



***Exploring How Sickle Cell Disease Impacts the Selection of Romantic
Partner and Reproductive Decision Making of Adults with Sickle Cell
Disease Living in The United Kingdom***

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ABSTRACT

This thesis is an empirical exploration of how Sickle Cell Disease (SCD) impacts the partner selection and reproductive decision making of adults with SCD living in the United Kingdom. Its impact on status disclosure and moral responsibility of the study population will also be elucidated.

Drawing on qualitative interviews of 23 adults with SCD in the UK, I used the concepts of *Embodied Risk*, *Social Model of Disability* and *Social Model of Relational Disability* to explore and describe how embodying SCD impacts the lives of these individuals as they select partners for long term relationships and exercise agencies to make reproductive decisions.

For study strategy, the participants were recruited from the target population as the *experts* since they are the '*experiencers*' of the phenomenon being studied, to ensure that the research makes their voices heard rather than the voices of '*Outsiders*' who are not embodied with SCD *nor* its burdens.

I situate this analysis within a wider context of normal/*abnormal*, *health/illness* dichotomy created by the medical hegemonic culture that seeks to eliminate SCD from society while probably unintentionally neglecting the social, political and psychological oppressions of the target population.

I argue that the impact of SCD on partner selection, reproductive decision making, status disclosure and moral responsibility of these adults living in the UK offers an understanding of the level of stereotyping, marginalization, discrimination and stigmatization this target group are subjected to as inaccurate genetic information is flung into society '*unhinged*'. The life course of these people whose bodies happen not to fit into culturally accepted norm for romantic partnership and reproduction are thereby '*disrupted*'.

Findings reveal the widespread psycho-emotional disablism experienced by the participants and the '*complex invisible works*' they perform as they struggle to find partners with whom to form romantic relationships and possibly parent children. These '*works*' or '*labours*' in their romantic spaces are embedded in the oppressive and partial information of the popular culture. This thesis brings to light these difficulties faced by people living with SCD, the restriction and isolation they experienced as they try to make family, bringing chaos and disruption to their life-pathways. The genetic screening result of the SCD-affected individual becomes defined and understood, not just as a biological phenomenon assumed by the NHS but by damaging consequences within the social domains of life. It is hoped that the

thesis will contribute to the deconstruction of the inaccurate narratives of genetic information perpetuated by the dis/uninformed powers in the public forums that label SCD-affected persons as unsuitable for romantic partnerships and reproduction.

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Contents

ABSTRACT	2
ACRONYMS & OPERATIONAL DEFINITIONS	10
CHAPTER 1	12
INTRODUCTION	12
1.1 Introduction	12
1.2 Why Sickle Cell Disease?	13
1.3 Romantic Relationships	15
1.4 Reproductive Decision-Making	16
1.5 Problem Statement and Purpose of the Study	18
1.6 Aims and Objectives of the Study	20
1.6.1 Aims of the Study.....	20
1.6.2 Research Questions	20
1.7 The Theses Outline	20
CHAPTER TWO	22
LITERATURE REVIEW	22
2.1 Introduction	22
2.2 Sociology of Chronic Illness	23
2.3 The UK Approach to Management of Chronic Illnesses	24
2.4 Creation of ‘Risky Bodies’ in Society	25
2.5 Chronic illnesses, Partner Selection and Reproductive Choice	27
2.6 Genetic Risk and Responsibility	29
2.6.1 Ethical Issues to concept of Genetic Responsibility (GR)	30
2.6.2 To know about the Self for Sake of Self	32
2.6.3 To know for sake of <i>Others</i> (Offspring)	33
2.6.4 To know Self to oblige <i>Others</i> to know (Disclosure).....	36
2.7 The Theoretical Concept	37
2.7.1 Embodied Risk	38
2.7.2 Social Model of Disability (SMD)	41
2.7.3 Social Model of Relational <i>Disablism</i> (SMRD)	45
2.8 Stigma	48
2.9 <i>Disablism</i> and Emotional Work	53
2.10 Conclusion	55
CHAPTER 3	57

RESEARCH METHODOLOGY	57
3.1 Introduction	57
3.2 Adopting Qualitative Approach	57
3.3 Adopting Phenomenological Design	59
3.4 Data Collection Instrument	63
3.4.2 Pilot Study	66
3.5 Sampling	66
3.6 Ethics	67
3.7 Recruitment Process	69
3.7.1 Interview Process	72
3.7.2 Data Analysis	76
3.7.3 Research Trustworthiness	77
3.7.4 My Familiarity with Research Subject	78
3.8 Conclusion	80
CHAPTER 4	81
SICKLE CELL DISEASE	81
4.1 Introduction	81
4.2 What Is Sickle Cell Disease?	81
4.3 Epidemiology	84
4.4 Clinical Manifestation of SCD	86
4.5 SCD Management	87
4.6 Sociology of SCD	89
4.7. SCD in UK	92
4.8 Socio-psychological burden of SCD	97
4.9. Cultural Understanding of SCD	99
4.10. Conclusion	101
CHAPTER 5	103
GENETIC RESPONSIBILITY	103
5.1 Introduction	103
5.2 Attitudes/Motivations of Participants to Concept of GR	105
5.3 Genetic Responsibility for Self	107
5.4 Responsibility for <i>Others</i>- Potential Partner	109
5.5 Personal issues and Responsibility for <i>Others</i>- Offspring	111
5.6 Factors Influencing GR	119

5.7 Conclusion.....	127
CHAPTER 6	131
STATUS DISCLOSURE	131
6.1 Introduction	131
6.2 Attitudes of Participants to Genetic Status Disclosure	132
6.3 Whom to Make Disclosure.....	134
6.4 Non/Disclosure for Lack of Awareness.....	135
6.5 Disclosure Strategies.....	137
6.6 Impact of Family and Friends on Disclosure.....	145
6.7 Outcome of Disclosure.....	147
6.8 Conclusion.....	152
CHAPTER 7	156
STIGMA.....	156
7.1 Introduction	156
7.2 Structured or Institutional Stigma	158
7.3 Stigma from Family	164
7.4 Stigma from <i>Others</i> in Society	168
7.4.1 Stigma in privacy of Intimacy	172
7.4.2 Attribution of Blame by <i>Others</i>	174
7.4.3 Stigma Effect on Partner’s Support System	175
7.4.4 Resignation/Termination of relationship.....	178
7.5 Conclusion.....	179
CHAPTER 8	186
CONCLUSION AND RECOMMENDATIONS.....	186
8.1 Introduction	186
8.2 Study Findings.....	189
8.2.1 Genetic Responsibility.....	191
8.2.2 Status Disclosure	193
8.2.3 SCD Associated Stigma.....	195
8.3 Study Limitations	198
8.4 The Implications of My Findings.....	199
8.5 Recommendations.....	202
8.6 Directions for Future Research	204
8.7. My Reflections and Conclusion	204

REFERENCES	208
APPENDICES	237
APPENDIX ONE: Letter to Organisations.....	237
APPENDIX TWO: Participant Information Sheet.....	239
APPENDIX THREE: Participant Consent Form	242
APPENDIX FOUR: Participant Bio Data Form.....	244
APPENDIX FIVE: Interview Tool	245
APPENDIX SIX: Ethics Application.....	246
APPENDIX SEVEN: Ethics Approval	253

ACRONYMS & OPERATIONAL DEFINITIONS

A&E: Accident & emergency

Autonomy: Independence, to govern oneself, live in accordance with one's basic desires or values. Theoretically it is designed in medical ethics to protect the right of patients to make decisions based on their own values and for their own reasons.

BRCA: Genes found to impact a person's chances of developing breast cancer

Burden of disease: A measure used to evaluate the virtual effect of various diseases on populations by quantifying premature death, morbidity, or financial cost in terms of using disability-adjusted-life-year (AIHW, 2013; WHO, 2014).

by highly specialized stem cells that develop into healthy bone marrow (CDC, 2015).

Chronic Illness: Chronic conditions, defined as illnesses that last longer than 3 months and are not self-limiting (Von Korff *et al.*, 1997). Most have semblance of permanence and not curable but can be ameliorated with medical intervention.

EPP: Expert Patient Program in the UK

Gene therapy: An experimental technique that uses genes to treat or prevent disease by inducing the formation of normal red blood cells by the bone marrow (CDC,

GI: genetic information

GR: genetic responsibility

Haemoglobin A (HbAA): When red blood cells contain only normal blood cells (Serjeant *et al.*, 2001).

HbF: Foetal Haemoglobin

ICF: International Classification of Function, Disability, and health

IVF: Invitro fertilisation

NGO: Non-Governmental organization

NHS: National Health Service, UK

NIH: National Institutes of Health in the US

Oxygenated blood: Red blood cells that take oxygen to body cells (Fisher, 2014)

Deoxygenated blood: Red blood cells cannot take oxygen to body cells (Fisher, 2014)

PGD: Pre-implantation Diagnosis

PND: Post Natal Diagnosis

Quality of life (QOL): Positive and negative aspects of life which can affect the mental and physical state of individuals, determined by health status, level of comfort and state of happiness (CDC, 2011).

RBCs: Red Blood Cells containing haemoglobin that transport oxygen to the whole-body organs and cells

SCC: sickle cell crisis

SCT/Haemoglobin AS (HbAS): Sickle cell Trait: Genotype HbAS. A person with SCT has recessive Sickle cell gene which can be endowed to offspring but he himself does not suffer from the disease.

Sickle cell anaemia: Old name by which sickle cell disease used to be called because of the major symptom, anaemia.

SCD/Haemoglobin S: Sickle cell disease, a genetic blood disorder that is life-threatening.

Sickle cell disease (HbSA): The most common and severe variant of the disease

Sickle cell disease (HbSC): A variant of Sickle cell disease.

Sickle beta-plus thalassemia (HbSβ+): A variant of Sickle cell disease

Sickle beta-zero thalassemia (HbSβ0): A variant of Sickle cell disease.

Sickler: A slang label in Africa for individual with SCD, sometimes it has a negative connotation

Sicky-Sicky: A derogative name for individuals living with Sickle cell disease in some parts of Africa because of the frequent crisis

SMD: Social Model of Disability: (Oliver, 1991)

Stem cell transplant: A procedure in which diseased bone marrow is replaced

UK: The United Kingdom

UPIAS: Union of the Physically Impaired Against Segregation (UPIAS)

WHO: World Health Organization

Various sickle cell organizations: (where many participants were recruited):

- *OSCAR Sandwell* located in West Bromwich. It is a registered charity that was established in 1988.
- *OSCAR's ASYABI* (Association of Sickle Cell Suffers of Yorkshire and Africa and Basic Information) is based in Leeds.
- *Croydon Sickle Cell and Thalassemia Support Group* based in Croydon, London
- *Sickle Cell Society* are based in London.
- *Sickle Cell Cause*

CHAPTER 1

INTRODUCTION

1.1 Introduction

This thesis explores the impact of Sickle Cell Disease (SCD) on the partner selection, reproductive decision-making, genetic status disclosure and moral responsibility of adults living with the disorder in the United Kingdom. SCD is a debilitating, genetic blood disease associated with many health complications; the main manifestation being insidious episodic pains which very frequently require medical intervention in hospitals. This frequent ill health tends to disrupt the lives of people with the condition within the family and society. SCD affects all physical and social facets of living including physical body structure, schooling, career and even relationships.

The clinical impact of SCD on lives of the people affected and their families is well described in literature and the UK Department of Health have protocols for its management. However, there is a need to study in-depth its impact on their socio-cultural life-worlds because the clinical aspect does not fully represent the multidimensional burden of the disease. There is theoretical discourse that people living with SCD face some challenges in partner selection and reproductive choice making (Gallo *et al.*, 2010), however, there is a need for empirical evidence of this among the UK population.

I will present a detailed literature review of an increasing body of work on the socio-psychological domains of living as experienced by people living with SCD in the next chapter. Much of the sociological research done till date include, healthcare difficulties experienced in families with a child with sickle cell disease (Midence, Fuggle, & Davies, 1993; Brown *et al.*, 1993), disruptive life impact of chronic illnesses (Bury, 1982; Charmaz, 1983; Giddens, 1991), discrimination and stigma experienced by people living with SCD (Anionwu & Atkin, 2001; Maxwell, Streetly, & Bevan, 1999; Caird, Camic, & Thomas, 2011), quality of life (Anie, Steptoe, & Bevan, 2002), social attitudes to chronic illness implicated in decision-making regarding genetic screening, (Ross, 2013 & 2015; Bediako and Haywood, 2009), high levels of depression and anxiety with SCD (Belgrave & Molok, 1991; Thomas & Taylor, 2002; Edwards *et al.*, 2009). Other aspects of social life highlighting personal challenges of adults living with chronic illnesses such as the benefits of being in a long-term relationship (Chun and Lee, 2001), disabled people wait longer than non-disabled to engage in romantic relationships (Fine & Asch, 1988; Gill, 1996), impairment of SCD alone not

responsible for its impact on the psycho-social lived experience of the affected (Anie, 2005; Mishler *et al.*, 1981; Helman, 2007; Kelleher and Hillier, 1996; Radley, 1993), reproductive decisions for individuals with genetic conditions shaped by complex socio-medical factors (Atkin *et al.*, 2008; Tsianakas & Liamputtong, 2002), issues of individual ethical responsibility (Kenen, 1994; Lupton, 1995; Steinberg, 1996), cumbersome reproductive healthcare (Smith, 2005; Daniels, 1996, Gallo *et al.*, 2010), genetic and prenatal screening (Dyson, 1997, Petrou *et al.*, 1992), chronic diseases effects on romantic partner selection, (Gherasim & Mihalca, 2006), disability and intimate relationships (Liddiard, 2014; Shakespeare, 1999; Thomas 1999; Morris 1989) psycho-emotional disablism in disabled people's sexual relationships (Liddiard, 2014; Shakespeare, 1999; Thomas 1999; Morris 1989).

While there have been some studies around reproductive decision-making of adults with SCD, the impact of SCD on partner selection and reproductive decision-making among adults embodying SCD in the UK has not been critically explored. To fill in this gap in knowledge, I employ the thematic analysis of the lived experiences of twenty-three participants in the UK to have an in-depth understanding of the impact of SCD on partner selection, reproductive decision making, including their experiences of genetic status disclosure as well as perspective of moral responsibility towards future generation.

1.2 Why Sickle Cell Disease?

Bury (1982) conceptualised 'biographical disruption' of life in describing the nature of the impact of chronic disease on the life-course of an individual who suddenly develops an incurable sickness such as late-onset arthritis. Other scholars soon extended the meanings to include all other long-term chronic illnesses and impairments such as SCD. Some inheritable diseases like diabetes may or may not develop later in life if some environmental factors like lifestyle modification are employed so the individual averts the disease. SCD does not have that component of being dependent on other factors; once genotype is *HbSS*, that individual has SCD. Another important aspect of SCD is the social construct and prevalence in terms of demography. For instance, certain genetically acquired mental illnesses, down syndrome or *BRCA range* breast cancer risk-associated genes are equally widespread among world peoples and population. This means there is no socio-economic issues such as ethnicity or demography identified with their prevalence. Thus, they are readily visible to all (governments and academia) for funding and research. SCD, on the other hand, exists in certain demographical locations which are intersected by other

identities such as race, ethnicity. The lifespan of people with SCD some six decades ago used to be at an average of fourteen years and so not well known but because of the hi-tech treatment procedures, people with SCD now live well into adulthood (Carroll and Haywood, 2013; Platt *et al.*, 1994). Some scholars suggest that because of the erstwhile short life expectancy, many of the studies existing in literature were more about child and adolescence (Ross, 2013). It has a political history of being invisible and inconsequential for public health concerns in the western countries and so did not attract the attention of researchers who were mostly situated in predominant locations of affluence. Anionwu & Atkin (2001) argued that discourses about haemoglobinopathies are marginalized in the mainstream concerns of social policy and political philosophy. Though SCD has become more visible in the past few decades, available literature demonstrates the enormous disparity in SCD research when compared with other conditions of same category (Ross, 2013).

Bury (1982) suggested that the disruption of life due to chronic disease impact social relationships. The impairments effects of the illness, the inevitable changed self-perception of the individual and other external factors such as socio-cultural norms cause incapacitation and oppression to the affected persons. For the minority population who are already marginalized, oppressive effects can be colossal (Anionwu & Atkins, 2001).

SCD is currently the most common genetic blood disorder in the UK. Sickle Cell Society of Great Britain reported well over 12,500 people living with SCD as of 2008 (Sickle Cell Society, 2008). About 14.8 per 1,000 infants are affected among British Black population, 5.6 per 1,000 among the British Black Caribbeans and 0.08 per 1,000 infants in British Indian populations (Hickman, Model, & Greengross, 1999). The recognition of SCD as an important public health concern by the UK department of health has attracted clinical and sociological studies. Three decades of hi-tech genetic screening has grown the field of predictive medical genetics thus enabling early awareness of own genetic status for purpose of mitigating the implications of the disorder. There remains a need to focus on SCD with its unique challenges of not only being a genetic inheritable disorder, but also being constructed within the broader context of cultural understanding as an ethnic disease, prevalent among minority population in the UK. Furthermore, with the backdrop of its genetic and transmissible nature, the selection of romantic partners and reproductive decision-making remain areas that has been largely under-researched by disability researchers, possibly because of the lower strata it occupied among the hierarchy of genetic diseases in UK, and possibly because people with SCD lack a voice in the public discourse.

This study is firmly grounded on disability studies which has been extremely useful in discourses about chronic illnesses such as SCD. The medical model of disability views disability as a '*problem*' that is inherent in the person living with a disability. The '*problem*' is expected by society to be repaired or removed so that the individual can be normal again. On the other hand, the Social Model of Disability (SMD) views disability as being caused by the way society is organised, excluded the person living with a disability or impairment from participating fully in the society. Proponents of SMD argue that the medical model uses what the normative culture dictates as normal to describe and dictate the '*wrong*' in the people with disability creating low societal perspectives of the affected individual. This results in loss of independence, and constrained choice of life opportunities. Ferrie & Watson (2015) argued that while '*problem*' *does* exist in the understanding and behaviour of the society, impairments also contribute to the oppression (socially constructed psycho-emotional *disablism*) experienced by the affected individuals in the various social aspects of life. From the analysis of the narratives of 23 adults living with SCD in the UK, I hope to explore and gain in-depth understanding of how embodying SCD impacts the partner selection, reproductive decision making, disclosure and moral responsibility. I also hope the study will highlight the tensions and psychological challenges experienced by these adults within the wider framework of *normal/abnormal bodies* in society, the general behaviour of normative culture at the various intersections of embodied individuals with society. It is hoped that the study will unfold what it is actually like to live with an impairment like SCD and struggle to construct a path for self in areas of selecting romantic partners and parenting.

1.3 Romantic Relationships

Romantic relationship carries a wide range of meanings, depending on the social and cultural interpretations in that geographical location. For instance, it can be used when referring to sexual relationships which may be private or commercial. It can also apply to homosexual or heterosexual coupledness. For this study, romantic relationship will refer to a private heterosexual relationship. Self-disclosure involves exchange between two people of deep, private and personal information about oneself that may not otherwise be known (Christensen, 2011). Christensen (2011) argued "Since the friendship relationship has the potential to be short-lived and unpredictable, effort needs to be put in to maintain a sense of continuity. The communicative practice of self-disclosure is one such way to promote longevity in a friendship" (p. 1). Knowledge of such information can exist between people

with no special relationship such as a doctor and a patient. So that on its own, is not enough to characterize the target relationship phenomena being described. Laurenceau *et al.*, (1998) described intimate relationship as close bonding or association where mutual acceptance and trust are shared and experienced. Moss and Schwebel (1993) also defined intimacy in romantic relationships as “the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal relationship” (Moss & Schwebel, 1993: p. 33). In this study, the relationships referred to are those planned to be serious, planned to be long-term or life-long, characterized by closeness, commitment, strong emotional connectedness, sex and self-disclosure.

1.4 Reproductive Decision-Making

Lipkin and Rowley (1974) conceptualised genetic responsibility (GR) as a moral obligation all people are expected to undertake to ensure future generations do not inherit any genetic diseases as a responsible citizen. This involves an individual making it a duty to be informed about own genome for sake of self and managing its consequences to ensure the offspring is not endowed with the defective gene. It is assumed such decisions are made autonomously without interference from others such as medical professionals or other social actors. The UK Article 8 of the Human Rights Act protects the privacy of all people living in the UK and this includes sexuality/intimacy, family life, personal autonomy (right not to be physically or psychologically interfered with), reproductive rights etc. (Human Rights Act 1998). Michael Arribas-Ayllon *et al.*, (2008) argued that “genetic responsibility has emerged as a key notion for understanding how genetic risk reshapes patterns of choice, identification and obligation within families” (Arribas-Ayllon *et al.*, 2008: p. 1521). Thus, society expects all life’s choices around reproduction will require an ethical obligation to mitigate the risk of transmission of gene to next generation. For instance, a good citizen should select partners that will not cause an affected offspring to be born. Or an at-risk pregnancy should be screened for purpose of possible termination if affected.

Though genetic reproduction decisions should be autonomous as personal human rights of an individual, many studies have shown that there are other competing factors within the wider cultural, societal environment as well as the NHS policies that can influence the decision making of these individuals (Shakespeare, 1998; Boardman, 2013). Shakespeare (1998) argued that pre-natal screening is highly contentious both ethically and politically. Some identified factors include personal experiential knowledge of the disorder and level of genetic information available to the individual, (Boardman, 2013; Asgharian & Anie, 2003);

ethical beliefs affecting decision making (García *et al.*, 2008), cultural beliefs of society (Lippman, 1991; Markens *et al.*, 2010; Atkin *et al.*, 2006), family perspectives (Downing, 2005), legality of abortion of affected foetus (Green *et al.*, 1993; Press, & Browner, 1997; Markens *et al.*, 1999), attitudes of clinical personals (Dyson, 1997); experiential knowledge of caring for a disabled child (Lawson, 2001), issues of the affected person being a proponent (or opponents) of pro-life and pro-choice (Shakespeare, 1998).

Waskul & Vannini argued that impairments alone cannot define or give the total meanings of impairments effects of a person without considering the social interactions of the embodiment with *others* within the society (Waskul and Vannini, 2006). This makes embodied illness a social category in terms of identity such as, say, race, gender, ethnicity etc.

The intersection of these various categories of identities become factors that affect all other domains of life such as decision-making in partner selection, parenting, reproduction, pregnancy termination and so on.

Therefore, with the new genetic information being used to determine some social dimensions of life such as romantic partner selection, and reproductive decisions or termination (or not) of a pregnancy, there is a notion of emerging concept of medical procedures moving beyond medical treatments and encroaching into social domains of life. These involve need for surveillance, monitoring of own bodies and bodies of *others* for social relationships. Thus, in social agency, people who were healthy get labelled non-healthy/healthy in light of the social activity being contracted. An example is insurance and selection of romantic partner. Conrad conceptualised medicalization as medical interventions extension as answers to social problems (Conrad, 1992; Zola, 1972). He argued that nonmedical issues become defined and treated as medical problems. Thus, there is medical surveillance for the at-risk individual selecting a romantic partner, or a medical monitoring so that an at-risk individual does not transmit disorder to offspring. Thus, the introduction of medicalization through genetic screenings and testing can become problematic for the at-risk individuals as they are constrained to constantly make decisions which can be difficult if there are some backgrounds competing social factors.

