Health/ and Attitude
   - Genetics/ Choices/ Genetic testing
   - Health Behaviours / and Psychology/ Psychological
   - Immigration/ Immigrant/ Migration/ and Health
   - Kinship/ Relationships/ and Genetics
   - Minority / Ethnic Minority/ Ethnic Health
   - Multicultural
   - Religion/ Religious
   - Reproduction/ Reproductive choice/ and selection
   - Power / and Social Class/ and Race / and Gender
   - Pregnancy/ Childbirth and Choice
   - Prenatal Diagnosis/ Amniocentesis
   - Psychological Tests/ Testing
   - Risk / Risk Behaviour/ Risk Assessment
   - Sex/ Sexuality / Power/ Class
   - Sickle Cell/ and Psychology
   - Tropical health / and sickle cell
2. **Databases searched included e.g.**

   African Studies Journal
   Asian and Pacific Migration Journal
   CINAHL
   EMbase
   InfoPsyche
   International Organization for Migration
   Journal of International Migration and Integration
   LILACS
   Medline
   NHS Trust and related Health Libraries
   PsychLIT
   PsychMED
   Scisearch
   Social Science Libraries
   University Libraries including USA, West Indies and Africa

3. **Other Sources include:**

   Amazon Internet Library Archive
   British Library Archives
   Cochrane Library
   Cross Cultural Research
   Hand search Journals – British Library
   Sage Publications

4. **Journals:**

   African Journal of Medicine and Medical Sciences
   American Journal of Medical Genetics
   Annals New York Academy of Sciences
   Blood
   British Journal of Haematology
   British Journal of Social Psychology
   British Medical Journal
   Clinical Genetics
   Community Practitioners Journal
   Ethnicities Journal
   European Journal of International Migration and Ethnic Relations
   Human Reproduction
   Journal of Ethnic & Migration Studies
   Journal of Genetic Counselling
   Journal of Medical Genetics
   Journal of Medical Screening
   Journal of Reproduction and Child Psychology
   New England Journal of Medicine
   Nursing Times
4. **Journals (continued...):**

   - Nursing Standard
   - Prenatal Diagnosis
   - Psychology, Health and Medicine
   - Race & Class Journal
   - Seminars in Haematology
   - Social Science of Medicine
   - Sociology of Health and Illness
   - West Indian medical Journal

5. **Documentation and storage**

   - N6 Qualitative data storage software
   - Endnote Reference Manager
Qualitative interview coding and data selection

The qualitative interviews were transcribed and coded by the researcher and a research assistant independently in order to select the themes identified in literature review and to observe and identify themes newly emerging from the raw data. These were entered into Nudist 6 and stratified into 'tree nodes' as illustrated below.

All the coding themes were agreed between the researcher as the first line coder and the research assistant as the second line coder. Where there was discrepancy in coding a third coder was given the task of coding the discordant section of the interview independently and a final code was agreed between the researcher and the third coder.