The impact of SCD on these areas of life should be evident from the narratives of the participants about their decisions-making processes in the partner selection, reproductive decision making, disclosure and moral responsibility.

1.5 Problem Statement and Purpose of the Study

Although there are some studies about reproductive decision-making and healthcare among people living with sickle cell disease in the United States, (Ross, 2013, 2015; Gallo *et al.* 2010), research about partner selection and impact of SCD on reproductive decision making among adults with the disorder in the UK is virtually non-existent. The report in literature on this target population in the UK has been mainly on healthcare management and transitioning (Anie & Telfair 2005, Howard *et al.*, 2010, Telfair *et al.*, 2004), genetic responsibility and genetic/prenatal screening (Dyson 1997; Asgharian & Anie, 2003, Shakespeare, 1998), cultural beliefs of society (Lippman, 1991; Markens *et al.*, 2010; Atkin *et al.*, 2006), family perspectives (Downing, 2005), issues with termination of affected pregnancy (Atkin, Ahmad, & Anionwu, 1998; Green *et al.*, 1993; Markens *et al.*, 1999), fragmented counselling services (Anionwu & Atkin, 2001; Atkin & Ahmad, 1998), stigma (Annie, 2005).

SCD is inheritable and affects all aspects of life including physical, social, psychological and even occupational functioning (Annie, 2005). It exists mainly among the ethnic minority populations in the UK. The last few decades have seen mammoth global migration of people particularly from countries where SCD is prevalent to the West including the UK where SCD did not previously exist (Piel *et al.*, 2014). With the migration, social integration with migrant population inevitably results in relationships and biracial children who may be endowed with *HbS* allele. It is being predicted that there will be up to 25% rise of the incidences of SCD in UK by year 2050 as inter-marriages increase (Piel *et al.*, 2014). The findings of Piel *et al.* (2014) was that “the estimated global number of migrants with *HbS* increased from about 1.6 million in 1960, to 3.6 million in 2000. This increase was largely due to “an increase in the number of migrants from countries with *HbS*, sickle cell allele frequencies higher than 10%, from 3.1 million in 1960, to 14.2 million in 2000” (Piel *et al.*, 2014: p.80).

These statistics of increase in people with SCD led the UK Department of Health to institute strategies and policies such as genetic screening to mitigate genetic transmission to future generations (Morden *et al.*, 2012). Contemporary studies in the UK show that children are still being born with SCD even though people living with the disease consider genetic screening an important intervention tool against transmission of SCD to future generation (Oni, 2006). This may be interpreted to mean that either there is a low uptake of SCD education resulting in a low perceived susceptibility of giving birth to a child with the disease (Long *et al.*, 2010), or as in Hill (1994) while studying this phenomenon among low-income African American women, there is an *obfuscation of SCD medical knowledge*.

Many studies have demonstrated evidence of sociopsychological complications across the life span of people living with SCD in the UK due to the devastating effects of the disease (Anionwu, 2001; Anionwu, 1982; Atkin and Hussain, 2003; Annie, 2005). This has resulted in many of these individuals feeling depressed and somewhat socially isolated from society. Some sociological studies of some equally severe chronic illnesses as SCD such as Huntington Disease, epilepsy and HIV infections reported psycho-emotional tensions and “spoilt” identity but there is paucity of reports in literature about the impact of SCD on these domains of living. Studies by Ross (2015) addressed some very crucial aspects as it affects women in the United States. She argued that the intersection between embodied experience and accurately embodied genetic information will produce accurate informed decision. She further explained that the knowledge influences the level of moral responsibility affected women take as they choose between “stability of their intimate relationship and respect for partners' wishes, the desire to have biological children, or the need to prevent having children with SCD” (Ross, 2015: p. 42). Oni (2007) also proposed that the level of genetic knowledge available to the population in the UK would influence the choices made. Since SCD exists mainly among minority populations in the UK, and genetic information and tests only began barely two decades ago, it can be assumed therefore that a high percentage of the target population may have limited genetic information about choices of reproductive options available (Vali et al., 2020). Although there has been unsubstantiated assumption that the affected persons are well informed about their choices and genetic information with all options available in the UK, empirical proof is still lacking.

Being an inherited condition that can be transferred to future generations, it is of utmost importance to understand the challenges faced by the target population as they seek to engage in romantic relationships that can lead to bearing children. It is pertinent to understand how the individuals face and navigate the challenges involved in selecting appropriate partners and also making informed reproductive choices. The factors that influence the processes should be elucidated. This understanding should serve as critical data for developing strategic intervention tool and support which can help them mitigate the consequences of the condition for the individual and the society. This study fills in the gap in literature and brings to the open the purported assumption about the struggles and pain of the target population to enable open discussions. The narratives of this population, whose identities may have been disrupted by this chronic disease need to be heard. Hopefully, the information gathered will also lead to development of more specific ideas for further future research.

1.6 Aims and Objectives of the Study

The aim of this study is in two parts:

1.6.1 Aims of the Study

1. To explore and describe how sickle cell disease (SCD) impact on the selection and forming of an intimate romantic relationship of adult living with SCD
2. To explore and describe how SCD impact on the reproductive decision-making of adults living with SCD.

1.6.2 Research Questions

I will employ a qualitative research approach for this study drawn from interviews of 23 adults (men and women) living with sickle cell disease in the United Kingdom. The questions this research explored are

- In what way is SCD status a consideration in selecting romantic partners and negotiating the relationships? This will involve questions about how they select partners, whether or not other people such as family members are involved, the attitudes of the potential partners and others in the society to their selection or to the relationships, whether or not support is given. Are there difficulties experienced during disclosure of their embodied risk and how do they navigate the intimate spaces of the relationship
- To what extent does this health status feature in people's account of reproductive decision making? Does the severity of the symptoms affect the decisions, is the decisions only dependent on the woman who is bearing the pregnancy or does the partner also contribute to the decision-making; are others such as family members involve in the decision making? What about the medical professionals; what are the attitudes of the affected people towards genetic responsibility
- How do people living with SCD view the cultural understanding of their condition particularly as it relates to romantic relationships and parenting? Is their perspective in congruence with the perspectives of the society?

1.7 The Theses Outline

This research seeks to explore the impact sickle cell disease (SCD) on the partner selection, reproductive decision making, disclosure and moral responsibility of adults living with SCD in the UK. The subsequent research questions are 1) In what way is SCD status a

consideration in selection of romantic partners and negotiating the relationships? 2) To what extent does SCD feature in participant's account of reproductive decision making? 3) How do people living with SCD view the cultural understanding of their condition particularly as it relates to selection of romantic partners and parenting? Is their perspective in congruence with the perspective of the society?

Chapter 1 gives the broad introduction to the study, giving overview of the existing studies in literature and the gaps that still exist to be researched. I attempted to argue about the uniqueness of SCD in the society and the need for a study such as this one that concentrate only on SCD, and the phenomenon being studied. The statement of problem and the purpose of research is clarified.

In Chapter 2, a detailed review of literature is presented. What is known in literature about the various domains of living impacted by SCD is reported followed by literature on romantic relationships and role chronic diseases on their selection. An extensive report on chronic illness such as SCD being a disruption on the identity of an individual and how this affects the perception of self is also presented. Genetic responsibility as it relays to the advanced technological methods is also elucidated. This chapter further presented the use of the concepts of embodied risk and experiential knowledge to construct the understanding of how SCD impacts the reproductive decision making and romantic relationship partner selection of an individual living with the condition.

Chapter 3 describes the method of study which includes the development of instrument, the process of participants recruitment and the challenges, the sampling and eligibility criteria as well as determining sample size, the in-depth interview processes, the ethical considerations put in place to ensure participants rights are observed as well as ensuring thick descriptive narratives, the data analysis methods and accuracy

Chapter 4 gives details about SCD, history, prevalence, clinical management and trend of future management

Chapters 5, 6 and 7 are devoted the data analysis with each chapter dedicated to the main emerging themes.

In Chapter 8, the discussions and concluding research outcome is presented. The significant contributions of the study as relating to the study topic and research questions and the areas that could be studied in the future is elucidated.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This study is an empirical exploration of how SCD impacts the partner selection, reproductive decision making, disclosure and the moral responsibility of adults living with SCD in the UK.

This chapter will evaluate existing literature relevant to sociology of SCD as it relates to romantic relationships and reproductive decision making in order to conceptualize this study. Hopefully, the gaps in currently available literature will be identified to demonstrate the need and significance of this study. Drawing from a wide range of disciplines including Medical Sociology, Sociology of the Body & Embodiment, Sociology of Health & Illness and Disability Studies, I will engage in a detailed discussion of the various relevant themes and theories related to sickle cell disease as a chronic disease, the understanding and meanings of the dominant culture about SCD as a genetic condition and its impact on the partner selection, reproductive decision making, disclosure and moral responsibility of this target population living in the United Kingdom.

The impact of chronic illnesses on romantic relationships of people with disability has generated a lot of interest among researchers since the mid-1970s, when disability rights movements in the UK fought to end their exclusion from participation in public life activities. They demanded that their civil rights in all facets of the society be respected. They protested that society has been oppressive to them by denying them equal rights to education, community integration, environmental accessibility, among other benefits of citizenship (Shakespeare, 2006; Finkelstein, 2001).

SCD, as a genetic illness, characterized by episodic excruciating pains which often require frequent hospitalization, is prevalent among ethnic minority populations in the UK (AlJuburi *et al.*, 2012). Being inheritable and known to be a debilitating disease attracts discrimination from society, particularly in selection of romantic partners for relationships and reproduction (Billings *et al.*, 1992). It is expedient, using the narratives of the participants, to uncover the impact of embodying SCD in a society where genomic prediction of disease risk can be estimated.

For this review, I will present literature reports on impact of chronic illnesses on reproductive decision-making, the UK approach to managing genetic illnesses such as SCD and impact

of the social understanding of SCD on the partner selection for parenting of affected individuals. I will address the key emerging components that constitutes the impact, so as to gain a deeper understanding of the nature of the impact. The theoretical frameworks underpinning the study will also be presented.

2.2 Sociology of Chronic Illness

Chronic diseases, being long-term and incurable by available medicines, must be managed to ensure highest possible quality of life. Kleinman (1988) conceptualized three distinct identifiable dimensions to understand nature of chronic illness such as SCD. These are, 1) the body impairment of the disease with all the symptoms, 2) the lived experience of the clinical disease, which is personal to each affected person, (For instance, some people have severe disease symptoms and may be on admission often, while others experience mild symptoms), 3) the experiences due to socio-normative factors while is informed by social understandings and beliefs about the condition. While the lived experiences are embedded in these three sources, the individual has to struggle to make sense of the experiences and re-construct the self/identity to enable stability within the socio-cultural ecosystem.

Chronic diseases disrupt the bodily activities and functions in a way that threatens the self-concept of the affected person. Bury (1982) described this phenomenon as a '*biographical disruption*' of the life of the individual. The physical assault and limitations, the uncertainties of the direction of the ill-health, and very often the socio-cultural factors experienced in the daily life of the individual create psycho-emotional tensions that tend to erode confidence and self-concept. The usual taken-for-granted assumptions about own body and its capabilities get so disrupted that the coping strategy will be to force a change in identity by seeking to balance "the unity between body and self" (Charmaz, 1995: p. 657). Bury suggested that this unification will require "a fundamental rethinking of the person's biography and self-concept" (Bury 1982: p.169).

Some studies have reported that individuals living with chronic illness often feel socially isolated (Charmaz, 1983) because of the physical burden of the condition, social factors such as stereotyping, stigma which causes internalised oppression. Charmaz posits that "self is fundamentally social in nature and is developed and maintained through social relations" (Charmaz, 1983. p. 170). She argued, just as Kleinman (1988), that chronic illnesses need both medical and sociological interventions because of the sociological component of chronic illnesses. She argued that medicalized intervention without addressing sociological aspect is "a narrow-medicalized view of suffering, solely defined as

physical discomfort, ignores or minimizes the broader significance of the suffering experienced by debilitated chronically ill adults” (Charmaz, 1983; p. 168). She described this disruption of life as a *‘loss of self’*.

Kleinman (1988) argued that individuals with chronic illnesses understand the meaning of their condition in terms of their value or worth in their social environment. In many instances, this emotional component of their suffering outweighs the physical burden of the impairment. Thus, chronic ill health can generate internalized oppression because of how the individual feel perceived or acceptable in the eyes of other people in society.

From contemporary studies of chronic diseases, the socio-psychological impact on self and identity have been found to be very similar, regardless of the nature of disease (Kelly, 2010).

2.3 The UK Approach to Management of Chronic Illnesses

The UK National Health Services (NHS) launched *The Expert Patient Program (EPP)* in 2002 as part of self-management strategy to enforce a reduction of public health spending because of the rising number of persons living with chronic illnesses of which SCD is one. The program assumes that the intrinsic knowledge of the patient about the illness can count as some expertise towards healthcare management. Clinicians will provide as support, the appropriate disease knowledge base, while the patient takes responsible ownership of plans for wellbeing of self and society. Such decision-making responsibility is assumed to be of benefit both to the patient and the society as a *‘good citizen’* (Morden *et al.*, 2012: p. 83).

As part of the self-management program, the UK Department of Health in 2013 created *A Strategy for Rare Diseases*. This group of chronic conditions, though affecting a comparably very small percentage of the British population, were found to make a significant dent in terms of their demands on the financial and other resources in NHS; about 80% of these were of genetic nature such as SCD (Taylor & Frankl, 2012; Evans & Rafi, 2016). With predictive genetic screening of people and risky pregnancies, people are armed with genetic knowledge to make decisions for sake of self, kin and society. This strategy is to proactively empower the people at-risk of genetic conditions or at risk of transferring disorder to offspring to make responsible choices that will mitigate these possibilities (Morden *et al.*, 2012). For example, decision can be made to opt for adoption rather than have biological children. Selection of romantic partners may be tailored to avoid the risk and even in situation of a risky pregnancy, the affected person can opt to terminate the pregnancy. Thus,

the policy encourages responsible reproductive decision making to thwart transfer of the illness to future generations and individual improved quality of life.

This strategy extended the responsibilities of medical professional beyond just caring for the SCD as a pathology, to being involved in other areas of life of the individual, beyond healthcare to social areas of life. For instance, medical surveillance becomes paramount when an individual with SCD is making decisions in selecting romantic partners as well as making reproductive decisions because the result of the genetic testing will inform the choice. Conrad and Zola coined the concept *medicalization* to explain the phenomenon of extending medical authority and practices to cover not only the treating of sicknesses, but other sociological domains of people's life course. Zola defined it as “process whereby more and more of everyday life has come under medical dominion, influence and supervision” (Zola, 1983: p. 295; Conrad, 1992). The medical intertwining with the every-day life decisions of the affected persons at all levels of medical, social activities reveals the dominance of genetic status in the life of an individual living with a genetic disorder.

2.4 Creation of ‘Risky Bodies’ in Society

The genetic screenings and diagnosis of the NHS genomic medicine service has made it possible for people possessing genes responsible for certain genetic diseases to be identifiable in society, a phenomenon Novas and Rose (2000) called “a mutation in *personhood*” (p. 485-6). The identification of the mutated gene makes possible future ill health predictable so that the at-risk individuals can modulate the implication of the genetic disorder. These individuals who may or may not be bodily ill are labelled to be at-risk of those disorders and diseases. With the creation of *Expert Patient Program* (EPP) and Strategy for Rare Disease programs within the self-management scheme, these individuals are expected to exercise agency laid out in these programs to ensure personal healthcare and, as a good member of society, ensure the condition is not transferred to future generations for the sake of the society. These individuals must develop consciousness of their embodied risk as a major aspect of their identities which is expected to shape their behaviours and life’s choices through responsible decision-making (Beck, 1992).

From existing studies, it is known that the individual with a genetic disease relies on multiple sources to inform the reproductive decision-making processes. They integrate personal impairment experiences with social and cultural understandings of the condition as well as the medical perspective of how decision making should be arrived at (Taylor & Bury, 2007;

Morden *et al.*, 2012). The interface between medicine, genetics, society and culture has been called *Geneticization* (Ten Have, 2001). The downside of this is the fragmentation of society into *normal people* with no risk of genetic disease and the *abnormals* who are at risk of genetic disease. Feminism provided a way of understanding how genetic knowledge of the dominant culture is constructed from biomedical discourses. The knowledge creates split terms of *health/ill*, *able/disabled*, *normal/abnormal* in society, with the so-called *abnormal* bodies being *misfits* or *unfit* while the *normal bodies* are *fit*. The biomedical diagnosis of *pathologizing* certain bodies plays a leading role in shaping the individual's identity because medical diagnosis is accepted culturally as unchallengeable 'facts' and 'truths'. This confers a somewhat *authorization* for social construction of '*risky body*' label which disables the individual (Gillman, Heyman & Swain, 2000; Link & Phelan, 2001; Novas & Rose, 2000). The understanding is that the *abnormal* person (person with disability) is a hazard, unable to perform some ordinary social things every other *normal* person (non-disabled person) does because of the disease. This mark becomes problematic for the bearer within the society because of its implications of encroaching into many social benefits and opportunities ranging from education, career, jobs, selecting romantic partners, parenting etc. With the underpinning of medical diagnoses, society can justify their attitudes of isolation, discrimination and oppression caused the embodied individual (Campbell, 2008; Gillman, Heyman & Swain, 2000). Biomedical power gets exercised not primarily by direct coercion but rather "through persuading its subjects that certain ways of behaving and thinking are appropriate for them" (Lupton, 1007: p. 99). Feminist scholars have echoed these same ideas of women considered inferior to men in the societal hierarchy (Young, 1980; Morrison, 1992), in the same way the disabled person is constructed to be inferior in society. The most damaging result is the psychological effects on the personhood because the individual is undermined in what they can be or do. According to Wendell, while diversity of biology is undeniably fact of disability, the disablement due to the biology is due to flawed social attitudes towards difference (Wendell, 1996; Oliver, 1990). Biomedical discourses are that the genetic information will enable the at-risk individuals take advantage and make concerted efforts to manage their lives instead of leaving their life-course to nature or fate. This way, the disease may be phased out of the country since the future generations will no longer be endowed with the abnormal gene. While this is laudable from the perspective of policy makers, the socio-psychological consequences in the everyday life of the people affected were not considered or accommodated into the discourses.

2.5 Chronic illnesses, Partner Selection and Reproductive Choice

Seeking for a partner to make a family with is an essential part of human existence, and an important determinant of the adulthood of a human being (Illouz, 2012; Priestley, 2000; Furman, 2006). Socialization, communal living, human pleasure and ultimately reproductive activities, are all universally social functionalities of human life.

For the purpose of this study, I define romantic partnership as one where deep psychological engagement, mutual acceptance and trust are shared, including the sharing of all dimensions of life and which may or may not lead to parenting (Laurenceau *et al.*, 1998). This type of relationship is considered in many cultures as 'life partner' or in sociological circles, 'significant other'. In every culture, romantic partnership can exhibit positive consequence of well-being, togetherness, safety and sense of satisfaction or negative implication of depression, regret and depravity, depending on the intrinsic and extrinsic factors that bear on the relationship.

Illouz (1997) suggested that people select romantic partners for three main reasons; 1) to have some companionship and establish a feeling of closeness to *others*, more so with contemporary decline in human interactions (p. 143). 2) All humans are social beings that need recognition within bonded relationships, where one's social worth and value are established (p. 120). 3) A relationship where psychological and physical needs can be met, including social support in times of distress (Illouz 1997; Guerrero, Andersen, & Afifi, 2007). In most culture, romantic relationship is a source of social validation for people and though not openly spoken about, any individual who is unable to secure a partner feels a sense of isolation, shame and lowered self-esteem (Guerrero, Andersen, & Afifi, 2007 In Christensen, 2011).

As established in literature by scholars such as Bury and Chamaz, chronic illnesses disrupt life and relationships. Since long-term relationship will affect all fundamental decisions to be made in life, particularly if reproductive decision-making is involved, (Alavi *et al.*, 2014), forming such partnership can be a challenge at the intersection with a chronic illness. Buunk *et al.* (2002) pointed out that risk such as health among other issues, will ultimately affect choice.

The body is central to the experience of its social worlds (Merleau- Ponty, 1962). It is also a site of negotiation between socially constructed meanings of intimate relationships and personal meaning of the relationship.

Some studies have demonstrated the negative outlook of people (non-disabled people) to persons with chronic illness. For example, there is a report that dating persons with chronic

illness can be complicated because they are difficult, socially anxious and not confident (Fichten, 1989; Evans 1976); Persons with mental health disorders are not socially acceptable (Link & Phelan, 1999; Martin, Pescosolido & Tuch, 2000); people avoid persons with learning disability more than people with physical disability (Socall & Holtgraves, 1992); people would rather relate with people with disability at work or home environment than select them for romance relationship (Wright, 1988; Grand, Bernier & Strohmer, 1982). Clarke & McKay (2014) reported that a much lower percentage of disabled persons are involved in intimate romantic partnership as compared to the non-disabled in the UK and divorce or marriage separation involving people with disability are twice the percentage of the able-bodied in society. The statistics describes the difficult lives of the affected persons when it comes to relationships. Much of the literature addressed issues of impact of chronic illness on partner selection and reproductive decision-making of people with disability from the medical model of disability perspective which frames impairment as the sole cause of the problems experienced by these individuals. While the impairments are problematic, I suggest that much of the oppression they experienced are more complex in nature than problems of the impairment.

Self-disclosure is one of the most important relationship enhancement behaviours in intimate relationships. If successful, it can create a sense of acceptance and approval. However, factors influencing the meanings of the information shared will ultimately determine if expected intimacy does occur (Christensen 2011; Fehr, 2004). Christensen (2011) described self-disclosure as “dyadic communication phenomenon, affecting both the person disclosing and the person being disclosed to” (p. 2). Self-disclosure has to do with revealing deep things about self to *another*. Its nature explains why it does not exist in casual relationships or why in cases of stigmatizing information, care is taken due to consciousness of vulnerability and risk of rejection.

Alavi *et al.* (2014) argued that selecting a mate is one of the most important decisions any individual will make in their lifetime because it will dictate the direction their lives will go (Abdullah *et al.*, 2011; Alavi *et al.*, 2014). The essential attributes for any lasting partnership are foremost the personal meanings and understanding an individual has about the attributes existing in the partner, willingness to meet the expressed and unexpressed needs of another person, respect (an awareness of the person as a unique individual, characterized by a concern for their independence and growth) and self-disclosure, (reflexive deep self-information) (Christensen, 2011). Giddens posits that loving intimacy

easily sparks up between two persons who complement each other and help with the process of self-realization (Giddens, 1992).

From contemporary studies, many social factors have been found to inform the process of partner selection. Some extrinsic factors such as, beauty, race, proximity and others more of intrinsic nature such as character, intelligence, and religion. A person's identity is formed by their social interactions, beliefs, understanding of life, life experiences and meanings given to those experiences. (William, 1984). While chronic illnesses have been reported from some studies to impact partner selection, the nature of impact of SCD in the UK on choices or selection of romantic partners remain under-theorised.

2.6 Genetic Risk and Responsibility.

"Genetic responsibility has emerged as a key notion for understanding how genetic risk reshapes patterns of choice, identification and obligation within families" (Ayllon *et al.*, 2008; p. 1521).

The implementation of genetic screenings and diagnosis tests for SCD in the UK assumes that knowing one's genetic status will ensure right medical care and social life management to ensure optimum quality of life for the person affected for sake of self and *Other*. The management of social areas of life involves making responsible choices to mitigate the burden of impairment and also avert the possibility of transfer of illness to their offspring, (Weiner, 2010; Etchegary, 2006). The normative culture expectation of an individual with a genetic inheritable disorder to be *prudent* and make these rational life choices is termed *Genetic responsibility*. This term, first coined by Lipkin and Rowley in 1974 is defined by Weiner (2010) as the will to know and manage one's own genome for oneself and the sake of *others*, focusing particularly on responsibilities to family and kin. Weiner further elaborates that this implies "an obligation to become informed about one's genetic constitution..., to undertake risk management to monitor and try to modulate one's own genetic risks..., and the responsibility to one's own kin" (Weiner, 2010: p. 1760).

Etchegary *et al.* (2009) summarized genetic responsibility as meaning "(1) to know about the self for self, (2) to know about the self for others, and (3) to know about the self to oblige others to know" (p. 252).

The assumptions made with the concept of genetic responsibility is (1) it "casts the at-risk person as an independent decision-maker, rationally weighing the pros and cons of risk-management options" (Etchegary *et al.*, 2009: p. 252). (2) It assumes that a '*good citizen*' who is adequately informed about the danger posed by the embodied risk has a moral

obligation to strive to avoid the empirically defined health risks, for sake of self and society (Dean, 1999a; Department of Health, 2005 p. 3). Some scholars like Harris, 1998 had argued that it is 'morally dubious' to depend on nature to take its course when a preventative action can be taken in the presence of a genetic risk (Harris, 1998).

2.6.1 Ethical Issues to concept of Genetic Responsibility (GR)

Some ethical issues challenge the GR as a concept. Firstly, the genetic information acquired from screening is expected to be acted upon as a moral obligation to ensure illness is not transferred to next generation. This assumed obligation raises some ethical issues for the embodied person because choice is expected to be automatic within the human rights act (Etchegary, *et al.*, 2009). Though dominant culture assumes these rational decisions are voluntarily made, yet many studies have shown that decisions are often influenced by external factors in society such as family, clinicians and experiential effects of disorder (Wöhlke & Perry, 2019). Society normally casts an individual who makes decisions contrary to expectation of the patriarchy culture as *irrational*.

Some studies elsewhere demonstrated that people with SCD theoretically consider it morally right to know their status and disclose such status to potential partners for purpose of making informed decision about the relationship and parenting. However, studies have confirmed some extrinsic factors can influence their decisions. The autonomous component of the process of decision-making seems challenged by the assumed societal expectation of the individual making rational choice.

Secondly, the laypeople's understanding of genetic risk seem flawed. Studies abound that demonstrate the variance that exist in the scientific facts presented by geneticists and layperson's interpretation of those information (Parson & Atkinson, 1992; Wöhlke *et al.* 2019). Parson and Atkinson (1992) drew attention to the lay understanding of "probabilistic notion of 'risk' which is turned into definitive, descriptive categories" (p. 453-454). So, the perception of individual living with the disease of their personal vulnerability due to their genotype can be sometimes at variance with the genetic calculations. Such conflicts in understanding of how risk is transferred do challenge people's reaction to management of the risk (Walter *et al.*, 2004).

Thirdly, socio-cultural environment of an individual can influence the understandings and perception of the genetic risk. (Meiser (2001). The person's consciousness of the embodied risk enforces continual creation of strategies to mitigate this bodily harm (Weil, 1991; Richards and Ponder 1996). Philosopher Merleau- Ponty's assertion that "We are in the

world through our body, and we perceive that world within our body” (Merleau- Ponty, 1962: p. 206) suggested that the lived experiences of the individual who is affected are both within and constructed by factors embedded in the society’s interpretations of SCD and their prescript management. The culture will include the ethnicity, education, religion, lived experiences of impairment and the clinically accepted outcome.

Fourth consideration is the psychological impact of the condition on the individual. Numerous literature document factors that inform people’s attitude towards the concept of genetic responsibility; factors such as cultural and religious beliefs, socio-economic level of the participant, lived experiences of the individual amongst others, (Lippman, 1991; Lawson, 2001). However, lived experiences of the disease has been found to play the most significant role in reproductive decision making (France *et al.*, 2011; Carter *et al.*, 1971; Boardman, 2014).

The notion of genetic responsibility is laudable in the sense that knowing one’s genetic status as *risky* should be expected to elicit spontaneous strategy to mitigate the risk. Nina Hallowell also argued, “the rhetoric of the new genetics constructs individuals as having a responsibility to obtain genetic knowledge and subsequently attempt to modify their risks” (Hallowell, 1999: p. 615). However, recent studies suggest that in practice, reproductive decision-making is not that straight forward and can be very complex (d’Agincourt-Canning, 2006). How the management strategies are perceived, decisions arrived at and experienced by persons who are at-risk has conflicted earlier assumptions that all people will embrace the screening. People at risk have reported that genetic testing constrains them, they literally feel a sense of loss of freedom. Hill in her study in 1994 reported that more than half her study participants chose to ignore medical knowledge, have children even with risk of affected new-born, to protect their reproductive freedom (Hill, 1994). Hill’s report gives the indication that the concept of genetic responsibility has a high self-reflective component that affects the *self* inside, causing performance of ‘complex invisible work’ (Church *et al.*, 2007, p. 1). Asgharian and colleagues in the UK also reported that many women with the embodiment had trouble with status disclosure to their partners and would often risk having a child who is affected than initiate discussions that could lead to termination of their relationship as well as possibly giving up the right to motherhood (Asgharian *et al.*, 2003). These studies suggest that the socio-psychological dimensions of decision-making in partner selection and reproduction is significant. Emotions can be strong and be effective influencers of judgement and decision-making. Rothman, in her study among pregnant women undergoing genetic tests to rule out a genetic risk, revealed some level of emotional

pressure from the uncertainty of the outcome of the tests. She said, “the investment in pregnancy with the question of ‘genetic risk’ renders women’s relationships with their own pregnancies as ‘tentative and fragmented’ because the pregnancy cannot be fully accepted until abnormalities are ruled out by the tests” (Rothman, 1993, In Ross, 2013). In the process of partner selection, particularly at the point of disclosure, the same phenomenon of unease, uncertainty or outright pain is experienced by most people who are affected. The process involves “evaluating disabilities, deciding which disabilities make life not worth living” for the foetus (Rothman 1993: p. 160, In Ross, 2013).

SCD is experienced and understood in myriads of ways, of which I present three distinct ways as conceptualized by Kleinman (1988). The first is the impairment effects of the condition as experienced by the affected person, the second is the clinical presentation of the disease and the third is the social understandings and beliefs about the condition. The lived experiences are embedded in these three sources which the person living with the disorder struggles to make sense of and to re-construct biography. Emerging from adolescence into adulthood, selecting romantic partner and making reproductive decisions with an awareness of *risky* embodiment that can affect most of life’s trajectory, will affect an individual’s perception of self and possibilities of the future endeavours (Thomas, 1999). The moral ethics to know one’s own identity and avail such information, when necessary, can become problematic (Reed, 2011). Societal construction and tolerability of the illness can challenge the autonomy of decision-making.

In conclusion, the three dimensions of genetic responsibility suggested by Etchegary *et al.* (2009) which are (1) to know about the self for self, (2) to know about the self for others, and (3) to know about the self to oblige others to know, will be elucidated as related to this study to discover *if* and *how* SCD impacts partner selection and reproductive decision making.

2.6.2 To know about the Self for Sake of Self

Research has revealed that the social context and cultural perceptions of SCD do affect how a person living with the disease view and manage strategies for self (Higginbottom, 2006a, b, In Morden *et al.*, 2012). With the clinical sequelae of SCD, any rational person would readily want to prevent disease for sake of personal wellbeing and ease of living. However, the interpretation of ‘*sake of self*’ may differ from the interpretation given by the clinical fraternity. ‘Motherhood’ may take precedence over a woman’s body when it comes to ‘*sake of self*’. For example, both Pearn (1979) and Finucane (1998) in their studies

reported that majority of women have a desire to nurture and reproduce a child even in situation of a risk as serious as genetic disease. In the UK, Oni (2007) argued that many women believe that the state of motherhood is the only rational reason of being a woman despite any other life affirming roles and this view is considered common worldwide. So, most women feel being women imply they must be mothers, even in the presence of life-threatening disease.

2.6.3 To know for sake of *Others* (Offspring)

Engaging in genetic screenings and tests for sake of offspring is assumed to precede intentional decision making if say, pregnancy is affected (Farrant, 1985). Abundant studies confirm attitudes and motivations of people with genetic diseases to engage in genetic screenings and diagnosis for purpose of making prudent genetic choice (Rothman, 1998; Ross, 2015; Etchegary & Fowler. 2008; Jenerette and Brewer, 2010; Boardman, 2013). Though culture consider genetic screening empowering for making partner selection planned to involve parenting, many study reports reveal that the individuals consider the reproductive decision-making, at the level of partner selection and foetal diagnostic testing level, restraining (Ross, 2015; Himmelweit, 1988). Many people feel these processes intimidating and burdensome; and sometimes feel the decisions made are imposed on them (Himmelweit, 1988).

Ross (2015) reported that these individuals face dilemma when selecting long-term partner and when making reproductive decisions. Even when they believe it is ethical to make responsible choices, at point of making those decisions, personal interests and some social concerns compete with moral stance. They have to decide on what is more important to them, the future of the offspring if endowed with SCD or other social issues such as desire for motherhood (and fatherhood), emotional attachment to the partner, religious concerns, and so many other personal interests (Ross, 2015). Self-restraining factors included the stability of relationship, (Ross, 2015; Hill,1994), commitment to motherhood (Hill, 1994) and illiteracy (Hill,1994). Studies by Ross (2013 & 2015), just like Hill (1994) reported on how participants with SCD stated that their embodiment limited their choice of non-affected partner. Though they considered not transmitting the SCD risk more important than their own personal relationships, some of them did not integrate that knowledge into their choice of partner or their reproductive choices as other competing aspects of living took pre-eminence over the genetic knowledge. Some rejected genetic testing for spouses because

they found it easier to risk giving birth to a child with disease than insist on partner testing for status (Ross, 2015; Hill, 1984).

Hill (1994) however explained that her findings seem to suggest that such behaviour may be more common among uneducated, low-income women whose priority lies in embracing their motherhood and marital relationships above medical knowledge. Ross who conducted her study 20 years later noted that participants in long-term relationships were more readily predisposed to ask potential partners to screen for SCD. they were more educated so well informed of consequences; some have embodied experience of the disabling and impairment effects of SCD. Ross (2015) argued that genetic tests are of intimate private nature and that there is a need to thoroughly understand the complexities and damaging consequences of not being rational about choice; to be able to confront potential partners to undergo a genetic test, even at the risk of losing the partner (Ross, 2015: p. 41). Asgharian *et al.* (2003) also confirmed that people with SCD considered their (potential) significant other's genetic status before reproducing with them or *even* entering a relationship with them. This subtle developing attitude among the people who are affected validate the UK policy of genetic screening of new-born to establish the genotype early in life so that the individual can form relationship with responsible intentionality, rather than wait for screening after relationships have been formed (Acharya *et al.*, 2009; Asgharian *et al.*, 2003; Hill, 1994).

Ross (2015) pointed out that "The meaning women gave to having a child with SCD and the knowledge of how they came to have it themselves caused them to be diligent in preventing passing SCD along to their children" (p. 41-42). Their lived experiences of the illness informed by how severe the disease sequelae, biomedical discourse of genetic information and their experience of negative social intrusiveness shape the thoughts, beliefs and reproductive behaviours as they sense an obligation to ensure their offspring do not go through same experience (Etchegary & Fowler. 2008; Ross, 2013 & 2015; Boardman, 2013).

Reproductive decisions and behaviours are complex according to myriads of studies (Ros, 2013; Ahluwalia *et al.*, 1999; Asgharian *et al* 2003). Post-conception genetic risk diagnosis is often expected to lead to termination of pregnancy; however, study reports reveal it does not necessarily result in pregnancy termination (Acharya *et al.*, 2009; Gallo *et al.*, 2008). Social factors such as religion, motherhood instinct of protecting the unborn baby, and other cultural issues may influence the normal obligation they have for responsible choices. There are reports of the women having a sense of guilt and emotional turmoil after termination of

pregnancy (Ross, 2013: p. 163). Some have blamed the medical professionals who advised them while some reject the medical counsel outrightly. Oni (2007) also reported that some women rejected genetic testing during pregnancy due to fear of miscarriage, foetal abnormality due to procedure, or other cultural norms of religion, family preferences (Hill, 1994; Asgharian *et al.*, 2003, Oni, 2007).

Society generally constructs women as having the rights to make independent reproductive decisions without patriarchal constraints (Markens *et al.*, 2003), being the carrier of the pregnancy. Current NHS policy supports father`s involvement of shared responsibility for reproductive decisions making. Fathers have traditionally been estranged from taking part in these responsibilities publicly so that their contribution to the decisions used to be subversive. Reed (2011) in her study of male partners involvement in prenatal blood screenings in the UK, reported on increasing presence of male partners in the prenatal blood screening clinics. This demonstrates that men within the UK health system, are active participants in all issues of genetic responsibility, whether at the personal level of knowing their status or at the reproductive decision-making level (Reed, 2011; Redshaw & Henderson, 2013).

Ross (2015) argued about knowledge of genetic information being an important determinant of the reproductive decisions made. In her study, she demonstrated that the level of education affected the attitude of people living with genetic illness to genetic responsibility. The more educated the individual, the more predisposed they are to ensure they do not transmit the gene to future generations. These group of educated women understood the genetic transmission pattern and so some who are in stable relationships they wanted to keep, decided to forego having biological children. When compared to the Hill (1984) study, possessing robust genetic knowledge framed their responsible obligation and was less constraining. Oni (2007) also proposed that genetic knowledge can influence decision making of these adults.

Rance & Skirton (2019) reported the influence of modern advanced reproductive genetic testing on reproductive decision making. They reported that pre-implantation genetic diagnosis/Invitro fertility methods (PGD/IVF) option was favourable to most persons who are affected. (Boafer *et al.* 2015; James 2014). With this technique, the embryo is tested invitro for *HbS* before implantation into the uterus. There will be a need for studies to find out how these individuals accepted and utilised this offer. Vali *et al.*, 2020 reported that in the UK, the current policy of the department of health is that those “who are at risk of having a child affected with SCD and have no unaffected children are entitled to a maximum of

three state-funded PGD cycles” (Vali *et al.*, 2020: p. 1). Vali *et al.* (2020) reported that over a 5-year period of adoption of strategy by NHS, uptake of PGD is still hampered by “other factors associated with the acceptance of PGD need to be considered, including moral, political and religious values” (Vali *et al.*, 2020: p. 4).

2.6.4 To know Self to oblige *Others* to know (Disclosure)

To know one’s genetic status to oblige potential partner to know requires a status disclosure. The genetic screening policy in the UK assumes that in the context of the genetic services, the person living with a genetic disease has a moral obligation to disclose the result to relational kin to empower their own automatic genetic decision-making.

Klitzman & Sweeney (2011) argued that disclosure can be problematic for the person with a genetic disease. Several complex socio-psychological factors cause dilemma about status disclosure. For example, the possibility of rejection, difficulty of finding another willing partner, and sheer shame because of the rejection cause internalised tensions for the individual. Klitzman & Sweeney (2011) stated that “dating situations are critical to the possibility of establishing an ongoing supportive relationship—usually the most important of one’s adult life—and of having children. In dating, two individuals each consider whether to make extraordinary and unique investments into each other’s lives, and hence they closely and carefully assess each other” (p. 98-112). A romantic relationship between two people whose relationship is classified as at-risk of bearing SCD-embodied offspring that or possible lowered quality of life due to impairments can be anxiety-laden. There would be dilemma regarding the strategy of disclosing; *how* and *when* to disclose. The laypersons limited understanding of the statistical probability of transmission of the gene may also create some challenges to process of disclosure because of the vague understanding of genetic risk of SCD (Meiser *et al.*, 2001; Meiser *et al.*, 2017).

Though it is assumed that disclosure is autonomous, yet societal attitudes can become subtly coercive, making decisions involuntary, being psychologically enforced. Negative social reactions at point of disclosure do cause “socially engendered undermining of their psycho-emotional well-being” (Thomas 1999: p. 115).

Socio-psychological challenges encountered by affected people at point of disclosure is well documented. For instance, anxiety in HIV/STIs (McCaffery *et al.*, 2006), disclosure easier for casual relationships (Green *et al.*, 2003), extended families (Wilcke *et al.*, 2000; **Hallowell *et al.*, 2003**, Arribas-Ayllon) and delayed timing of disclosure (Lee & Craft, 2002) and strategizing timing of disclosure as also mentioned in Klitzman & Sweeney (2011)

“...‘get to know prospective partners at a much slower pace,’ creating a ‘screening period’, and usually telling only partners ‘whom they expect to remain in the relationship even after hearing’ the diagnosis” (Klinzman & Sweeney, 2011: p. 98-112). All study reports in literature on status disclosure, however, identified factors influencing individuals with SCD are visibility/non-visibility of disease, difficult lived experiences of condition, scientific knowledge of the disease, psychological, and social factors (Klinzman and Sweeney 2011). None the less, most people feel an obligation to make status disclosure to their potential partners, though problematic, because “they felt that expectations of, and desires for, mutual trust in the developing relationship dictated that they be as forthcoming as possible, and that their partner thus had a right to the information. They felt that these implicit expectations of trust outweighed fears of rejection” (Klinzman & Sweeney, 2011). Some people abandon dating and romantic relationships altogether because of the stress of dilemma faced at disclosure, (Klinzman & Sweeney, 2011: p. 98-112). Werner-Lin in 2008 reported that people who do not plan to parent do not seem to face the same pressure of dilemma about disclosure.

2.7 The Theoretical Concept

In developing a theoretical framework for this study, it is important to consider the SCD as an impairment of the body and the meanings generated from interaction with the world. Kleinman (1988) argued that three identifiable dimensions to chronic illness are, the body impairment of the disease with all the symptoms, lived experience of the disease which is personal to the affected person and then the experience of the person imposed by the socio-normative factors. In all the three dimensions, the body is central to the various experiences. Merleau-Ponty (1962) suggested that “We are in the world through our body, and... we perceive that world within our body... Thus, by remaking contact with the body and with the world, we also rediscover ourselves” (1962: p. 206). All experiences are through the corporeal body.

This study is an exploration of how SCD impact the selection of romantic partners and the reproductive decision making of adults with the disorder living in the UK. It is vital in the study to understand about how bodied bearing SCD are assigned meaning in society and how cultural discourse creates and apply social control at the points of selecting romantic partner and making parenting decisions. Thus, I will utilize the theoretical frameworks of Embodied Risk and Social Model of Disability (SMD) for this study.

2.7.1 Embodied Risk

The sociology of the body has been studied under three main approaches. The first is the social constructionist approach. It indicates that bodies are regulated, controlled and monitored by social forces. Foucault's concept of "*biopower*" in society, as an authorizing power that subjects *bodies* to governance through first, external surveillance and monitoring and then secondly internal self-surveillance /policing thus objectifying bodies as docile bodies, (Thomas, 2007, p. 37) has helped provide understanding of how bodies are created based on specific historical and cultural "relations of power" (Reeve, 2002, p. 496). Since various segments of the society work together to meet the need of the society, bodies align with the set values, laws, beliefs or customs to meet the need of the society (Wainwright 2008). For example, women police their physical appearance to align with historical and culturally accepted norms of femininity under the coercive gaze of patriarchal male (Wolf, 1991). So, bodies are socially constructed and defined by the social culture or values in which the body functions. Foucault argued that the body is "directly involved in a political field; power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs" (Foucault, 1977: p. 26). Social and cultural factors alone assign meanings to bodies, so in cases of chronic disease, the dominant culture perspective will dictate how the body experiences the illness (Ross, 2013). A medical diagnosis is historically and culturally accepted as unchallengeable 'facts' and 'truth'. It therefore represents a hegemonic patriarchal tool for social control within society. The diagnosis categorizes *normal/abnormal, fit/unfit* bodies through external regulation of bodies by observing, testing, screening bodies, while it also prescribes tools to discipline the bodies to align with these normative standards. The biopower system of governance are somehow not imposed on the subjects but in subtle insidious ways, subjects are coerced to voluntarily submit to the inscriptions of compulsory normalization (McRuer, 2006), which cause the internalization of oppressive normative standards (Campbell, 2008). The second is the naturalistic approach. This approach focuses on the ontology of the body. Bodies are assigned meaning based on some physical characteristics to which society has dictated its class. For example, a woman's wage must be less than a man doing the same job irrespective of the woman's skill. Shilling, (1993) argued that the body "is not simply constrained by or invested with social relations, but also actually forms a basis for and contributes towards these social relations" (p.12-13). Thus, the natural biology of the body defines the body within the society. Foucault argued that all meanings are grounded in discourse (Foucault, 1972 in Hall, 2001, p. 73). Biomedicine as a dominant discourse

shapes our understandings of bodies ascribed as either *healthy* or *ill*, *able* or *disabled*, *normal* or *abnormal*. Feminism draws attention to how these hierarchical binary categories provide justification for the oppression and marginalization of those *othered*.

The third approach has to do with the lived experience of the body owner. In other words, consciousness is embodied. According to Nettleton (1992), the lived body constructs, is constructed and is within the life worlds. This is the phenomenological approach which is referred to as the Sociology of Embodiment. While it accepts that the body is sociologically constructed, it also considers the reaction of the owner of the body to the stimulus of the social factors. William (1996) further describes the sociology of the body in situation of chronic illness as a move from an initial state of embodiment when the body is taken for granted in daily activities to a state of embodiment in which the body is not in sync with self, as in a dysfunctional state. For movement back to *re-embodiment*, the owner of the body must perform an enormous *re-construction work* of their life-worlds (Nettleton, 1999).

The phenomenon being studied is interfaced by three distinct actors. The first is the medical diagnosis of the genetic status. The assigned risk is an invitation for action by the owner of the body, the affected person. The second component is the social activity of selecting of romantic partner and engaging in reproductive decision-making. The perception and attitudes of the *Others* in society such as the potential partner, families, associates and indeed the opinion of the clinician who is involved in health and welfare support of the affected person informs the impact. SCD, as a genetic disorder, poses as a risk of being endowed to future generations.