The coding went through rigorous coding and thematic analysis – First, second and third line coding.
<table>
<thead>
<tr>
<th>NODE - LEVEL 1</th>
<th>NODE - LEVEL 2</th>
<th>NODE - LEVEL 3</th>
<th>NODE - LEVEL 4</th>
<th>NODE - LEVEL 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Coping with a child with SCD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Not offered PND</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LEVEL 1</td>
<td>LEVEL 2</td>
<td>LEVEL 3</td>
<td>LEVEL 4</td>
<td>LEVEL 5</td>
</tr>
<tr>
<td>---------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>6. Religion</td>
<td>1. Influenced Decision</td>
<td>1. To accept PND 2. To accept TOP</td>
<td>1. To accept PND 2. To accept TOP</td>
<td></td>
</tr>
<tr>
<td>8. Tested for SCD</td>
<td>1. Not aware Hb type preconception</td>
<td>If I had known my Hb type before relationship started it…</td>
<td>1. Would not influence my choice of partner 2. Would influence my choice of partner</td>
<td></td>
</tr>
<tr>
<td>9. Knowledge of Hb Status</td>
<td>1. Told ‘I am OK’ (normal) 2. Told wrong result 3. I chose to ignore result</td>
<td>1. Told ‘I am OK’ (normal) 2. Told wrong result 3. I chose to ignore result</td>
<td>1. Told ‘I am OK’ (normal) 2. Told wrong result 3. I chose to ignore result</td>
<td></td>
</tr>
<tr>
<td>LEVEL 1</td>
<td>LEVEL 2</td>
<td>LEVEL 3</td>
<td>LEVEL 4</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>--------------------------------</td>
<td>----------------------------------------------</td>
<td>-----------------------------------------</td>
<td></td>
</tr>
<tr>
<td>10. Experience of genetic counselling</td>
<td>1. Good</td>
<td>(Directiveness for 5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Poor</td>
<td>1. Non directive</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Not counselled</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. Increased my anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Reproductive attitude</td>
<td>1. Important to have children</td>
<td>1. Biological reasons</td>
<td>1. Selfless (someone to care for)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Cultural reasons</td>
<td>2. Body clock demands</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Not important to have</td>
<td>1. Biological reasons</td>
<td>1. Society pressure</td>
<td></td>
</tr>
<tr>
<td></td>
<td>children</td>
<td>2. Cultural reasons</td>
<td>2. Duty to maintain family line</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3. Investment for old age</td>
<td></td>
</tr>
<tr>
<td>12. SCD illness perception</td>
<td>1. Severity perception (clinical)</td>
<td>1. Mild acceptable</td>
<td>1. No society pressure</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Mild but not acceptable</td>
<td>2. Decision is independent of family's need for continuity</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Severe acceptable</td>
<td>3. No need for kids to care for me in old age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Severe but not acceptable</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Social perception</td>
<td>1. Stigma in my society</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Maintain secrecy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Prevent SCD at all costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. SCD is acceptable in my society</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LEVEL 1</td>
<td>LEVEL 2</td>
<td>LEVEL 3</td>
<td>LEVEL 4</td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
<td></td>
</tr>
</tbody>
</table>
2. Positively |         |
|         | 2. Perception of faith | 1. Faith for faith's sake  
2. Help prevent bad things happening to me  
3. God's will, will be done anyway |         |
| 14. Effect of having a child with SCD on personal relationships, with my… | 1. Partner | None  
1. Good effect  
2. Detrimental (bad) effect |         |
|         | 2. Own extended family | None  
1. Good effect  
2. Detrimental (bad) effect |         |
|         | 3. Own Children | None  
1. Good effect  
2. Detrimental (bad) effect |         |
|         | 4. Partner's family (in-laws) | None  
1. Good effect  
2. Detrimental (bad) effect |         |
|         | 5. Friends / wider community | None  
1. Good effect  
2. Detrimental (bad) effect |         |
| 15. Effect of having child with SCD on self and family | 1. Positive | 1. Will improve my knowledge of SCD  
2. Will increase my coping skills  
3. Will improve my attitude to SCD illness |         |
|         | 2. Negative | 1. May limit my self progress  
2. May limit family's progress  
3. May limit affected child's progress |         |
SECOND LINE CODING

1. Cultural attitude to having children
   Biological drive theory
2. Children as a pension plan for old age
3. Cultural attitude (general not sickle related)
4. Knowledge of sickle cell disease and decision making
5. Attitude to sickle cell disease
   Choosing partner
6. Perceived health and social impact of sickle cell disease
7. Impact of religion and influence on attitude to sickle cell
8. Response to being at risk of having a child with sickle cell anaemia
   Management of haemoglobin result
9. Attitude to prenatal diagnosis/termination of pregnancy
   Religious impact
10. Counselling Experience
11. Factors influencing genetic decision making
   Relationships
12. Determining family size and future procreation

THIRD LINE CODING

1. Attitude to procreation and childbearing
2. Knowledge and perception of sickle cell disease
3. Factors influencing decisions about an at-risk pregnancy
4. Prenatal diagnosis (acceptance or rejection)
5. Influence of religion on decision making
6. Possible impact of having a child with sickle cell anaemia