The gene, *HbS* is embodied, located in the body thus provoking the possessor to set up agency to manage or control any possible hazard. Turner (2004) argued that embodiment is a series of social processes taking place in the life of an individual which results in life experiences, meaning and identity. Thus, the *HbS* gene becomes a major contributor to the identity of the bearer, it defines who the affected person is. Merleau- Ponty, the philosopher said, "We are in the world through our body, and... we perceive that world within our body" (Merleau- Ponty, 1962: p. 206).

'Risk' is a term used where an exposure of an individual to a hazard will increase the likelihood of or cause an injury or disease. Genetic risk is the probability that a mutated (or *abnormal*) gene will be passed on to an offspring based on knowledge of its genetic pattern of transmission. There are environmental risks which are things that come to people, things done to people (such as climatic and clinical waste) and lifestyle risks which are things people do to themselves (such as obesity, anorexia). The genetic risk is innate in nature,

described by Kavanagh and Broom (1998) as 'corporeal' or 'embodied' risk. It does cause ill-health if the individual possesses full blown form of *HbSS* or in some cases, the bearer is a recessive carrier of the gene and not the full-blown disease.

Ross (2015) argued that "embodied risks define who a person is rather than what they do or what is done to them. With embodied risks, a part of one's body poses a threat to the self, resulting in dissociation between body and self. Imposing a threat from within the body, embodied risks have the potential to define who a person is as opposed to what they do in lifestyle-related risks or what is done to them in environmental risks" (p. 36). All lives activities such as social, career, relationships or reproduction are affected by SCD (Ross, 2015). All taken-for-granted assumptions of these life activities for an unaffected person must be reconsidered by the affected individual. In the area of romantic relationships for instance, the *body is risky* and so partner selection will have to be by informed decision to avoid transfer of gene to the future children. According to Gifford (1986), the risk is internalized and experienced as a state of being, persistently in the consciousness of the individual. The continuous awareness of the embodied risk creates a sense of intentionality as they interact with others in their daily lives, seeking for strategies to control and manage their risk (Burton-Jeangros, 2011). This implies that an individual with SCD constantly bears this burden of the knowledge which affects all the decision making in the life-course, especially in the private spaces of selecting romantic partners. Kavanagh & Broom (1998) suggested that people who embody SCD do consider their bodies as *dangerous* because of experiences of crisis, frequent ill-health and embodied knowledge of possibility of gene transmission to offspring thus sensing their bodies as '*Other*' (Kavanagh & Broom, 1998). This could create some internalized tensions and lowered self - esteem.

Medicalization of life are performed at all levels of the lifecycle of partner selection and parenting decisions of an affected person because of need for constant surveillance and assessment to ensure responsible choices are made as the risk is being managed (Kavanagh & Broom, 1998). While this can be seen as a positive issue, the downside of it is that the private space of forming, engaging in and making reproductive decisions and choices is being subjected to publicization, a process that can lead to feeling of public stripping, shaming, and downright debasement as the society may perceive romantic relationship with them negatively because of the risk of producing affected offspring.

Embodying both the genetic risk and the experiential knowledge of SCD which is "acquired through the individuals' direct interaction with the physical, social and intellectual world," (Borkman, 1979 p. 450), gives the affected person lived experiences and understandings of

the impact SCD makes on romantic partnership engagement. As mentioned at the start of this subsection, an understanding of embodied risk is vital in understanding the impact of SCD on selection of partners and reproductive decision-making of this target population.

2.7.2 Social Model of Disability (SMD)

In the UK, in the early 1970's, some people living with disabilities campaigned against social and political policies that marginalize and exclude them participating fully in society. They demanded for the removal of those social barriers which render them unable to participate fully in the affairs in the society to which they belong. They asked for equal access to civil rights, autonomy in all the other facets of human citizenship. A segment of their documents states, *"In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society... Disability is the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities"* (UPIAS, 1976, p. 15).

Their advocacy caused major change in how disability was viewed and handled in the world over. An academic, Michael Oliver, himself a tetraplegic, developed the concept of Social Model Disability (SMD) from those advocating statements of the disability activists, *The UK Union of the Physically Impaired Against Segregation (UPIAS)* in 1990. He describes disability as a socially constructed phenomenon rather than a medical issue. He suggested that disability is about the lived experiences of the people with disability facing consistent systemic exclusion, oppression, discrimination, inequality and devaluation from the wider non-disabled members of the society. He argued that disability is not situated in the impairment of the body but rather in the society that failed to take the needs and perspectives of the people with disability on board during policy development and services appropriation in its social organization. He complained that this minority of people are excluded from full participation in the societal life. Oliver distinguished impairment (a medical condition or disease which may require a medical intervention) from disability (which is discrimination and prejudice based on the cultural meanings and understandings of society about the impairment) to address the misunderstanding about the origin of disability.

The move from the traditional way of thinking conceptualized as the medical model, to the new philosophy of social model of disability completely transformed attitudes towards disablement.

The medical model is rooted in the paternalistic medical concept that define bodies against set attributes believed to be *normality*. Any deviance from the set normality (intolerant to any diversity) must be cured or eliminated. That stance become disenchanting for minority population living with disability that is permanent and incurable because the implication is that people with impairments are less than human (Oliver 1996a; French 1993; Barnes 2003; Murphy 1987). Davis (2012) also argued that disability problem “is not in the person with the disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled” (The Disability Studies Reader, 2nd Edition 2012: p. 3).

The philosophy behind Oliver’s SMD is that society is made up of diversity of people and there must be equity in the ways social amenities and opportunities are shared. He criticised the medical standpoint of creating the notion of fragmenting society into *normal/abnormal*; thus, causing inequality and oppression for some people (Oliver, 1991).

Understanding the culture and norms of a society is relevant in investigating and understanding the meanings given to an attribute such as a chronic illness and the impact that meanings will have on the life-course of individuals who are affected in that society.

Oliver criticized the notion of extending the expertise of medical professionals beyond treating pathology to social aspects of life such as decision-making in romantic partnership and reproductive choice making, using parameters drawn from culture and philosophy of ‘*able-bodiedness*’. This perception creates social barriers for this ‘*different*’ individuals, casting them in a lower *hierarchy* in society and be viewed as ‘*incomplete*’ or ‘*abnormal*’. The point made by the UPIAS and conceptualized in the Social Model of Disability is that these individuals may be different from the larger percentage of the population, but they are complete human beings as they are, and must be accepted by society “as we are and not molded to what the non-disabled people think we should be” (Oliver, 1990). Davis (2013) said “the “problem” is not the person with disabilities; the problem is the way that normalcy is constructed to create the “problem” of the disabled person” (Davis, 2013).

SCD, the condition being researched in this study, is not curable and so is the ‘*normal*’ for the individual living with it and should not be perceived as less human by society. The persons affected by the disorder are part of the *normative* members of the society, with same rights to all that can be enjoyed as citizens, including rights to love, engage in romance

and become parent if they so desire. The coerced view of medical practice is to treat, control or dictate how the social lives of this minority population should go should be challenged.

Feminine researchers such as Ross (2013) suggested that beyond being biological, the body is socially constructed, and develops its value, identity, and its lived experiences from interactions with social or cultural environment (Ross, 2013, Nettleton, 2001). The interactions with cultural systems shape the meaning of the body within its social environment (Turner, 1996).

The theory of Feminism gives nuanced understanding about how dominant cultural forces, devalue and oppress women all over the world in a way that their life chances are limited. (Lorber and Moore 2002). The theory helps to unearth factors causing or sustaining such oppression for purpose of social justice. Feminist scholars criticize patriarchal toxic contending attitude towards the female body which is at variance with dominant accepted '*maleness*' standards and so considered subordinate or inferior to the male body.

The culturally accepted '*normal*' dictates the ideal structures which in turn police the deviating '*abnormal*' to 'fit in' or be counted as '*other*', '*not like us*'. These deeply inbuilt beliefs marginalize and disable non-compliant bodies.

Feminist theory and SMD are synergistic notions about concerns of oppression, and '*otherness*' of non-compliant bodies by the patriarchal dominant norms. The feminist approach questions the dominant culture power of value determination as society is segregated, gendered into compliant/non-compliant bodies in terms of embodiment, biological body, and identity and how this creates social hierarchy in society for allocation of social capital (Wendell, 1989). SMD concept asserts that the disablement experience of people living with disability is embedded in the dominant ableist society rather than the impairment embodied (Olivier, 1990). In other words, all bodies in society are normal though diverse in biology, and function. The agent perpetuating alienation of bodies thought to be different is the dominant culture that will need to change its attitude towards this minority of people, the people with disability do not need to be fixed.

Medical practise is acknowledged as social expertise and so is authoritarian in its diagnosis. As part of the medical model, it authoritatively assigns meanings to bodies as *normal/abnormal*. Nye (1997) suggested that science and medicine are cultural practices governed by masculine honour codes. The nature of the practice necessitates allocating health states in dualism (either normal or abnormal) in connivance with set standards of what wellness is prescribed to be. Thus, as a patriarchal entity, the medical fraternity has a

history of doling out cruel diagnostic verdict on feminized and disabled bodies, through its declarations of authoritarian power, turning the marginalized bodies into “*spoilt identity*”. These bodies being labelled ‘*sick*’, ‘*abnormal*’ ‘*crippled*’ or plain ‘*non-human*’ create stigmatizing meanings in society and even *within* the bodies themselves, they are judged as flawed. With the patriarchal standards of society being the reference, the victims are marginalised and stigmatised. The assigned meanings in society will influence the way the illness is experienced (Turner 2009).

Michael Foucault had argued that “the body is a site of the manifestation of power relations, and it is managed by ideological constraints and everyday practices” (Foucault 1978). He gave example of the medicalization of women’s bodies for cosmetic purpose. Hi-tech medicalization promises capability to correct and cure the seemingly socially constructed deviant or dysfunctional bodies. The medical perspective is that society must have flawless bodies, so ‘sick’ bodies must be either be cured or eradicated from society because impairments or chronic illnesses cannot and must not be tolerated. The psychological impact of these cultural stance on the people with these bodies are not considered or taken on board.

A healthy woman endowed with heavy breasts may be asked to undergo a ‘reconstructive cosmetic surgery’ so as to fit the dominant accepted standard shape and size acceptable for male erotic pleasure. Thus, the original natural breast is presented as abnormal, sick and deviant from acceptable proportion and so needs to be surgically mutilated to become normal. Garland-Thomson (2002) argued that the emphasis of correcting body variations and vulnerabilities judged to be defective creates more intolerance in society for the person with disability (Garland-Thomson, 2002; Wendell, 1998).

The program of post-conception genetic screening of the at-risk pregnancy is based on the proposition to what the dominant culture considers as deviance. Garland-Thomson (2002) posits that illness and disability are gendered feminine because of the cultural understandings and stance. According to feminism, just like women are imagined to be abnormal in behaviour, needing discipline to conform to norms acceptable to men, sickness and disability are abhorrent so must be cured or disposed (Garland-Thomson, 2002, p. 10). As a departure from paternalistic medical model of disability in which the doctor knows it all, the Feminists stress the equality in the relationship between the medical professional and the patient who owns the body and experiences the body in all social interactions. The

feminist perspective is that the dominant culture is empowered to be overly intrusive into the autonomy of the patient, the choice of the patient is thus downplayed.

The notion of SMD that disability is a social construct inherent in the attitudes and behaviours of marginalization and stereotyping of the wider mainstream segment of society to people with impairment, complements the perspective of the feminist theory. Impairment of the body itself is assumed not to be contributory to the disabling oppression in the lived experiences of the individual concerned. This contrasts with dominant medical models which considered disability to be due to the *broken* body of the individual which needs to be *normalized* or else be discarded from society. This view does not represent the perception of the population in question but the perspective of the mainstream society who decide that the people living with disability are repugnant and cannot fit society (Lord, 2009). Non-compliant bodies become subordinate in society hierarchy to bodies that meet with cultures perception of norms. The coercing of compulsory *able-bodiedness* expected on those who do not fit the patriarchal dominated medical order passed as the universal *normal*, disable these minority population.

NHS employ of medical genetics as authority to diagnose and break society into *risky/non-risky* bodies, *sick/healthy* bodies according to the ascribe genotype 'othered' people living genetic illnesses such as SCD. Social capital in form of acceptability, imbibed in the ensuing social hierarchies according to the created culture influence how different groups of bodies are viewed and treated. Feminism adopted 'gender' to highlight the ways 'othered' segments of society with ascribed divergence from accepted norms, are codified by dominant meanings of society; their bodies being blemished with chronic illness. SMD therefore is an appropriate framework with which to explore how SCD impact the selection of partners and the making of reproductive decisions of the adult embodying SCD. With the clinical and genetic nature of SCD, the attitude and behaviour of the wider society to people with impairment, trying to select a romantic partner from *within* society and making reproductive choices should help understand the impact of SCD on the process.

2.7.3 Social Model of Relational *Disablism* (SMRD)

Although the SMD philosophy permeated the UK and many countries all over the world causing changes to be made to public policies with the perspectives of people with disability taken on-board, some feminist scholars started to query the truism of SMD that the entire disablement of the disabled rests squarely on the society, and that the impairments effects were wholly neutral (French 1993, Thomas 2002; Thomas 2006; Shakespeare & Watson

2001; Morris, 1991; Crow, 1996; French, 1993). These critiques, who were mostly disabled themselves, argued that impairments do contribute to the disablement and restrictions experienced by the disabled persons. Shakespeare & Watson (2001) stated that while SMD for British disability movement enabled the identification of a social problem faced by a group in the society, which is structural and psychological barriers (and policy makers were able to implement strategies to remove those barriers for better inclusion into the society), the impairments remain limiting and oppressive to the disabled. Thus, for SCD, their argument means that there should be no need to screen for SCD gene and avoid transferring HbS to future generations if SCD was not a problem in itself. They concluded, “people are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial” (Shakespeare and Watson, 2001: p.15). Thus, SMD empowered people with disability in terms of visibility in society and public policy-enacting but did not cover all of the lived experiences of the individual affected according to the critics.

Thomas (1999) therefore proposed an extension of the SMD as Social Model of Relational Disablism (SMRD). She proposed embracing the psycho-emotional dimensions of the disability debate which involves the psychological and emotional dimensions, leaving the ‘impairments effects’ which is not constructed by society.

Traditionally all ‘disability’ is regarded as a homogenous experience across different impairments without considering the possible intersectionality of other identities such as age, ethnicity, socio-economic class, education, gender, age and other co-morbidities that bear on the disability in question thereby altering the impact of their experiences of disability (Boardman, 2013; p. 1-2; Thomas, 2007, p. 169). Thus, other factors of the environment of the individual in question do play a role in the disablement. For instance, an adult living with SCD in the UK may have a lived experience totally different from the United States of America because of social policies that are different.

Thomas (1999) suggested that *disablism* is a social relational phenomenon that occurs at points of social interactions between the disabled persons and non-disabled, casting the disabled as of lower ranking than the non-disabled people in the citizenship hierarchy. She argued that “the oppression that disabled people experience operates on the 'inside' as well as on the 'outside': it is about being made to feel of lesser value, worthless, unattractive, or disgusting... and such encounters have indelible consequences on disabled individuals' sense of self, identity, self-esteem, and existential security” (Thomas, 2004: p. 73). Thomas coined these experiences of oppression and intimidation as *disablism*. She defined it as “a form of oppression involving social imposition of restrictions of activities of people with

impairments and the socially engendered undermining of their psycho-emotional well-being” (Thomas, 2007: p. 73). She suggested that while there are the physical or structural dimensions of disability such as barriers such as non-accessible built roads, there are the emotional dimension of disability such as intimidation and oppression which is felt in the deep personal self, ‘restricting who people can be’. She further suggested that the oppression experienced by the people who are disabled are due to “social beliefs and actions that oppress/exclude/disadvantage people with impairments” (Thomas, 2007: p. 13). Reeve (2004 & 2012) gave tangible examples of these oppressions as having to deal with hurtful comments, stigma, being stared at, gossiped about, making policies about disability without representations of the disabled community, and all other sorts of activities by society which can leave disabled people feeling worthless, ashamed, devalued; internalized oppression which can damage someone’s psycho-emotional wellbeing and sense of self. This became an extended explanation to Oliver’s argument that disability “is wholly and exclusively” socially constructed (Oliver, 1996a: p. 35), placing the disabled on an inferior pedestal and giving preferences to the non-disabled people. For the people who are affected by this phenomenon, the burden of this societal attitude and behaviors far outweighs the burden of the impairment. While most people who are not-disabled might be appalled at being labelled oppressors to the target population, the bearer of the reality of the insidious experiences in their everyday lives are the people who are disabled. According to Duncombe, “reality is always refracted through the imagination, and it is through our imagination that we live our lives” (Duncombe, 2007: p.18).

The critiques of the SMD concurred with Bury (1982) that chronic illnesses are a ‘biographical disruption’ of the every-day living of a person. The argument is that the impairment as well as the disability are just different sides of the same coin in terms of the inner oppression experienced in the life of the individual. Shakespeare and Watson posit that “impairment and disability are not dichotomous, but describe different places on a continuum, or different aspects of a single experience. It is difficult to determine where impairment ends and disability starts, but such vagueness need not be debilitating. Disability is a complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision” (Shakespeare and Watson, 2001: p. 22). The notion from SMD is that “nothing about disabled people is wrong that needs to be fixed... medical intervention is not appropriate... instead, disabled people are better advised to struggle for changing a society” (Anastasiou & Kauffman, 2013: p. 443), did not sit well with the critics because they argue that the whole issue of belonging to the marginalised group

called disabled is because there is a problematic issue with the body called impairment which may or may not have been well handled by the normative culture.

The call for abandonment of SMD by some within the disability academia was contested as the scholars settled for the explanation given by the proponents such as Oliver (1996). He responded that SMD is only a model, a tool to help understand the meanings of disability in the lives of the disabled (Oliver 1996, 2001). He said, "The social model of disability is a practical tool, not a theory, an idea or a concept" (Oliver, 2008: p. 408).

In conclusion, the SMD and its extended form remains one of the most effective frameworks to use to study and understand the difficulties experienced by the chronically ill, particularly in the areas being studied in this research, making decision about partner choice and reproduction.

2.8 Stigma

Goffman (1963), first conceptualized stigma as a feature society cast on a person or group of persons which makes them to be perceived as lower than the rest of the people in the society, reducing the bearer "from a whole and usual person to a tainted, discounted one" (p. 3). When socio-cultural forces identify an undesirable attribute such as chronic illness in a person, society labels the individual, setting them apart from the rest of the population into 'us' from 'them'. This leads to an "experience status loss and discrimination" (2001, p. 367-369). This separation assigns them with a lowered status from the rest of the people, causing them to be at a disadvantage when it comes to a general profile of life chances which can include income, education, psychological well-being, housing status, medical treatment, and even choice of romantic partner with whom to parent children (Link & Phelan, 2001). The stigmatized individuals often internalize this societal behaviour, causing feelings of shame, and revulsion, and a lowered self-concept (Link & Phelan, 2001).

SCD is an undesirable attribute which creates being '*othered*' in a society. The medicalization of the bodies constructs *normal/abnormal* within society because of biomedical hegemonic assumptions of normality, accepted as truth in society. This sends negative messages about the abnormality of the bodies and creating a "community-led exclusion from important domains of life" (Major *et al.*, 2017: p. 3). This stereotyping of these individuals manifests as "that one is 'out of place'" (Kitchin, 1998 In Reeve, 2013: p. 123).

Goffman (1967) argued that stigmatized individuals could very well hide their unwanted attributes from others sometimes but cannot hide it from their inner selves. So, the dilemma is resolved by either confining themselves to the groups of people with same attributes and

deny the identity assigned by society as 'different' or take a 'pass', to conceal the real identity. The persistent life experiences of hurts and abuse are stamped on the self-concept of the individual to produce a damaged identity. Goffman coined it '*spoilt identity*'.

Among African community in the UK where SCD is prevalent, people with the disorder are called '*Sicklers*', a derogatory slang by the early clinicians due to the debilitating nature of the condition (Glassberg *et al.*, 2013: p. 532-533; Ola *et al.*, 2016). Thus, *indignity* is experienced in all strata of society from healthcare facilities, places of worship, and even from social institutions like family and workplaces (Gherasim & Mihalca, 2006; Dyson *et al.*, 2010; Anionwu and Atkins, 2001). Shannon (2007) defined personal dignity as a self-worth and self-esteem and how one likes to be viewed by others. Johnston *et al.* (2015) argued that dignity comprises of two dimensions, the internal dimension which is influenced by culture and how individuals constructs and re-construct self, and the external dimension which is the worth or respect conferred by the acts of others in society, and which does not depend on an individual's performance, choice or rights (Johnston *et al.*, 2015: p.107).

So, when the society tamper with personal self-esteem and autonomy, *Dignity* gets damaged (Johnston *et al.*, 2015: p. 106). The individual experiences stigma at all levels of consciousness. For example, a stigmatizing comment can bruise an internalised hurt the individual already has so resulting in a tainted self-concept. Link & Phelan (2001) called this a stigma-consciousness (p. 374). At other times, stigma may be cast interpersonally, such as between two or more persons. An example is when a potential partner dissolves a relationship because of the embodiment or when family members disavow a relationship between two people because of the embodied risk.

Drawing from the Social Model of Disability (SMD) and the extended understandings of Social Relational Model of Disability (SRMD), Thomas (2004) coined these oppressions "that disabled people experience operates on the 'inside'... it is about being made to feel of lesser value, worthless, unattractive, or disgusting..." *disablism*. Thomas (2004) argued that the source of the *abuse* is 'located' in the society and not in the limitations of the body due to impairments of the disabled persons. Further to this, Thomas argued that this experience causes a 'collateral damage' to the self and identity of the affected individual, though the oppressions might be unintended, the effects are nevertheless real and indelible (Thomas, 2004).

Link and Phelan (2001) argued that it takes power to stigmatise because "stigma is entirely dependent on social, economic, and political power" (Link & Phelan, 2001: p. 375). For example, the medical authority that marked a possessor of HbS as being disabled

possesses social power to uncontestedly *name* an individual *abnormal*, socially disempowering the individual. That is social power, or as Foucault called it, *biopower*.

Ethnic minorities in UK among whom SCD is prevalent comprise majorly of immigrants or children of immigrants and for most those communities, religion is still a well acceptable social phenomenon (Ahmed *et al.*, 2006). Faith institutions (like mosques, temples and churches) have prominent social and moral authorities over people in these communities. (Atkin, & Ahmad, 2001; Toni-Uebari, & Inusa, 2009). Asekun-Olarinmoye *et al.* (2013) reported that faith leaders are very influential in decision-making processes of most Nigerians. Many government departments and Non-Government Organizations (NGOs) have turned to these faith institutions to reach out to their communities and advocate for support for many public programs and policies such as genetic responsibility for obliteration of genetic diseases (Atkin & Ahmad, 2001; Toni-Uebari & Inusa, 2009). Gbenol *et al.* (2015) and Ezugwu *et al.*, (2019) reported that some religious bodies in Nigeria have already incorporated premarital SCD testing into their organizational marriage regulations as prerequisite for marriage. Some of these churches have branches in the UK and many immigrant Nigerians, for example, are members of those churches (Atkin & Ahmad, 2001; Maier, 2012; Burgess, 2009, 2011; Hunt, 2014; Adedibu, 2013). The thrust of these campaign, in the case of SCD, is that marriages are disavowed between persons with *HbSS* and any other persons with *HbSS* or *HbAS* (WHO, 2010).

Predictive genetic screening creates *normal/abnormal* bodies, resulting in “the creation of two worlds: the public world of the ordinary citizen and the hidden world of people with disabilities, who are implicitly held to have no right to inhabit the public world” (Nussbaum, 2004, p. 308). The *defective* bodies experience socially induced labelling due to their genotype. Such stigmatization can become problematic when in search for a romantic partner. Oni (2007) reported attitudinal discrimination experienced by individuals when searching for romantic partners or making reproductive decisions.

The community institutions such as the faith places of worship that adopt policy banning weddings of genetically incompatible individuals cause the affected person to feel a sense of being *publicly stripped* of dignity, a dressing-down, shame, isolated and lonely within the community when a potential wedding is stopped. The disavowal constructs the person with the label as less than human, unfit for romantic partnership and parenting. Link and Phelan (2001) calls it ‘status loss’.

Many research reports have demonstrated that lay person’s perception of genetic information vary considerably (Blaxter, 2004; Parson & Atkinson, 1992; Walter *et al.*, 2004).

The advanced genome tests and diagnosis produced genetic information that may not be fully comprehensible to the lay person in society. Discourses about probabilistic statistic of transferring mutated gene to offspring prove that many lay people are still ignorant of the fact that these figures are not actual values of transmittance but rather probability value. This idea has been translated into a guide for approval or disapproval of weddings between two people in these churches. Such dominant cultural mindset becomes social barriers for the affected population.

There are some advanced technology procedures that are emerging that can influence some decision making in the area of reproduction and relationship such as the Pre-implantation In vitro fertility tests. With this procedure, eggs are screened for *HbS* and fertilised in-vitro with sperms that have been screened as well before implantation into the uterus. At times, such latest techniques may not be well known by the community institutions for purpose of getting guidelines updated. The potential couple may also not be educated about them. For example, when a Rhesus (Rh) negative woman and a Rh-positive man have a baby, it is known that the body of the woman develops antibodies against Rh. In a subsequent pregnancy, Rh antibodies from the woman will attack the Rh factor on foetal blood cells causing foetal anaemia in the foetus so the pregnancy terminates. However, it was discovered that if the woman is injected with a drug, Rh immune globulin (such as RhoGAM), it can prevent the development of the antibodies. With this advance tech procedure, Rhesus positive women are no longer anxious about partners who are rhesus negative. In the same vein, with the Pre-Implantation procedures in place, selecting of romantic partners can become less constraining for the people embodying SCD. Link & Phelan (2001) stated that “stigmatisation is entirely contingent on access to social, economic, and political power that allows identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of power, disapproval, rejection, exclusion and discrimination” (p.367).

Being discredited dis-human in mainstream society, the form of stigma driven by a hegemony of medical/social power will isolate and dissocialize an individual into less involvement in community activities. This form of structured or institutionalized oppression evidenced by isolation, ostracization, and a sense of worthlessness creates “a lower position in the status hierarchy can have a cascade of negative effects on all manner of opportunities” (Link & Phelan, 2001). Such lowering of status hierarchy can impact on partner choice for the affected individual, resulting in lowering of his preferred set values for choice.

Link and Phelan (2001) had argued about the tussle of power or authority to stigmatized in institution of power such as places of worship. “If powerful groups are motivated to discriminate against a stigmatized ‘*them*’, there are many ways in which such discrimination can be achieved. If stigmatized persons cannot be persuaded to voluntarily accept their lower status and inferior rewards, direct discrimination can be used to accomplish the same outcome. If direct discrimination becomes ideologically difficult, sophisticated forms of structural discrimination such as tests that induce stereotype threat can achieve some of the same ends” (p. 375). In this case, the weapon that is usually used is denial of access to be married in the church. This is further isolation and exclusion phenomenon.

Article 8 of the Human Rights Act 1998 for the disabled protects the fundamental rights of the disabled to private and family life. This will mean they have a right to ‘be who they want to be’. According to Thomas (1999), this segment of the law addresses individual or organization who institutes structures that disables a disabled person. In the UK legal document, The Act requires all public authorities (such as government departments, councils, hospitals, the police, and those acting on behalf of public authorities) to act in a way which respects and protects an individual’s human rights. This seems to challenge the institutional stigma observed in the religious organizations presented above. With the drive for campaign against SCD in the society, a ‘disabling environment’ can be created for affected persons who are members during the presentation of the marriage guidelines to the entire community. Some questions that should be asked to ensure that the organization is mindful of the feelings and welfare of the affected are:

1). *Is an individual living with SCD in the committee drawing up the Guidelines?* UPIAS, in their 1975 submission said, “disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.” Inviting someone with the impairment to be among those who draw up the policy guidelines shows respect for the affected members of the organization and will assure them that the policy is not “the socially engendered undermining of their psycho-emotional well-being” (Thomas, 1999: p.60). “One of the often-said slogans in Disability Studies is ‘nothing about us without us’, the idea that no policy should be decided by any organization without the full and direct participation of members the group(s) affected by that policy” (Bergen Community College, PSY 207; p. 3).

2). *Does the committee present the whole of genetic information to enable the affected people to make informed decision?* UPIAS said, “We reject also the whole idea of ‘experts’ and professionals holding forth on how we should accept our disabilities or giving learned

lectures about the 'psychology' of disablement... if we as disabled people do not become our own experts but concede... we will be helping them (the able-bodied) to advance their cause as our new social controllers!" (UPIAS, 1975). Pre-Implantation Invitro fertility, for example, should be entrenched in the genetic information for public education as people with *HbS* can co-parent children with persons with the trait; offspring will only bear the trait, not the full-blown disease. The Medical discourses around SCD and genetic screening are geared towards prevention thus neglecting the socio-psychological implication of the policy.

2.9 Disablism and Emotional Work

Chronic illness attracts stigma because of being socially constructed as having a somewhat dysfunctional bodies, being located outside the boundaries of what is considered as normal functioning body.

Drawing on Goffman's work, labelling of a human difference in line with the dominant medical diagnosis separate the gendered minority from the mainstream society; it becomes, 'us' and 'them' dichotomy. The 'us' are on a higher societal pedestal above the 'them' who are discredited. The medical report, which is culturally accepted undisputable truth, marginalise these individuals into a category that is stigmatized.

For a person embodying SCD, with the culturally accepted *normal/abnormal* body, selecting a romantic partner that can lead to parenting in the light of the assumed possibility of transmission of abnormality to offspring can become daunting (Oni, 2007). This attribute of disability will evoke some marginalization due to disapproval, disavowal and general isolation of the individual. Goffman (1968) described this as stigma, "as an attribute that is deeply discrediting" (Goffman, 1968: p. 13-14). The individual possesses a *personal self-concept or identity* which is at variance with the identity created in the social arena because of the discrediting attribute embodied (Goffman, 1968). Balancing these identities as the individual interacts within the social environment will require some emotional work to re-construct self for purpose of managing self-perception and self in relation to others (Bury, 1982; Reeve, 2013). The emotional labour is undermining to well-being.

Hochschild (1983), coined the concept of *emotional work* while observing flight attendants and debt collectors put up happy, or pleased demeanor to please customer, as that was the requirement of the job, for which a wage is paid. She explained that these workers do this to comply with company rules. She defined it as "the management of feeling to create a

publicly observable facial and bodily display; emotional labour is sold for a wage and therefore has exchange value" (Hochschild, 1983; p. 7). Brook (2009) explained it as "the commodification of human feelings as customer service" (Brook, 2009: p.8). Other scholars explained it as a performance of deep-acting, putting up an embodiment of artificial emotional state, totally in variance with the deep emotion within just to please the client in a workplace. While in the workplaces, people are paid money for this deep-acting, in the private spaces of intimate romantic relationships, emotional labour is carried out for acceptance and love (Liddiard, 2014). Reeve (2013) argued that one of the outcomes of social inter-personal interactions in the society is positive or negative self-identity because the awareness of how one is perceived by others affect self-concept and confidence.

Some dominant cultural beliefs about people who are disabled stem from stigma. For example, Liddiard, (2011) posits that people with disability are believed to lack sexual feelings or desire (Liddiard, 2011). Also, people with SCD are believed by many to be unsuitable for reproduction (Ross, 2013). Such notions are oppressive for the person who is affected. Thomas (1999) described these oppressions as *psycho-emotional* dimensions of disability, or *psycho-emotional disablism*. She argued that these oppressions experienced on the inside along emotional lines are more toxic and difficult-to-handle phenomenon than the difficulties of the impairment (Thomas 2004). Reeve (2013) also suggested, "it is far more difficult to challenge prejudices and assumptions which lurk at the level of the unconscious" (p. 122). Reeve (2012) argued that constant experience of *psycho-emotional disablism* in life's path can be likened to emotional abuse because of its long-term and damaging effects on self-esteem and identity.

Church *et al.*, (2007) argued that people with chronic illnesses execute "complex invisible work", in the inner private self, daily, to keep to the norms set by the society. The people with disability perform emotional works by hiding impairments effects or working extra harder than is required to conform to normative expectation. They do this by "work of telling, hiding, teaching, networking, negotiating" to manage the intimate private oppressions being experienced deep in the heart (Church *et al.*, (2007: p. 10).

Selecting romantic partners for reproduction is culturally in a completely private sphere but with embodiment of *HbS*, medicalization of the body in terms of genetic assessment, counsel and sometimes scrutiny by other social factors such as medical officers, family or churches create a sense of loss of autonomy, control and sometimes choice for the individual. This process of *indignity* can disable an affected person. *Disablism* involves inflicting restrictions on one's autonomy and choice and "psycho-emotional well-being"

(Thomas, 1991, p. 26–27). Societal structures and actors literally force “exclusion, discrimination, and marginalization resulting from inaccessible community spaces, thereby threatening external dignity by creating a diminished state of being human” (Johnston *et al.*, 2015: p.109).

Selecting a partner without the genetic disorder from among a society with often partial or inaccurate genetic information, can be a rich site for *psycho-emotional disablism*. Liddiard (2014), stated that these affected individuals perform emotional work in their intimate sexual lives to manage ‘competing intimate oppressions’ thrust by their partners. Reeve (2004) had argued that the oppression which produces this emotional torture “operate at both public and personal levels, affecting what people can do, as well as what they can be” (p. 84). In these cases, the individual develops tainted self-esteem and lowered confidence; personal dreams and life goals are lowered to accommodate the societal prejudices and emotional abuse.

For instance, French and Swain (2001) argued, “psycho-emotional dimensions of disability are particularly relevant to a discussion of the relationships between professionals and disabled people, a key factor of which is the inherently unequal balance of power” (French & Swain, 2001. In Reeve 2007). The *Ableist* society seem to interact with the target individuals at the level of *unequal balance of power* at all facets of life, even when trying to engage in a romantic relationship with a person who is unaffected, or while negotiating with a clinician a reproductive desire. Thus, the emotional work to be performed by the person who is affected in such instances is phenomenal.

2.10 Conclusion

SCD, being a genetic disease is a chronic condition that is experienced throughout life. Its insidious and debilitating nature disrupts all of life’s activities including the selection of a long-term partner and making reproductive decisions.

Embodying the SCD gene in the UK, where predictive genetic testing is implemented and affected persons are encouraged to make responsible life choices to mitigate effects of their embodied risk, there is an incidental implication which makes the at-risk individual to be *marked* by society as unfit for long-term relationship and parenting.

The lay social construction of SCD developed from the drive by the Department of health to ensure the condition is not transferred to future generations, creates tensions for the affected persons as they navigate these important areas of life. The genetic monitoring and

surveillance by the clinicians extended to those social areas of life further place emotional tension on the affected individual.

Social Model of Disability (SMD) (with the extended form, Social Model of Relational Disability) and Embodied Risk are therefore appropriate theoretical frameworks to adequately study the impact of SCD on the selection of romantic partners and the making of reproductive choices of adults living with SCD in the UK.

Up till date, there has not been a study about the nature of the impact of SCD on these dimensions of life in face of disabling effects of SCD and its social consequences.

The medical diagnosis assigns them with an abnormal label causing them to be at a disadvantage when it comes to a general profile of life chances which can include income, education, psychological well-being, housing status, and even choice of romantic partner with whom to parent children (Link & Phelan, 2001). The stigmatized individuals often internalize this notion causing oppressions and a dent to their identity (Link & Phelan, 2001). With lowering of confidence, lowered value in eyes of society, selecting partners and making reproductive choices can be complicated and difficult.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

The purpose of this research is to explore how SCD impacts on the partner selection and the reproductive decision making of adults living with SCD in the UK. The thesis will also focus on genetic status disclosure, how much of genetic knowledge inform their relationship choices and the moral responsibility of the participants as they negotiate with social actors in these domains of life. Their lived experiences, normative meanings ascribed to SCD as they interact with various identities in society and how they engage their challenges within the assumed '*ordinary*' human activities of selecting partners and making parenting choices within normal culture will be explored.

This area of study relating to SCD is relatively new because the current treatment strategy and ground-breaking medical therapy has elongated the lifespan of the affected people, making domains of selecting romantic partners and parenting of adults living with SCD prominent for study.

This chapter describes the research methodology, the sampling, research questions, data collection strategies, and adopted data analysis methods.

3.2 Adopting Qualitative Approach

With the presentation of the literature review and applicable theories, it was important to adopt the most appropriate methodology and design that will enable a comprehensive exploration of the impact of SCD on romantic partner selection of adults with the disorder living in the UK as well as its impact on their reproductive decision-making.

It was important that the personal experiences of the target population as they seek to situate themselves in society while selecting romantic partners and making reproductive choices within the dominant cultural structure be well captured.

Guba (1981) suggested that in choosing a suitable research methodology, "it is proper to select that paradigm whose assumptions are best met by phenomenon being investigated" (p. 76). Choice of a research approach will depend on the goal of the research. King & Horrocks (2010) posits that "our understandings and experiences are relative to our specific cultural and social frames of reference, being open to a range of interpretations" (King and Horrocks, 2010, p. 9). Appropriate study design will reduce the possibilities of drawing incorrect conclusions from the data collated (Creswell, 2009).

One of the goals of this study is to give the adults living with SCD in the UK a voice, allowing them to give accounts of their lived experience with SCD on their terms, in their own way as they select romantic partners and make reproductive choices.

Previous studies related to this study topic were conducted in the USA and Africa using African American and African participants (Bediako & Haywood, 2009; Hill, 1994; Ross, 2015). Studies that used British participants living in the UK addressed some other aspects of the social lives of the affected people such as jobs, schooling and healthcare (Caird *et al.*, 2010; Annie, 2005; Ahmed, Atkin, Hewison & Green, 2006; Dyson, 1997). Therefore, this study conducted in the UK using participants living in the UK is an attempt to unearth some social phenomenon experienced by adults with SCD living in the UK, and the researcher hopes the understanding of such phenomenon can effectively elicit a change in the way SCD is perceived in the society.

Anionwu & Atkin (2001) had suggested that SCD being mostly among the ethnic minorities in the UK had not received equitable public funding in terms of research or management and has been largely invisible to the policy makers when it comes to allocation of resources (Anionwu and Atkins, 2001). They alleged that "haemoglobinopathies would have higher priority if they were not seen as 'black' conditions"; as they argue for health policy equality for all chronic conditions (Anionwu and Atkin 2001). Ahmad & Atkin (1996) and Dyson *et al.* (2007) also suggested that people with SCD face discrimination and disablement at some social services nexus. Hence contemporary research into these areas of study being addressed has been very limited

SCD is a genetic disorder that is debilitating and life-threatening. SCD comprises of a group of autosomal recessive inherited blood disorders, called hemoglobinopathies. There are four major disorders of which the most severe is HbSS (Brawley *et al.* 2008). Though the major manifestation is pain which can be anywhere in the body, it is known that there are individual idiosyncrasies about how the illness is experienced. While some individuals can have very severe and disabling disease, some others seem to be able to live fairly better than others

(Ross, 2013). The clinical sequelae is insidious and unpredictable (Ross, 2015). Qualitative methodology, rather than numerical-based quantitative approach, permits an exploration of “deep level of knowledge and understanding” of a complicated and new phenomenon among a “erstwhile” hidden minority population (Johnson, 2002, p. 106). Exploratory studies such as this requires a method that can focus on experiences and meanings allocated to them as central since the phenomenon being researched is relatively new and under-researched. Quantitative survey-based approach will not be appropriate because of its inflexible pre-determined, closed answers system. Being a relatively new social inquiry, people who experience it are better placed to give an account or explanation of how the phenomenon is experienced. Personal stories are the “‘inside perspective’ or describe experiences through the eyes of the experienced, and they bring with them the richness of personal and social history” (Kvigne *et al.*, 2014: p.200). Thomas (1999) also posits that “experiential accounts can act as windows on the social” (Thomas, 1999: p. 75).

Creswell, (1994 & 2003) described qualitative research approach as the natural lived setting which allows the researcher to become immersed in the world of the participants in an exploratory manner, while the stories of the participants, enable deeper understanding of meanings and perspectives the participants made about the phenomenon and make sense of their experiences (Creswell, 1994: p. 1-2; Maxwell, 2005; Denzin & Lincoln, 2011). As mentioned above, this aspect of the lives of adults in UK living with SCD is a rather new phenomenon and under-researched, so qualitative approach will best be suited to explore such socio-cultural issue. Researchers agree that study of such complex human behaviour and interactions is best researched through qualitative approach which unearths hidden thoughts of the heart of an individual (Denzin & Lincoln, 2003 & 2005), the *how* and *why* they made certain decisions and choices.

Thus, I decided to utilize a qualitative research approach, employing the narratives of the people affected to gain an in-depth understanding of how embodying SCD impact the lives of these individuals as they interact with dominant socio-cultural beliefs to select a romantic partner and make reproductive decisions.

3.3 Adopting Phenomenological Design

Drawing from the works of Merleau-Ponty who constructed the body as the experienter, the “medium whereby our world comes into being” (Leder, 1990, p. 5), many in academia have adopted the phenomenological strategy to study embodied experiences of chronic illness. “The body and experiences of embodiment are layered, nuanced, complex, and

multifaceted – at the level of human subjective experience, interaction, social organization, institutional arrangements, cultural processes, society, and history” (Waskul & Vannini, 2006).

Making sense of the life experiences of an individual about an embodiment in interaction with cultural environment requires a phenomenological approach in which the everyday life experiences of the embodied individual is studied (Langdrige, 2017; Ross, 2015). The biomedical approach would normally present the meaning of the phenomenon from the researcher’s perspectives without reference to the opinion or understanding of the population being studied. This becomes particularly problematic especially when an aspect of personal identity informs the phenomenon (Heidegger, 1926, 1962). For two decades, feminism scholars emphasised the need for participatory research which strongly endorses that people who are being studied should be part and parcel of the research so that the analysis will be a true reflection of the perspectives of the study population. This notion emanated from people with disability. They argued that only disabled people can adequately and legitimately represent the interests of disabled people (Linton, 1998). The political slogan “nothing about us without us” emphasises that no policy should be created without the full and direct participation of those it affects (Charlton, 2010; Barton, 1998; Kitchen, 2000). Thus, it is expedient to prioritize the narratives of the study population as part of the research data.

Phenomenology was developed by the German mathematician, Edmund Husserl last century. He philosophized that objects in the external world do not exist independently, and so information that individuals present about how things appear to their consciousness can be reliable; (Groenewald, 2004). This approach deals with the ‘reality’ of how the individual sees and understands the lived experiences. This is not measurable in a laboratory because it has to do with abstract dimensions of perception and experience. Van Manen (1990) described phenomenology as being used to “reduce individual experiences with a phenomenon to a description of the universal essence” (van Manen, 1990, p. 177). Moustakas (1994) suggested that the stories of the target population produce the general meanings from which the essence or structure of the experience itself is extracted. The phenomenological notion of the lived body is useful for highlighting how “disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help constitute its meaning” (Hughes and Paterson, 1997, p. 335).

Phenomenology strategy, as an inductive method, provides a rich description of experience just as it is, not based on history, culture, theories or biases/preconceived ideas of researcher, but on the meanings the participants construct of their own lived experiences (Moustakas, 1994; Creswell, 2003, 2009; Omery, 1983). It describes the phenomenon and draws conclusions rather than explaining and re-constructing meanings which might not be the meanings the participants ascribe to their experiences. Some critics have argued that certain study populations may be too emotional for their narratives be credible as research data. They subscribed to the ancient methods of 'sharpening up' the account of participants to be fit or presentable as research material. Previously, academic researchers considered *emotion* as inferior to *reason* because being 'emotional' is thought to mean being irrational (Thomas, 2005). More recently, within phenomenology, the various types of emotions are viewed as different ways of being-in-the-world and experiencing the social dimensions of living. (Fischer et al., 1989). I contend that the nature of the 'emotion' leads to a deeper understanding of the event that caused the emotion.

The overarching aim of this thesis is to understand how SCD impacts on the selection of romantic partners and reproductive decisions-making of adults living with the disorder in the UK. Exploring the subjective experiences of these individuals, "thick descriptions" need to be generated (Waskul & Vannini, 2016). The various behaviours and decisions of the participants, the factors that motivate or influence their choices and behaviours, the varied nature of their social encounters with mainstream societies and how they navigated the encounters for sake of self-preservation demonstrate that there exist many and varied objective realities of lived experiences. The aim was to employ interpretive methods to understand the '*how*' and '*why*' of these numerous subjective realities of the participants and the dominant culture (Campbell and Wasco, 2000).

This form of research is popular among social and health scientists who argue that an organization like a family will interpret their own reality according to how they perceive them and give meaning to their experiences, notwithstanding how those realities are perceived by an 'outsider' (Dahl & Boss, 2005; Hess and Handel, 1959) Studies about lived experiences of persons living with chronic diseases, such as SCD, are best approached using comprehensive descriptive methods to gain deep understanding of the complex psycho-sociological factors influencing their choices along their life-path including, intimate relationships, career, where to stay etc. The hidden feelings, emotions, behaviours, and opinions of participants are brought to the fore and properly made visible during the interviews.

The participants are the '*experiencer*' of the phenomenon and so are the '*experts*' of their lived experiences. The interpretations and meanings given to their experiences are taken as valid (Creswell 2003). Waskul & Vannini (2016) argued that the narratives in a study such as this becomes an environment for "socio-political emancipation of those whose *abnormal* bodies have been silenced by the embodiment of their impairment" (Waskul & Vannini, 2016: p 13). The narratives, thus, serves to empower the participants, as they speak out, accept self as is and also give recognition to others as they are. The '*speaking out*' acts as resistance to the erstwhile unchallengeable dominant/cultural understanding of disability and thus, a strategy of social change (Reeve, 2002; Denzin, 1987; Irvine, 1999; Frank, 1998).

According to Yee (2013), phenomenological lens "allowed for the possibility of capturing the complex range of lived experiences in the disability experience, including the conundrum of impairment" (p.43). Participants' lives' experiences are expressed as is, as they describe them in their own words, "thick, rich descriptions" which reveal meaning they give to their life worlds experiences and how their lives have been impacted by the phenomenon being studied (Creswell, 2009; Patton, 2002; Waskul & Vannini, 2016: p. 8).

Since the purpose of this study is to explore how SCD impacts romantic partner selection and reproductive decision-making of adults with the disorder living in the UK, the researcher gained an access into the understandings of very personal and intimate experiences of each participant from their "personal point of view" (Leedy & Ormrod, 2001: p. 157). Such study approach will unearth the nature of the impact of SCD on the dimensions of life under study, the dependability of the meanings given to the phenomenon, and discover if diversity of cultures, religion, education and other social backgrounds influence the impact.

The philosophical premise of phenomenology that acknowledges the existence of reality is not quantifiable, but entirely based on the perception of the target people, guided this research to adopt phenomenology design. This is to make sense of the lived experiences of these individuals with SCD, and also explore how the dominant/culture understanding of SCD impacts the target population during partner selection and reproduction choice-making. The In-depth interaction between the participants and researcher gave an opportunity for the participant to create meaning of the lived experience through semantic narratives (Seidman, 2006, p. 7, 14).

Most older studies about the social lives of adults with SCD living in the UK had focused only on the biomedical perception, neglecting the social lives of the individuals. Drawing from the feminist approach, this study presents these adults embodying SCD as being the

'experts' in unveiling the phenomenon under study; their narratives being central to the analysis (Dei and Johal 2005). They are *co-researchers* with the principal researcher, on an equal level of importance in the study.

I adopted this method of inquiry as I seek to understand the ways in which these adults with SCD in the UK experience their world, how they perceive the intrusion of their environment into their personal spaces by dominant socio-medical structures as they tried to select romantic partners and make reproductive decisions and what methods they employed to mitigate the assumed tight location.

3.4 Data Collection Instrument

Interviews remain the most significant technique of data collection in qualitative research when study is about a "human experience, talk, interaction because qualitative interview is capable of grasping these features" (Leavy, 2014: p. 178; Rubin & Rubin, 2006). The interactive dialogue between the participants and the researcher exposes the essence of the phenomenon; the former hidden experiences and embodied meanings are brought to the fore. Leavy (2014) suggested that dialogue during an interview is a rich and indispensable source of knowledge about personal and social aspects of our lives.

There are three broad kinds of the interview methods used for research in socio-medical sciences, namely, structured, unstructured and semi-structured,

Structured Interviews: The questions and answers are pre-determined and fixed. All participants are asked same questions and in same sequence with brief answers, (mostly Yes or No), or ticking answers from a list. It does not allow for in-depth understanding that is required in this study. The difference between this form of interviewing and survey methods is that Structured interviews are orally conducted while surveys are written while answering a Questionnaire. Analysis of the data is done through quantitative methods.

Unstructured Interviews: These interviews, developed by ethnographic researchers, are informal, free-flowing interviews with minimal interruption from the researcher (DiCicco-Bloom & Crabtree, 2006). The topic questions, which serves to introduce the topic to the participants before they take over the lead of discussion, are normally limited to one or two at the most. They are encouraged to freely express their feelings, thoughts and views in an order, pace and way in which they want to. So, the '*what*', '*how*', and '*when*' questions are not known by the researcher at the beginning of the discussion but formulated later during the interactions, based on the information provided by the participant in the conversation.

The *probing* is spontaneous in nature and are meant for clarification only. Unstructured interviews are generally useful in ethnographic studies, where the researcher conducts long-term field work, studying the culture of a population of people by engaging with them, by participation, observing, interviewing and interacting over a period of time. The participant is normally selected from the group according to observed ability and position in the group for the unstructured interviews. The researcher would normally develop interview tool from observed behaviours, interactions, and other aspects of culture. The assumption is that the researcher is ignorant about the study areas, is only a learning listener, exploring the inner life world of the study population. The other assumption made is that the unstructured interview is given enough length of time to enable the researcher to glean deeper into the phenomenon being studied in more detail (Alvesson and Deetz, 2000). Questions are open-ended such as, "I'd like to hear your views on..." Or "What in your opinion does this mean?" Unstructured interviews are generally more in-depth and exploratory than semi-structured interviews and so data is considered more valid.

Semi-structured Interviews: I identified the Semi-structured interviews with open-ended questions as the most appropriate for this study. This approach allows for link to be made between the participants' narratives and their lived experiences within the dominant bio-cultural structures that shape these narratives. The reason for this is because the researcher is able to cover the main study questions in an ordinary way, with little or no boundaries, while allowing the participants to express themselves freely. Rubin & Rubin (2012) stated that "main questions assure that you cover each part of your research question and provide an overall structure to the interview, follow-up questions get depth and detailed on events or steps in a process, as well as the meaning of concepts, and themes, whereas probes encourage the interviewee to keep talking and stay on topic, ask for clarification, or ask for evidence and examples" (Rubin & Rubin, 2012: p. 119). Flexibility, freedom of conversation, good rapport between interviewer and interviewee and feeling of partnership in the study should result in an accurate, more in-depth understanding into the phenomenon, void of biases from the researcher (Chwalisz, *et al.*, 2008; Elliot & Timulak, 2005; Miles & Hubermann, 1994; Smith, 1995).

Semi-structured interviews are mid-way between structured and unstructured interviews. They are also in-depth interviews but with pre-determined, open-ended questions developed from the research questions. These provide useful and relevant information from a focused yet conversational two-way communication with the participants. The intent is to avoid a yes/no or rehearsed answers like in quantitative methods. This form of interview is

widely employed by healthcare professionals in research because they are easier to use, somewhat structured, but allowing more flexibility as well as thematic analysis (DiCicco-Bloom & Crabtree, 2006). The interviews are normally conducted once (unless the researcher is asking a specific question) and last usually for about 30 minutes to one hour. The pre-set questions in the interview tool help optimize interview time, ensure systematic and comprehensive interviewing of all participants as well as ensuring that the interview does not derail from the desired goal (Creswell, 2013). Normally a pilot interview is conducted to fine-tune the interview questions for purpose of ensuring the desired goal is well covered.

I adopted the semi-structured interviews for this study since the period of study is very limited quite unlike in the ethnographic study. Moreover, each of the 23 participants are interviewed individually for a period of not exceeding an hour and a half for each participant. The purpose of this research is to explore how SCD impact on romantic partner selection and reproductive decision making of adults living with SCD in the UK. The main study questions are:

- 1) In what way is SCD status a consideration in selecting a romantic partner for a long-term relationship?
- 2) To what extent does genetic status impact and feature in participants' account of reproductive decision making?
- 3) How do people living with SCD view the cultural understanding of their condition particularly as it relates to selection of romantic partner and reproductive decision making? Is their perspective in congruence with the perspectives of the society?

I developed some interview questions using the study objectives and the literature review to serve as a reference or guide. The questions were semi-structured, open-ended with allowances for probes to encourage the participants to share details regarding their experiences freely. Each question is framed based on a topic already identified from the research questions informally but in a methodical manner. Each participant is asked same questions, although probes may be different depending on the way the conversation goes. However, the questions are asked with a lot of flexibility during the interview, in order to carry the participant along as a partner in the study and allow freedom in the conversation (Liamputtong, 2009; Patton, 2002). The questions are clear, non-ambiguous and easy to understand. According to Kvale (1996) it "is literally an inter-view, an interchange of views

between two persons conversing about a theme of mutual interest,” while the researcher gains and “understands the world from the subjects' point of view, to unfold meaning of peoples' experiences” (Kvale, 1996: p. 1-2).

3.4.2 Pilot Study

Pilot Study to test the Interview questions

I conducted a pilot interview to enable me to test my interview questions, revise them and update them accordingly.

Interview Tool (Appendix 5)

1. *How did you come to know about your SCD condition?*
2. *In what way has SCD affected your overall health? In what ways has SCD affected you – what's it like to live with SCD?*
3. *Do you have support from friends or family? When you have crises? With your children?*
4. *How has the support you received assisted in aiding you back to health?*
5. *How does SCD affect the way in which you select/ maintain relationships (that is friendships)? Explain further? Has SCD affected the way you form friendships and who you are friends with?*
6. *Are you in a relationship at the moment?*
7. *Does your partner/girlfriend/boyfriend have SCD?*
8. *When did you first talk about SCD with your partner and at what point in the relationship did they become aware of your condition?*
9. *When did you become aware of their status?*
10. *Has SCD been an issue in your relationship? In what ways?*
11. *How did/does SCD affect the way in which you develop and/or maintain romantic relationships? (a life partner/ significant other). Explain further? Do you consider your partner's (future partner) genotype before entering or during the course of a relationship with them? Explain further?*
12. *Do you want to have children?*
13. *Are there any particular reasons why you are thinking about having children or not having children?*
14. *What issues might you face and how do you plan to manage them?*
15. *Before you have/had your child, did you know there could be a possibility they could be born with SCD? How did that make you feel (What did you think about that)?*

3.5 Sampling

To gain an understanding of how SCD impact romantic partner selection and reproductive decision making in adults living with SCD in the UK, I recruited 23 participants because analysing a larger sample can be time consuming and impracticable for the period allocated

for my research. Creswell (1998, p.64) and Morse (1994, p.225) recommended no more than 5 to 25 participants for qualitative research of this nature since the goal of this research is “*in-depth understanding*” and not to quantify or generate any statistical report.

For accuracy of data, target population was designed to be as diverse as possible, so no consideration was given to the social status, gender or culture of the participants. The inclusion criterion was only that participant must be an adult, resident in the UK, diagnosed as having SCD (*HbSS*).

In qualitative research, three main sampling methods are used to recruit participants:

Purposive Sampling is the most common sampling strategy where participants who researcher know will give rich information for the study are invited to participate in the study (Patton, 2002; Merriam, 1998).

Snowball Sampling, also known as chain referral sampling. In this method, the participants refer the researcher to others who may be able to potentially contribute or participate in the study.

Quota Sampling certain criteria such as age, sex, class, marital status is pre-set before recruiting participants.

When I test ran the questionnaire which I developed, I noticed that quite a number of people living with SCD in Sheffield area have participated in many study interviews and so not easily accessible; some were reluctant to avail themselves due to “interview-fatigue”. So, I found *Purposeful sampling* most useful for recruiting participants such as this.

From my involvement in some sickle cell social network support groups in the UK, I was also able to recruit participants using snowballing strategy which involves asking members of the support groups to refer potential participants for my follow up. This method worked well for me. This strategy is mostly used to locate samples in hidden populations who are not easily accessible through other sampling methods (Creswell, 2009; Marshall, 1996).

3.6 Ethics

Ethical issues are considered very important for any study of this nature because research data are sensitive information about the private and personal lives of the target population. Bury (1982) described the experience of living with the illness as ‘*biographical disruption*’ of their lives while Charmaz (1983) called it ‘*loss of self*’. For this reason, ethical considerations are put in place right from the beginning of the study, through the conduct of the study, the analysis of results and the final dissemination of the Research Report (Creswell 2013).

Basically, ethics of research involving human participants are based on four principles namely, respect for autonomy, beneficence, justice and non-maleficence. These principles ensure the minimizing of risk of harm done to participants, protecting their rights and dignity, maintaining their privacy/confidentiality, treating them with respect and avoiding deceptive practices, being transparent with them, and also providing their rights to withdraw from the study at any time. For all these, a participant is asked to sign the consent form for assurance that participation is voluntary (Beauchamp & Childress, 2001; Duncan *et al.*, 2009).

I applied and received an ethical approval for my research from the Department of Sociological Studies Ethics Review Panel in University of Sheffield in 2017 (Appendix 6). I developed a general letter titled *Participant Information Sheet* (Appendix 2) which is to introduce myself and explain in brief the aim of the study and what I expect it to achieve. This letter details the possible risks, rights, and confidentiality of the information given by the participant which will be through an interview with the researcher. They are required to sign *the Informed consent form* (Appendix 3) to confirm their agreement to participate voluntarily as a participant. This is given to every potential participant to read and confirm if they wish to participate. They are also availed of the confidentiality guidelines and my contact details. For some interviews that may be conducted via telephone (their preferences), the documents will be sent to the participants by mail. As detailed in the *Participant Information Sheet* (Appendix 2), each potential participant will be assured of the plan to ensure their confidentiality is respected. All the recorded interviews and related documents will be kept under lock-and-key and only pseudonyms will be used in place of their real names to ensure anonymity.

Despite taking appropriate measures to ensure the anonymity of my participants, I did struggle with upholding the research ethics. People living with SCD in the UK have formed a somewhat close community. Since I recruited my participants from key charities, I found that the participants not only knew themselves, but were familiar with each other's experiences. I often had participants either suggesting I recruit a specific participant, or on the occasion they were aware I had completed an interview, would request that I share the experiences of a specific participant. As I was acutely aware that this was a topic that had been discussed amongst themselves, I had to draw the line and inform the participants that I would be unable to divulge such information. In addition to this, ensuring my participants' anonymity and confidentiality proved to be a challenge because I was welcomed readily into the community for the research because of 'being one of them.' However, I found that

separating myself, the person also living with SCD from the researcher, I was able to explain the expectations of the research and the importance of ensuring that all participant's identity is kept in the strictest confidence.

3.7 Recruitment Process

I started the recruitment of participants mainly from non-NHS sickle cell organizations in 2017. I wrote letters to some non-NHS (NGO) sickle cell support organizations (Appendix 1) which agreed for me to approach their members to be part of my study. This is *Snowballing sampling*. These organizations provide support services to affected persons and families by promoting their wellbeing. They act as a link between people with SCD and the communities. They advocate for and promote research and educate the public about blood disorders.

- a. The first one is OSCAR Sandwell located in West Bromwich. It is a registered charity that was established in 1988.
- b. ASYABI (Association of Sickle Cell Suffers of Yorkshire and Africa and Basic Information) is based in Leeds.
- c. Sickle Cell Cause in London
- d. Sickle Cell Society is based in London.

I also recruited some participants by *Purposive Sampling* with some participants referring other potential participants, mostly from London.

From August 2017 when I started recruitment, three people signed up but very quickly I met with a lapse of recruitment uptake. From September, many potential participants started giving excuses that the weather was getting cold and so not conducive for interviews. I got these excuses from about four people. SCD crises are very common during winter periods because of the cold; viral infections such as flu are very common during that period. Many people living with SCD therefore, try to keep themselves very warm during cold seasons and so to avail themselves for study interviews was an uphill task. I decided to involve myself in as many social support groups as possible particularly in London which has the largest number of people with SCD. I attended many programmes and got to meet some of the people and administrators of the support groups. I was allowed at the end of each meeting to present my project to the members and avail the information sheet so that anyone who is interested in participating can contact me. Among the participants recruited in London, two of them contacted me on their own while I recruited the others right after the meetings, followed them up later to confirm interest and plan for interview.



My experience with the recruitment process was very much tougher than I had envisaged. I noticed that many participants have been involved in studies previously and were *'interview-fatigued'*. "I am tired of all these sickle cell interviews, they have pressed and pressed my body, I am not submitting myself to any research again." One of the potential participants introduced by snowballing made that remark as I tried to connect with her in London. Another potential one said "I have decided I will not participate in any study again unless I am paid. Why should I be wasting my time?" Clark (2008) described this phenomenon as a common feature. This is a phenomenon when a target population being researched on is small and so most members have been approached to participate in several studies previously. Clark (2008) opined that those individuals may have been enthusiastic to participate in studies but just got fed up as there have been no apparent benefit for participating in studies. Several scholars have also acknowledged that the willingness of people to engage in research should never be taken for granted. Armitage (2008) argued that where there has been history of promises of reciprocity made to participants without following through, they could become hostile and uninterested in future calls for participation in studies.



































At the beginning of my research, the sample was to be for persons between ages 25 and 35 years. I had to apply to change this age range to just adults, to gain additional increase in recruitment uptake.


Another difficulty I encountered with recruitment was follow-up of potential participants. Quite a few times, some interviewee cancelled firm appointments because they are on admission in the hospital. Some agreed to only telephonic interviews. I had to seek approval for that as well to allow for recruitment. I was careful not to *beg* them as this will defeat the voluntary consent in the ethical consideration. It took eleven months to complete the recruitment and interviews of participants for the study.





The table below shows the list of participants with their demographic information (Appendix 4), method of recruitment, and other details.

TABLE 3.1: List of all participants with details

ID	PSEUDONYMS	GENDER	AGE	MARITAL STAUS	CHILDREN	EDUCATIONAL LEVEL	INTERVIEW
1	Aaron		40	Married	◆	Masters	

2	Abigail		33	Single	◆	Bachelors	
3	Amos		38	Single	◆	Masters	
4	Caleb		36	Married	✱	Masters	
5	Damaris		33	Single	✱	Bachelors	
6	David		36	Single	◆	Masters	
7	Deborah		42	Divorced	◆	Masters	
8	Dorcas		51	Single	✱	No degree	
9	Eve		56	Single	◆ ◆ ◆	No degree	
10	Ezekiel		34	Single	◆ ◆	Masters	
11	Hannah		34	Single	◆ ◆	Bachelors	
12	Hosea		37	Single		Masters	
13	Jonathan		44	Married	◆ ◆ ◆ ◆ ◆	Bachelors	
14	Karina		35	Single	✱	Bachelors	
15	Lawrence		52	Single	◆	Not disclosed	
16	Mary		35	Married	◆	Masters	
17	Micah		34	Has a partner	◆ ◆	Masters	
18	Michael		39	Single			

19	Nathaniel		43	Single	◆◆	Bachelors	
20	Ruth		27	Married	*	Masters	
21	Solomon		43	Married	◆	Masters	
22	Theresa		32	Single	◆	Bachelors	
23	Ziporrah		54	Single	◆◆◆	No degree	

KEY:	
• Male	
• Female	
• Child	◆
• No Child	*
• Face- to Face	
• Telephone	

3.7.1 Interview Process

As mentioned earlier, I adopted both face-to-face and telephonic methods for the interview to facilitate accessibility, depending on the preferences of the participants. It was important that the participants felt they had control over their own narratives. Most of the face-to-face interviews took place in London so I had to travel several times to collect the data, which was very expensive, being a private student without any funding. I collected data from October 2017 to September 2018, a period of eleven months in all. All the time, I ensured

that I got a confirmation of appointment before traveling. The interviews lasted between thirty-five minutes and one-and half hours each in the location of preference by participant. Most participants wanted the interview in their homes, but some asked to have it conducted in restaurants or coffee shop because they want to talk freely as their spouses or partners are home. I had to go alone to places where those interviews took place. To ensure my safety, I would always inform a family member by phone where I am, before starting the interview and also when I was done.

There was an instance when two potential participants wanted me to conduct interviews right away after support group meeting but practicality of conducting two interviews in a day which would have been cost-effective was not feasible. I lost one of them as she claimed to be too busy to reschedule another meeting time. I was very disturbed by one potential participant who gave me an appointment for an interview and warned if I do not make that appointment, she may not be able to reschedule. I travelled to London because of her and also thought I may be able to follow up on some referrals. By the time I got to London, her phone was offline. Up till date, I have not been able to speak to her.

Bentz and Shapiro (1998) argued that for phenomenology, “the intent is to understand the phenomena in their own terms – to provide a description of human experience as it is experienced by the person herself” (Bentz & Shapiro, 1998: p. 96). Bailey (1996) posits that the “informal interview is a conscious attempt by the researcher to find out more information about the setting of the person” (Bailey, 1996: p. 72). With each participant before interview began, I reassured them that their identities and information will be protected.

While telephoning is not desired due to the need to observe the body language, when the participant disagreed with face-to-face interview, but agrees to utilize Skype or telephone, I consented. However, I noticed some differences with the telephone interviews. The conversations with telephone interviews were snappy and short although I utilized probes to stimulate the participant to give more details. I had more rapport and connection with participants I interviewed face to face. How significant this is to the information remains unclear to me. However, telephoning has been used in literature to capture rich, important and good data where participant`s geographical location is distant or participants for reason of social status, privacy, personal traits of shyness has turned down face-to-face interviews (Carr & Worth, 2001; Kavanaugh & Ayres, 1998).

I used active listening techniques to assure the participants of my full attention. This includes making eye-contact, nodding and smiling when necessary and for my posture, I maintained a slightly ‘lean forward’ posture in my chair to send a message of my total attention. I

deliberately turned off my phone to avoid distraction, and at appropriate times, used encouraging expressions like *'Uh huh'*, *'yeah'* and *'oh I see'* to assure the participants of my rapt attention. Where I was not clear about some statements, I made them repeat what they said by saying, *'so what you're saying is...'*. I made sure I never interrupted the participants during a conversation or complete their sentences for them so as not to introduce my own idea. This is to ensure quality of the data. I kept at the back of my mind throughout the interviews that it is not a debate, I am to listen and aim for a "deeper understanding that deconstructs and challenges the surface account" (Bazeley, 2013, p. 203), not to educate, judge, correct or advise the participants. I made notes during the interview of any observed body language as they describe their experiences.

During the interviews, I recorded the sessions with a voice recorder with the permission of the participants after assuring them of their privacy and anonymity. I noticed that not even one of the participants was bothered about the recording of the interview. A few even said *'how else will you save and work if information is not recorded.'* In one or two sessions, I took personal notes at the end of the interview while we were having tea. I was as flexible and unhurried as possible during the interview to ensure the participants are comfortable and interested enough to share the deep thoughts of their heart.

I had a few distractions during some of the interviews. For the interviews in the homes, there were no distractions because participants ensured this before starting the interviews. But for those in the coffee shops, noise and crowding were quite distracting and these eventually affected ease of transcribing. In one or two cases, the participants became emotional, breaking down in tears. Being a professional social worker helped me calm them down before completing the interview.

For participant motivations, I noticed that female participants were more interested in the study and more willing to bare their hearts in a deeper way. I also noticed that many of the participants were glad that I, the researcher, have SCD as well. That seem to readily motivate the interviewee to recount their experiences because they saw me as an "insider". They felt I understood what they were saying, and usually I did. Being also a black, belonging to their ethnic population could have been a motivating factor for them to be open as well.

I can also see that for this type of research to be conducted, maybe the researcher should be considering giving some financial token if it does not violate ethical standards. The research interview fatigue is quite phenomenal. I lost some potential participants because

of this. I note that some of these participants live in downtown low-economic areas and so may not want to participate as they do not want people coming to their houses.

Reflection and fine-tuning of Interview strategy

During the long haul of dearth of participants between September 2017 and April 2018, I was able to reflect on the data I had collected and fine-tuned my interview strategy. I believe this improved the information I gathered from the remaining participants. By the time I finished with the nineteenth participant and of course I had become more competent, I felt the information was beginning to be repetitive. This is the point Kerr, Nixon, & Wild (2010) defined as the *data saturation point*. This means no fresh knowledge is being obtained. Crabtree and DiCicco-Bloom (2006) also defines saturation as a point of “diminishing return when increasing the sample size no longer contributes to new evidence, an indication that the data collection process is complete”. For this reason, for qualitative research with phenomenology approach, Creswell (1998, p.64) suggested 5 to 25 participants as adequate; Morse (1994, p.225) suggested at least 6 participants while Guest *et al.*, (2006) suggested 6 to 12 participants. Data saturation is reached when there are no new emerging ideas in the data being collected (Bowen, 2008; O'Reilly & Parker, 2012; Walker, 2012; Fusch & Ness, 2015) and when there is enough information to replicate the study. Ritchie *et al.* (2003), suggested that since in qualitative research, the phenomenon only need to appear once among the participants' answers to be part of the analytical chart, sample size can be small.

Throughout the interview process I observed the highest ethical protocol, I adhered very closely to the approved ethical document by the research review board. I was completely transparent with the participants. Creswell (2013) argued that ethical issues can occur at any time during the life cycle of a research; at the beginning, during data collection or analysis, at the generation of the report and even after the conclusion of the research such as the storage of the raw data.

As it is in this study, personal information was being disclosed by the participants and so care was taken to ensure such sensitive information are treated with respect and confidentially. To ensure I followed this through, I explained clearly to each participant, rights of participant, the purpose and general scope of the study, confirmed that they understood very well the information in the document. Each participant was also provided with a copy of the semi-structured interview and asked to read through and make comments if they had any before the interview. This was to ensure they are comfortable with the scope of the

discussion and allow for flexibility. I also informed them that they are at liberty at any time to discontinue their participation in the study because it is entirely voluntary. It is therefore possible that a participant can regret some things that have been said particularly if s/he is a known person or someone I could easily meet again elsewhere. I therefore adopted a non-judgmental attitude and did not show surprise, revulsion or grimaces of face. I called a few days after each interview to thank them and ensure they are fine. DiCicco-Bloom & Crabtree (2006) argued that participant`s interests and respect must be safeguarded. For confidentiality, I went to great lengths to ensure information privacy and confidentiality during the duration of my study. I assigned pseudonyms to each participant for use throughout the study to ensure confidentiality. The electronic forms of transcribed interviews were stored in a password-protected folder in my computer while the actual audio instrument was locked away in a cupboard in my room.

3.7.2 Data Analysis

This study seeks to explore how SCD impact on romantic partner selection and reproductive decision-making in adults with SCD living in the UK. It focuses on how embodying SCD impacts on selection of partner, how these individuals formulate those relationships, how much of moral responsibilities they are willing to take as they make their relationship choices, how they navigate genetic disclosure before or after those relationships are formed and their lived experiences within those relationships.

According to Dahl and Boss (2005), analysing phenomenological research involves systematically describing and understanding the narratives of the participants without incorporating one`s own biases and “not to tie all loose ends together”. I employed the recommended steps of Dahl and Boss (2005) to analyse the data: (1) Ensuring the accuracy of the transcribed interview (2) bracketing the topic; (3) delimiting units into meanings; (4) clustering units of meaning into themes; (5) compiling individual textual and structural descriptions (interviews); and (6) extracting themes from descriptions and creating a composite summary of meanings and essences of the phenomenon.

This process of analysis goes through six stages:

- 1) Transcribing: I spent a considerable amount of time transcribing the recorded interviews. During this stage, I listened to the recordings to ensure accuracy and become familiar with the information before trying to develop the essence of experience being narrated without adding personal meanings and interpretations (Holloway, 1997; Creswell, 1998; Moustakas, 1994).

- 2) Bracketing the phenomenon: This step enabled me to eliminate my personal opinions or biases from the experiences of the participants. I 'bracketed off' in each of the transcribed document, statements that relate to the phenomenon being studied. Where I had doubts about any statement, I confirmed with the participant.
- 3) Delineating units of meaning: I extracted statements that inform the researched phenomenon being studied (Creswell, 1998; Holloway, 1997).
- 4) Clustering of units of meaning to form themes: I painstakingly grouped together units of meaning to form themes within the context (Creswell, 1998; Moustakas, 1994) and then identified significant topics. Holloway (1997) emphasizes the importance of the researcher repeatedly listening to recorded interview to confirm with the list of meaning to derive clusters of appropriate meaning. I converted themes into explanations of the textures of the experience while supplementing the explanations with quotes from the interview.
- 5) Extracting general and unique themes and making a composite summary: Summarizing each interview, validating it and where necessary modifying it, reviewing each statement for how accurately it describes the experience. According to Sadala and Adorno (2001) the researcher, at this point "transforms participants' everyday expressions into expressions appropriate to the scientific discourse supporting the research" (Sadala & Adorno, p.289).
- 6) Extracting themes from descriptions and creating a composite summary of meanings and essences of the phenomenon: The extracted themes are compared to the research questions to see if there is similarity. Unrelated or repetitive information are eliminated. This composite summary becomes the rich descriptions, the '*what*' and the '*how*' of the experience of the participants.

3.7.3 Research Trustworthiness

For accuracy and possibility of real-world usefulness, a study of this nature needs processes for trustworthiness (Lincoln, Lynham & Guba, 2011). Trustworthiness is associated with confidence that the study is of good quality and outcome is reliable. Paton (2002) called it *authenticity* while Creswell (2013) called it *validation*.

Four aspects of trustworthiness are confirmability, credibility, dependability, and transferability.

For validation of trustworthiness of the study, I embodied the followings into the processes of the research:

- a) Interview questions were explicit, open-ended with probes to ensure clarity as the participants narrated their experiences. I simply listened to the narratives without challenging or arguing with any participant. Sometimes I feel I misheard the answers, so I asked them to repeat what they said to ensure I completely refrained from my own opinion.
- b) I established a good rapport with each of the participants, so they do not feel they are talking to a stranger. This will make them more comfortable to reveal inner thoughts and feelings.
- c) I skilfully placed participants in position of authority as *expert* on the subject matter, and I, the researcher, a *learner*. In other words, they are the teachers of this phenomenon and so they are partners with researcher in this study of mutual interest. That position enhanced the participants to be very descriptive about their experiences and that mode became a source of collection of rich data.
- d) All interviews are audio taped, transcribed and triple verified for accuracy.
- e) All the research designs, data collection methods and report writing were detailed with thick descriptions of participants' accounts, direct quotes were extracted from the interviews to allow the emotions, thoughts and perceptions of the participants to enhance the descriptions of experiences in the study reports. The reports were also presented with clarity to readers to avoid ambiguity. This way, the study can be scalable to a wider population in event of any future study.
- f) After the first set of interviews, there was a scarcity of participants' recruitment because many potential participants complained about the weather, and said they were fed up with research interviews. I used that period to reflect on the study questions and updated the questions/probes accordingly. This improved the quality of the remaining interviews.
- g) Peer review with my supervisors and participants were used to review the quality of the study findings.
- h) The records of all aspects of study, including some notes I made during the interviews are available for auditing.

3.7.4 My Familiarity with Research Subject

Qualitative research of this nature that seeks to understand the impact of SCD on selection of romantic partner and the making of reproductive choices of a category of people in a

country requires analysis of rich, deep descriptive narratives of the private life experiences and the meanings they give to those experiences. Of the interviews in qualitative studies, Seidman (2013) argued that “Interviewers seek and are given the opportunity to enter the lives of their participants. Participants share and reflect on their experience with their interviewers. They entrust their interviews with a part of themselves. They make themselves vulnerable to their interviewers.”

My initial interest in this study is borne from my embodiment of the SCD, and my personal lived experiences of the pains and burden of SCD. Growing up in a society that has been bombarded with genetic information and has become insensitive about people living with the disorder in the community, I sought to unravel the burden of SCD as experienced by the target population. I became particularly interested in the critical social area of romantic partner selection and making of reproductive choices, a segment of living that most expose the real self and identity of an individual. The narratives collected from twenty-three individuals living with SCD in the UK, in their own words and on their own terms to expound how SCD has impacted on their efforts to select partners, and make reproductive decisions are thus presented.

I am a black woman of Nigerian origin. I found that my ethnicity, co-sharer in the condition under study, age, sexual orientation and socio-economic background influenced the bonding of *researcher/researched* relationship which in turn enriched the interview sessions. As I interacted with the participants and unravel deep feelings of ‘self’ which I share, I realized I needed to acknowledge my positionality and possible impact on the data generated as well as its analysis (Berger, 2015). Finlay (2002) argued that the researcher himself/herself is “a central figure who influences, if not actively constructs, the collection, selection and interpretation of data” (Finlay, 2002: p. 212). My familiarity with the phenomenon thus required my need for reflexivity. I was critically aware of the sensitivity and nature of the issues the participants were speaking about and knew I needed to be reflexive and ensure that the collation of study data and the ensuing analysis, produced outcome that should echo only the experiences of the participants and not my personal biases. I realized I needed to construct an enabling environment to elicit sensitive heart information the participants were about to share with me.

I revealed my genetic status to each of the participant before the interviews so creating rapport and trust with the participants as I interview them. My personal experiences enriched the understanding of the narratives of the participants. I was able to interact with them with

ease and seemingly trustful demeanour, after all I am not an *outsider*, I share the same pain and experiences.

For most of the interviews, it turned out to be like a discussion about our commonalities and that made the descriptions more credible or accurate as I am an insider and not alien to the lived experiences and the meanings ascribed to them.

In certain interactions during the interviews, I was able to echo an expressed fact which went down well with the participants and further helped the expression of deep-seated feelings. Such reflections on my experiences enabled participants draw out deep feelings about self willingly.

At the end of the interviews, I encouraged the participants to ask questions about my personal lived experiences of the disease and gladly answered the questions.

3.8 Conclusion

I have outlined, in this chapter, that I developed a research interview questionnaire from the study objectives with the literature review serving as guide as I conducted the semi-structured interviews with each of the participants. The questionnaire used in the study is presented in the Appendix. I also clarified the principles that guided the sampling, participant recruitment, interviews, and data collation. Throughout the data collection, I adhered strictly with all the ethical considerations to ensure that the participant's rights were not violated, and that the outcome of the study is not laden with my own biases and opinions but conducted to be as accurate as possible. I reported on my method of analysis of extracting common themes from the rich descriptions of the experiences of the participants and then clustering the themes to create significant meanings of the phenomenon being studied. I compared these with the research questions to confirm similarity. I consulted with many of the participants during the analysis for comments if any. The entire list of participants and their details are presented within the Chapter.

CHAPTER 4

SICKLE CELL DISEASE

4.1 Introduction

In this chapter, I will be presenting what Sickle Cell Disease (SCD) is, the clinical manifestations, the epidemiology and prevalence, the clinical and self-management protocols as well as the emerging high technological therapies. Beside this, I will also present the historical aspects of SCD, how it became politicised in the Western world as well as the struggle to make it visible to policy makers for better prospect of management. Another very important aspect that I intend to mention in this chapter is the sociological construction of SCD, how it is perceived and understood in the communities where it is prevalent, how it is constructed and assigned meaning by the medical professionals and government and the probable difference in the two understandings. I will also touch on some of the issues that may have a bearing on the topic of my study: how SCD impacts on selection of romantic partners and reproductive decision-making of adults in the UK living with the condition.

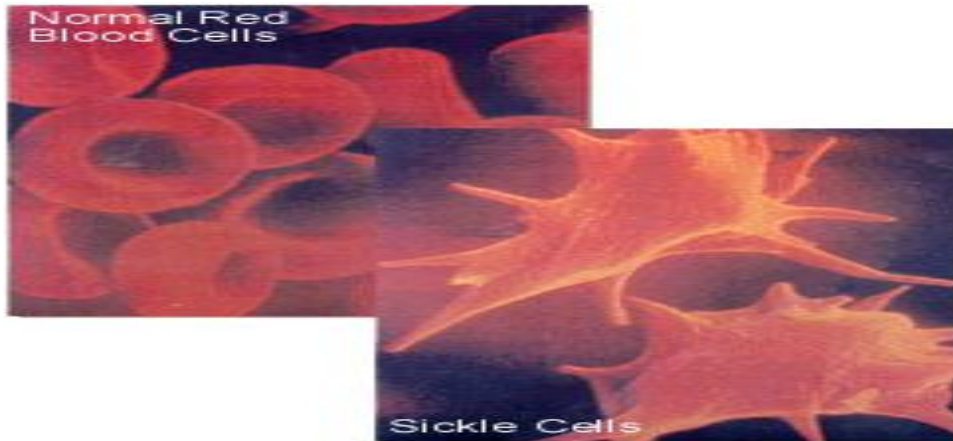
4.2 What Is Sickle Cell Disease?

SCD is a category of autosomal recessively inherited genetic blood disorders. The four major types include, SCD haemoglobin S (*Hb-SS*), sickle beta-zero thalassemia (*Hb-Sβ0*), SCD haemoglobin C (*Hb-SC*), and sickle beta-plus thalassemia (*Hb-Sβ+*). (Platt & Sacerdote 2006 In Newland & Dobson, 2006: p. 49). The most severe and common form is the *Hb-SS* (Ross, 2015; Brawley *et al.*, 2008). The disease manifests mostly but not exclusively in situations of extreme external factors such as change in weather (cold or hot), infections, dehydration or emotional stress such as extremely labour-intensive work, anger, tiredness, and sadness or grief. Red blood cells (RBCs) are normally round, pliable, soft and flexible, able to move smoothly through the narrow blood capillaries with even narrower diameter than itself, transporting oxygen throughout the body tissues and organs. They contain haemoglobin, the iron linked with protein, which transports oxygen, with the genetic

allele termed *HbA*. In SCD, when there is an increase in oxygen uptake in the body cells probably due to some stress, there is a deoxygenation of the RBCs. The abnormal haemoglobin (*HbSS*) in the RBCs gets distorted into sickle-shaped, rigid and unable to move smoothly through the narrow blood capillaries thus losing their ability to transport oxygen (Ballas, 2006; Frenette & Atweh, 2007). These deoxygenated RBCs eventually haemolyse or break down. When the rate of haemolysis become greater than the rate at which new RBCs are formed by the bone marrow, the individual develop anaemia. (Serjeant, 1997). Mason (1922) first named the condition, '*sickle cell anaemia*', a term derived from the abnormally sickle-shaped red blood cells (RBCs) found in the blood film taken from an affected person. (Mason, 1922). The small blood vessels sometimes do get blocked with the debris of the haemolysis causing some organs or tissues to become deprived of adequate oxygen. These body tissues can get inflamed and painful as the metabolic activities are interrupted. The pain and inflammation that ensue is termed 'Sickle Cell Crisis' (SCC) (Serjeant, 1997; Frenette & Atweh, 2007). Unpredictable frequent painful crisis episodes often require hospitalization to prevent extreme complications such as major organ failure (Seargent, 1997; Frenette & Atweh, 2007). Severity and length of crisis depends on the general health of the patient and the psychological and physiological state (Smith *et al.*, 2005).

Authorities in genetics believed there was a mutation in the haemoglobin gene with one of the two alleles of the gene encrypting *HbS*, to survive the malarial infestations because the sickled-cell haemoglobin is almost impenetrable by the malaria plasmodium. The *HbS* gene has an amino acid valine substituted for glutamic acid in the 6th position of the beta chain of the haemoglobin tetramer (Pack-Mabien & Haynes, 2009). The individual with one of the two alleles of the gene encrypting *HbS*, but with the other allele being *HbA*. (a combination of *HbAS*) has a sickle cell trait (SCT), which means being a carrier of the gene but not having the full-blown disease.

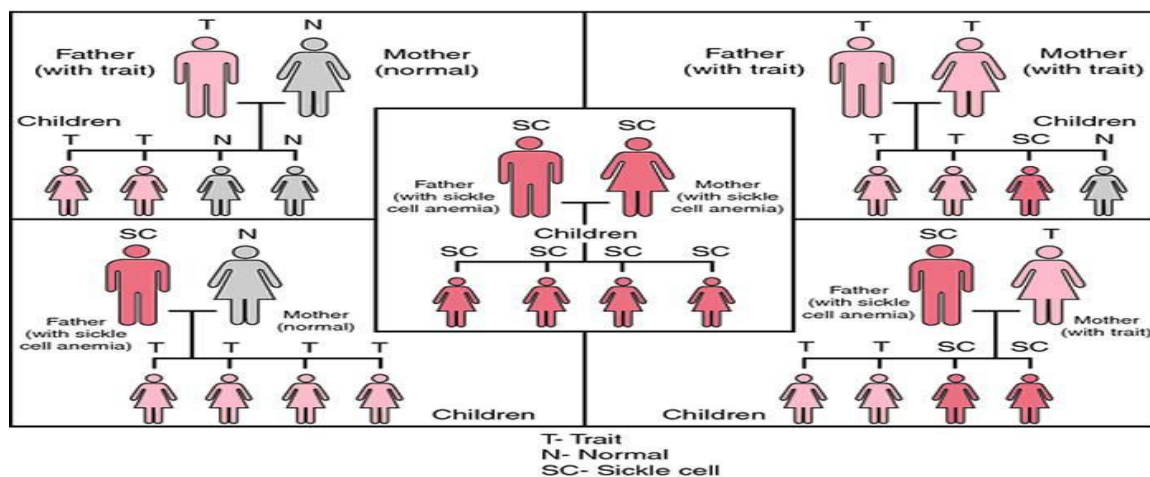
Normal RBCs (*HbAA*) have a lifespan of 100–120 days whereas the abnormal haemoglobin (*HbSS*) has a lifespan average about 16–20 days (Seargent, 1997; Frenette & Atweh, 2007). Since the bone marrow where they are produced cannot replaced them fast enough to normal level, the blood is chronically short of red blood cells, leading to a condition referred to as anaemia (Searjent, 1997).



Normal Red Blood Cells and Sickled Red Blood Cells
 (www.samc.com, 4/2/2006)

Chronic anaemia results in aplastic crisis, jaundice, possible organ failure, retarded growth and slow developmental milestones in children. SCD is inherited but not sexually linked, so male and female new-borns are affected equally (Pack-Mabien *et al.*, 2009; Seargent, 1997; Frenette & Atweh, 2007). The inheritance pattern of SCD is shown as follows (it is important to emphasise that these are statistical probability and not actual pattern):

Pictorial inheritance probability pattern



Inheritance Pictograms: Grey depicts normal Hb, shades of red to depict the genetic status of the body, compares the probability various other combinations.

Source: Miller-Keane Encyclopaedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition. © 2003 by Saunders, an imprint of Elsevier, Inc

TABLE 1: Tabular Pattern of Sickle Cell Disease Transmission

Couple Type	Parent 1	Parent 2	Offspring Probability
1	Genotype Hb-SS (SCD)	Genotype Hb-SS (SCD)	100% Hb-SS (SCD)
2	Genotype Hb-AA (normal genotype)	Genotype Hb-AA (normal genotype)	100% Hb-AA (normal genotype)
3	Genotype Hb-AA (normal genotype)	Genotype Hb-SS (SCD)	100% Hb-AS (SCT)
4	Genotype Hb-AS(SCT)	Genotype Hb-AS (SCT)	50% Hb-AS 25% Hb-AA 25% Hb-SS
5	Genotype Hb-AS(SCT)	Genotype Hb-SS (SCD)	50% Hb-AS (SCT) 50% Hb-SS (SCD)

As shown in the table above, if one parent has homozygous haemoglobin *HbSS* and partner has heterozygous *HbAS*, there is a 50% *probability* of transmitting sickle cell disease to each of their children. If one parent has the disease and the other parent has normal haemoglobin which is *HbAA* then all children will have sickle cell trait (SCT). However, if both parents are *HbSS* then it's a 100% chance of transmitting the disease to each child (Bediako & Haywood, 2009). It is extremely important to note that these are *probability* predictions and not actual. For instance, a couple with each of them having *HbAS* can have all children *HbSS* or *HbAA* or *HbAS*. It is important to note that the probability prediction of transmission is often not well grasped by lay people as they often interpret the prediction to be actual (Rowe & Wright, 2001; Etchegary, 2014).

4.3 Epidemiology

SCD is very prevalent in Sub-Saharan Africa, the Caribbean, Middle East, Mediterranean regions and Southeast Asia (Serjeant, 1997; Bloom, 1995). Epidemiologists and other scientists are agreed that the mutation of *HbS* is due to a natural body system reaction to the frequent malarial infestation of *plasmodium falciparum*. The evolution of the sickle cell is the natural survival selective factor against malaria in the regions where it is endemic (Serjeant, 1997; Luzzatto, Nwachuku-Jarrett & Reddy, 1970.) Its distribution pattern globally

is dependent on two factors; the predominant one being selection for the trait due to the advantage for survival in areas where malaria is endemic, and the second factor is linked to migration; countries where many people from countries where SCD is prevalent migrate to (Serjeant, 1997).

Globally, over 250 million people from a diverse range of racial and ethnic backgrounds suffer from SCD (Bediako & Haywood, 2009). It is estimated that 300,000 babies with SCD are born annually worldwide, of which 57% are born in Nigeria, Republic of Congo and India alone (Brousse *et al.*, 2014; Piel *et al.*, 2013). From local African histories and recorded folk tales, SCD has been a well-known disorder in West Africa which the West African natives call by all sorts of local names such as *abiku*, *emere* etc before being discovered by the Western medical people (Reid & Rodgers, 2007).

With the massive global migration of the 20th century spilling into the 21st century, countries where SCD was completely unknown have recorded increasing occurrences of SCD. There is a global concern, particularly in developed countries such as USA and European countries, that the disease incidences will continue to increase with migration and intermarriages (Ware, 2013). The World Health Organization (WHO) has acknowledged that SCD is a global health condition with a global impact (Locock & Kai, 2008; Weatherall, 2010). In 2008, the United Nations passed a resolution declaring World SCD Day to be observed on the 19th day of June to raise awareness and strategize for its eradication. Despite the prevalence of SCD and SCT globally, it is well known that it impacts mainly ethnic minority population in those countries (Anionwu & Atkin, 2001). It is only in the last twenty-five years that the attention of policy makers, as well as researchers (scientists and social scientists), have been drawn significantly into researching various aspects of this disease and its impact on the family unit (Smith *et al.*, 2006).

In the UK, it has been found majorly among diasporic minority migrants or children of migrants of Caribbean, West African, Mediterranean-Cypriots, South Asians and Chinese origin; traces have also been recently identified among white British people. It is the most common and fastest growing genetic blood disorder in the UK (birth incidence of 1:2000) and has attracted increasing attention from the Department of Health. The South - East of England (London) has the highest rate with birth incidences being 3 in 1000 babies and these present a significant health delivery challenge to the National Health Service (NHS) (Streely *et al.*, 2010; Pizzo *et al.*, 2015). The UK Sickle Cell Society claims that 12,500 people live with SCD in the UK as at year 2008, (Sickle Cell Society, 2008) and 24000 people with the trait. 14.8 per 1,000 infants are affected among the British Black African

population, 5.6 per 1,000 are affected among British Black Caribbean population and just 0.08 per 1,000 infants in British Indian populations. (Hickman, Model, & Greengross, 1999). The NHS records through the Sickle cell and Thalassaemia screening programme that 1 in 2300 new-borns in UK have SCD. The UK Census breakdown is, that SCT exist in the new-borns of about 1 in 540 white British, but 1 in 7 Black African (Streetly *et al.*, 2010).

4.4 Clinical Manifestation of SCD

SCD is a complicated illness that embroils the entire body system because of oxygen deprivation. The most common manifestation that frequently takes people who are affected to the hospital is the intermittent and unpredictable episodic crisis of severe pain.

A new-born baby's blood has its RBCs containing 80% Foetal Haemoglobin *HbF*. By six to eight months after birth, its RBCs haemoglobin gradually gets converted to its adult form. For the affected baby, SCD mostly manifests around age six to nine months when the foetal haemoglobin would have all been replaced by adult haemoglobin *HbAA* (Pack-Mabien & Haynes, 2009). Unfortunately, carriers of the trait who do not have full blown disease are often unaware of their status until their new-born get tested and diagnosed with sickle cell disease (Pack-Mabien & Haynes, 2009).

Most people with SCD first develop anaemia with or without other illnesses such as viral/bacterial infections, fever, pain not relieved by simple analgesics such as Paracetamol or Ibuprofen (Serjeant, 1997). SCD is a complex disease and can be life threatening.

SCD crisis (SCC) is a most distressing state that people living with SCD face. It occurs in any part of the body where a tissue is deoxygenated. A single SCC episode can last from a few hours to ten days (Elander *et al.*, 2003; Smith *et al.*, 2006). Onset is insidious and may be mild or severe. It is not well known why some people suffer more than others. However, it is known that triggers for crisis include untreated infections, high altitudes, malaria, viral/bacterial infections, environmental pollution, emotional stress or even academic or labour-intensive pursuit (Serjeant, 1997). SCC account for morbidity and mortality of many persons living with this condition particularly when *vaso-occlusion* occurs in vulnerable organs such as heart, brain, liver.

Other manifestations include acute chest syndrome which involves pain in chest with respiratory insufficiency which can threaten life (Ross, 2013); dysfunctional spleen, and infections such as tuberculosis (Brawley *et al.*, 2008). Due to the chronic anaemic state, crisis and episodic sicknesses, many people living with SCD can have stunted growth,

delayed sexual maturation, delayed puberty and sub-optimal cognitive. Their height, weight and body mass could be grossly reduced. (Platt 2008; Serjeant, 1997). Risk of death is highest among children under five years of age, however, with advanced technology and strategic monitoring in treatment, lifespan has increased tremendously over the past few decades (Serjeant, 1997). Socially, frequent and recurrent SCC cause a lot of absenteeism from school, workplace and even normal functioning at home (Dyson, 2007; Serjeant, 1997).

4.5 SCD Management

The mortality rate of people living with SCD has improved in the last three to four decades with improved advanced technology and medical care. Being a genetic condition, it has no cure so identifying sufferers early in life through genetic screening and giving prophylactic treatments such as antibiotics and supplements have reduced mortality appreciably (Serjeant, 1997; Steinberg, 2002). Many medical professionals have queried this because of antibiotic resistance that can develop, however, most treatment guidelines stress prompt administration of antibiotics at the slightest suspicion of infection to prevent any escalation of the infection because of compromised immunity (Serjeant, 1997).

Clinical Management: SCC pain can exhibit anywhere in the body and can be mild, moderate or severe, with description of pain being of varied experiences such as sharp, throbbing, stabbing, deep, achy, lacerating, or shooting (Ballas *et al.*, 2010). Analgesics are the mainstay pain-killers. For mild pains, non-opioid preparations are used and for the moderate to severe pains, opioids are used although they are frequently associated with substance abuse (Ballas 2006, Pack-Mabien & Haynes 2009). In the UK, specialists prescribe patients who have frequent severe pains limited quantity of the opioid, Oxycodone, to take home and use when they need them. One of the first steps taken during a crisis in an A&E is intravenous fluids for hydration. This has been found to unplug the vaso-occlusion caused by sickled cells and debris of haemolysed blood cells for optimum blood flow (Smith *et al.*, 2006). Supplementary oxygenation may be administered, if required (Smith *et al.*, 2006).

Hydroxyurea: A new medication, *hydroxyurea*, introduced in the past two decades has been described as a miracle medicine by many people. It stimulates the production of foetal haemoglobin, so raising the haemoglobin concentration in the blood and preventing anaemia. (Platt, 2008; Ware, 2010). It has been found to reduce the frequency of painful crises and reduce the need for blood transfusions in patients. This has brought a higher

quality of life to many people living with this condition because many have responded positively to therapy having milder and far fewer crisis episodes (Platt 2008; Pack-Mabien & Haynes, 2009). Unfortunately, side effects of hydroxyurea include sperm abnormalities, so it is avoided when parenting is planned. It can also cause foetal malformation (Griggs, 2007).

Other inpatient handling of extreme anaemia includes blood transfusions administered to increase the level of haemoglobin for oxygenation of the body organs and vitamin supplements with folic acid (Serjeant, 1997). This mainstay treatment quickly resolves vaso-occlusion and prevent complications of organ damage. There are upcoming high-tech therapies such as Bone marrow, stem cell transplantation and gene therapy (U.S. Department of Health and Human Services' National Institutes of Health (NIH), 2018). They are at various levels of clinical trials. Bone marrow transplant have been successfully administered to a handful of people, but the high level of adverse effects and mortality has prevented its widespread use. These advanced treatments target the genetic components of bone marrow cells which is the site for RBCs manufacture. These are currently the only probable cure for SCD. Other limitations are cost, availability of suitable donors, immunosuppression of donated substrates and non-perfection of procedures which have made these types of emerging therapies either unsuitable or too expensive for public use (Ataga, 2009; Buchanan, *et al.*, 2010). As of December 2018, Bluebird Bio, a clinical-stage biotechnology company in the USA reported promising early clinical development of LentiGlobin which is a one-time gene therapy being studied as a potential treatment to address the underlying genetic cause of SCD, to increase the production of normal haemoglobin. These and many more technologies are being reported on at professional meetings of haematologists.

Self-Management: In the UK, patients are well educated about their condition so that they can take measures to prevent precipitation of crisis. SCC is unpredictable and so self-management is the mainstay management strategy. (Platt & Sacerdote, 2006). Lifestyle habits like drinking plenty of water for hydration, getting enough oxygen, keeping warm particularly during the winter months, getting plenty of rest, refraining from over-exertion, taking prevention medications appropriately, avoiding extreme temperatures, promptly treating infections to prevent SCC, taking folic acid and other supplements daily to help the bone marrow make blood cells and replace the dead ones, taking adequate rest and sleep, living life simply and avoiding stressful situations is advised to be put in place. (Platt & Sacerdote, 2006). Serjeant, 1997 stated that learning to live with SCD, avoiding preventable

complications through health maintenance, and realistic expectations can help an individual improve their survival and quality of life. All patients are monitored routinely with laboratory tests at prescribed intervals to ensure there are no toxicity with hydroxyurea or damage to the major organs. In all other episodic cases, treatment is symptomatic.

Alternative Therapies- Other alternative therapies include supplements, herbal, hypnosis, heat packs, meditation, music, massages, acupuncture, to name a few (Ballas, 2007; Oni, 2007; Ross, 2013).

4.6 Sociology of SCD

History of SCD: The history of SCD is riddled in racial politics right from its discovery through the research and development of medical knowledge. The earliest reported description of clinical symptoms of SCD was by Dr Africanus Horton, a medical doctor in Sierra Leone of Igbo parentage, when he described the diseases, he encountered in some of his patients, “chronic rheumatism”, which certainly is SCD. (Horton, 1874: P. 282). In 1910, Dr James Herrick made the first official description in published literature of SCD, reporting the presence of “peculiar elongated and sickle-shaped red blood corpuscles” in the blood film of a Grenadian dental student in the United States by name of *Walter Clement Noel (1884-1916)*. He had a history of leg ulcers, shortness of breath and jaundice (Herrick, 2001: p.181). He displayed symptoms of what we now refer to as acute chest syndrome, a common but dangerous complication of SCD. Wailoo (2001) reported that several African American slaves were found to have the *HbS gene* and that served as confirmation of the notion that SCD was an exclusively ‘black’ disease, or an “emblematically black disease”, as described by Hall (Hall, 2003: p. 6 In Dyson, 2019). However, other ethnicities such as people from Asia, Mediterranean areas and even Europeans were also found to possess the disorder (Serjeant, 2013). Pauling and Itano, two laboratory scientists, established the fact that SCD was a molecular disease almost 50 years later, and described the structure of the *HbS* molecule, confirming the fact that it is a genetic disease (Serjeant, 2013).

Politicized SCD:

Tapper (1999) reported the tinge of racism attached to the labelling of SCD as a disease because of its being first diagnosed from a black person. James Herrick who first published the description tagged it as being exclusively in black people (Tapper, 1999). Tapper argued that similar conditions such as cystic fibrosis and haemophilia were not so labelled *disease* since they were found amongst the Whites (Tapper, 1999). Linus Pauling, an American biochemist, proposed that every young person with the abnormal sickle cell gene should

receive a *tattoo* on the forehead to prevent relationships that can lead to delivery of babies with SCD. He also proposed compulsory genetic screening of black people and disavowal of marriage in case of possibility of transmission of the *HbSS* to offspring. (Pauling, August 15, 1966). This drew a lot of criticism from the Black Civil Rights movement led by Martin Luther King Junior and Malcolm X who were protesting against systemic racism against black people. In the history of America, only slaves could ever be forced to have a bodily tattoo for public identification. They suggested that he could never have suggested that for haemophilia which was also prevalent among the whites. Tapper likened Linus Pauling's entire account to be like Adolf Hitler's 'ethnic cleansing' perception (Tapper, 1999). These early accounts started the politicizing of SCD.

Dyson (2007) reported the shock and embarrassment of some of the white population in the UK found to have the Sickle Cell trait when universal neonatal genetic screening was first commenced in early 2004. He said, "*White English*' carriers of sickle cell or beta thalassemia are reported to have reacted badly to news of their genetic status, considering themselves '*unclean*', '*tainted*', or '*contaminated*' by a condition, that for them, has strong connotations of *being black*. (Dyson In Kirkham, 2007: p. 244). Such reactions, he suggested, were drawn from the dominant cultural beliefs that SCD is a black person's condition. Tapper (1999) suggested that the stigmatization of SCD due to its racist undertone, must have contributed to the reluctance of the policy makers from recognising SCD and related conditions as an important area of public health. Its non-visibility in the national health policies meant it could not attract funding for research to promote a better understanding and to improve healthcare (Tapper, 1999). Dyson (2019) in the UK, suggested that SCD is often "rendered invisible in policy because of its problematic association with politically marginalized groups, the social study of sickle cell has been neglected" (Dyson, 2019).

Other reports in literature claim that this institutionalized systemic stigmatization towards persons with SCD cause them to develop an inferiority complex, a sense of shame and seclusion from society (Oni, 2006; Bradby, 1996). Studies confirmed that this stigma, and the ensuing racism form barriers for appropriate care for persons with SCD. Tapper, 1999 reported that the Civil Rights movement politicized SCD thus literally forcing the American government to give attention to the condition. In 1971, President Richard Nixon declared that "a second targeted disease for concentrated research should be sickle cell anaemia... It is a sad and shameful fact that the causes of this disease have been largely neglected throughout our history. We cannot rewrite this record of neglect, but we can reverse it"

(Wailoo, 2017: p. 806). In 1972, President Nixon provided funds for diagnosis, prevention through genetic counselling, and treatment of SCD and signed into law the Sickle Cell Anaemia Control Act (Tapper, 1999).

Even with this gain made by Black Americans about their health care recognition, wrong implementation strategies created further stigma towards the people affected. With President Richard Nixon's national law enactment, the New York State ordered a law that all persons that are neither Caucasian, Indian, or Asian be tested for sickle cell trait or will not be able to obtain a marriage license. SCD was thought to be exclusively among Blacks, the New York policy became a site of tension for the Blacks. With the universal screening, *HbS* gene was identified among non-blacks such as persons of Mediterranean origin and traces of whites. Bryant Rollins, the executive editor of the *Amsterdam News* (New York City), announced that the federal government's award of a five-year \$2.5 million grant to the Harlem Hospital for sickle cell research was a waste of Harlem community's resources, as "that might be better applied to the myriad social, economic, and health problems affecting it" (Markel, 1970-1997). Another scientist, Alfred Kraus, complained that funding for cardiovascular disease is being unthinkingly deployed for unnecessary waste on illness such as SCD, while editorialist, William Hines, described the shift in funding as a "robbing Peter to pay Paul for Dick's benefit" (Wailoo, 2017: P. 806). All these incidences of obvious inequity in healthcare created further mistrust in government health policies among black population. African Americans observed that carriers of the sickle cell trait are also being denied health insurances, employment opportunities, and even not accepted into the U.S. Air Force Academy. So, they were critical of the policy makers' offer of SCD screenings, arguing that such offers were an attempt to make Black people extinct. Others argued that SCD attention was a political effort to get black people's vote.

Lane & Scott's editorial article in the *Journal of American Medical Association* reported that as low as 20% of Blacks had any knowledge about SCD, not to talk of the mainstream white population that did not have the disease in their midst. The article deplored the government's disinterestedness in SCD, stating that the disease is of epidemic levels among a segment of the citizens and deserved to be visible and funded as other related conditions. He argued that reasons for the non-visibility in medical discourse and public health policies is because of its location among black people. The lack of knowledge even among black people stemmed from lack of interest by government to embark on public education programs (Lane and Scott, 1969). This summarized history presented above made progress towards

improved management of SCD very slow, not only in the US but right across the Western world.

4.7. SCD in UK

The history of how SCD is politicised in the United Kingdom cannot be divorced from that of the United States of America because of their joint history of involvement with slavery, their interrelationship with the Caribbean islanders and the UK colonization of some west African countries such as Nigeria.

There had always been numerous reports about inequity in the distribution of social benefits and services among UK citizens, with clear difference in what migrants and other ethnic minorities get when compared with the mainstream white population (Anionwu & Atkin, 2001). Grant (2016) argued that 'although non-white people may have had the status of formal citizens, they were not treated as such, politically or socially' (Grant, 2016).

From around post-war era to 1970's when the Caribbean and Commonwealth (post-colonization) citizens started emigrating to the UK in substantial numbers, the presence of SCD became more visible in the NHS facilities. It was always considered a black people's disease with traces among other migrant population so just like in the US, management in the hospitals was palliative. However, as the numbers increased, and many of the migrant population joined the workforce in the hospitals, it became obvious that NHS was reluctant to consider SCD becoming a public health issue. Policy makers kept treatment to palliative only. Ethnic minorities could not qualify for any public health attention, nor was there any treatment protocols for SCD as existed for other such conditions such as haemophilia which affects mainstream majority population. Anionwu & Atkin (2001) criticised the slowness of the department of health to treat SCD as an important public health concern and to be funded just as related conditions like haemophilia and cystic fibrosis found among majority of the British population were. Dyson & Atkins (2013) asked, "Why does cystic fibrosis (which in England affects 10,000 people, compared with 15,000 with sickle cell disorders) garner more than 30 times as much financial support as sickle cell disorders?" (Dyson & Atkins, 2013: p. 1).

Interestingly, SCD was completely absent from medical discourses or treatment management decision making among NHS policy makers. Reports abound in literature about the multiple ways NHS discredited minority population in UK, as patients, casting their

health needs like SCD as irrelevant and expensive and excluding them from their social rights as citizens (Scot, 1998; Redhead, 2021).

Advocates for better care of SCD which included some academics, medical professionals, nurses, and some other concerned people who were mostly black women like Elizabeth Anionwu started to engage with policy makers in government over SCD visibility public health. Anionwu argued that the stance of the dominant political culture is that Britain as a 'white country', SCD is primarily 'African', and 'Asian' so is not relevant for funding or even research. The number of people with the condition was, according to the politicians, too low to warrant any attention beyond palliative care (Anionwu & Atkin, 2001). Even a major medical textbook, *Genetic Counselling* (1976 edition) had these statements written, SCD "is not of great consequence to us in the context of genetic counselling in the United Kingdom", because 'confined to peoples of African and Eastern origin'. Such statement and wider discourse of "*whether 'black health' was 'British health'*" prompted sportsman Garth Crooks to make the popular statement, "Sickle cell is a British problem affecting British people" (Redhead, 2021: p. 211). The understanding that SCD is located among the migrants caused it to be invisible for development of better treatment, research or even public education about its genetic nature.

Dyson argues that linking of SCD with ethnicity draws attention to the inequities in service provision for health concerns for the ethnic population, and that could be the reason behind the invisibility of SCD as a public health concern. (Dyson, 1998; Dyson, 2019). Many feminist scholars contested the individual and institutional discrimination and health-related stigmatization experienced by people living with SCD as their health care was neglected (Ahmad & Atkin, 1996; Anionwu & Atkins, 2001). Atkin & Ahmad, 2001 suggested "that many of the difficulties they faced are a consequence of the wider society's inability to accommodate 'difference'" (Atkin & Ahmad, 2001: p. 615).

When the activists pressured the authorities that genetic screening should be included in the management of the condition, the authorities argued that the low educational status of black people would not permit them to understand the principles of genetics so implementation of such a program would not be useful (Redhead, 2021). Anionwu concluded that "underlying racist and patronizing attitude" influenced such response of the policy makers, who assumed that the black minority population were not educated enough to understand genetics.

Within the NHS, health workers activists pushed to make SCD visible and undeniable to the state, employing various strategies to convince the policy makers as they struggle to claim a space for minorities as deserving of health service.

After policy makers in the UK started accepting that SCD was really a public health condition that must be handled by NHS, the approach was informed from the biomedical concept. The perspective was that the condition is a major life-threatening one and should be expunged completely from society if individuals who are at risk make rational choices around selection of partners and selective reproductive agency for sake of public health, and national health budget (Dyson & Atkin, 2013; Etchegary, 2006).

From around 1980s, life expectancy of people with SCD was increasing significantly with advanced medical care, particularly with the introduction of hydroxyurea into treatment protocol, an average of some 2.5 years per decade (Storey, 2018; Kirkwood, 1999). With the increase in chronic illnesses generally, the burden on the healthcare resources, money and human resource, became of concern to the authorities. The NHS estimated 17.5 million adults living with chronic illnesses in the UK (Department of Health, 2005), occupying 50% of annual outpatient consultations and 70% annual hospital admissions which was considered a major financial burden for the health resources. SCD is one of the chronic illnesses that was noted to cause huge impact on health resources (Langer, *et al.*, 2013; Department of Health, 2010). People with SCD frequently utilized hospital services due to the recurrent crisis pain episodes more than many of the other chronic conditions like diabetes and hypertension, even though number of patients with the condition were much less. Its visibility in the hospitals became very concerning to NHS (Ghida AlJuburi *et al.*, 2011). Previously, the department of health in 1997 acknowledged that UK ethnic minorities had some unique health needs such as SCD but never considered them a significant public health concern because it was “relevant for a few areas” in the UK (Bradby, 1996; Dyson, 1998).

There were about 14000 people living with SCD in the UK as at 2015 records, equivalent of 1 in 4600 people; about 300 babies are diagnosed annually with the disorder (Dormandy, *et al.*, 2017). SCD exists predominantly among the immigrant communities of African origin, the Caribbean origin and to a lesser degree, Asian origin.

The UK department of health agreed in principle to approve a national new-born genetic screening for sickle cell in year 2000, introduced the new-born screening in 2001 and the linked antenatal and neonatal screening programme for haemoglobinopathies (sickle cell

and thalassemia major) between 2004 and 2006. (Department of Health, 2000). With the program, new-born babies are identified for early treatment management. Also, couples at risk of an affected pregnancy are identified and options including termination of pregnancy is offered. (Oni, 2006). While new-born screening is straightforward and welcome, decision-making around termination of pregnancy is known from literature to be a complicated process which can be stressful. Individuals making those decisions draw on a number of other social factors such as their personal understanding or experience of the condition, family attitudes, cultural beliefs which include religion, dominant meanings of the disorder and medical services available (Atkin *et al.*, 1998; Ahmed, 2001). A number of studies identified religion as a major factor affecting uptake of termination of pregnancy as solution to neonatal diagnosis of affected foetus in the UK population (Anionwu and Atkin, 2001; Ahmed, Atkin, Hewison, & Green, 2006; Alkuraya and Kilani, 2001). Some studies conducted in later years confirmed the importance of public education on reproductive decision-making. Atkin *et al.*, 2008 reported that while religion is an important factor on reproductive decision among the UK population, adequate genetic knowledge can render faith beliefs negotiable (Atkin *et al.*, 2008; Atkin & Ahmad, 2001; Shaw, 2011; Ahmed *et al.*, 2012).

The ethnic minority in UK who are disproportionately endowed with SCD, considered the national screening programme a positive initiative towards health equality. The possibility of preventing transmission of the disorder to offspring, made it possible to exercise control over one's life rather than leave issues to nature and this was presumed to be a positive change for the people affected (Hallowell, 1999). The dominant culture assumes that genetic screening to know genetic status, a rational individual has a moral obligation to make choices that will mitigate the burden of SCD and avert transmission of the disorder (Weiner, 2010; Etchegary, 2006). However, the promised informed decision-making did not quite work out as exercising personal choices in practical terms (Shakespeare, 1998). Dominant cultural concerns of obliterating the disorder from society featured in medical discourses so creating unexpected anxieties and stress, constraining choices of the affected people. Other phenomena of oppressive cultural attitudes, labelling, stigma and marginalization became the lived experiences of the people affected (Atkin, 2010; Bradby, 1996; Ross, 2015). Literature records some difficulties in finding a marriage partner with some individuals due to genetic disorders like Tay Sachs disease (Parsons and Atkinson, 1992). So, predictive genetic diagnosis constructed people with the condition as *abnormal* by the medical experts.

WHO declared in the 63rd World Health Assembly in May 2010 that the most cost-effective strategy for reducing the burden of haemoglobin disorders is to complement disease management with preventive programmes. WHO advocated for pre- and post-conception genetic screening so that at-risk persons can adopt measures to ensure the condition is not passed on to future generations. With such worldwide collaboration, many at-risk people are predisposed to the efforts, the psychological burden notwithstanding (Oni, 2007).

With colossal world-wide migration, migrants in the UK from countries where SCD is prevalent bring with them their cultures, beliefs and practices (Burgess, 2011). Burgess, (2012) reported on the phenomenal increase of Pentecostal churches with headquarters in Nigeria and Uganda dotting the UK religious landscape. These play active role in the social life of the ethnic minorities among whom SCD is prevalent. For example, the Redeemed Christian Church of God (RCCG) and Deeper Life Bible Church are two big movements with hundreds of branches within the UK (Adedibu, 2016). These churches bring with them the cultural practices and guidelines of the mother-churches in Africa. Owoeye recounted of Deeper life bible church guideline for marriage as "the church does not join HIV positive individual with another who has not tested positive. This underscores the importance of blood test and HIV/AIDS test in the church before two people can be joined together in wedlock. Where would-be-husband and wife are AS, AS, they are advised not to marry to avoid children with sickle cell anaemia in future" (Owoeye, 2011). With the inclusion of tenets of Genetic Responsibility in the marriage guidelines, the church raises awareness of SCD genetic nature of possible transmission of the disorder to future generations. There are some studies in literature that confirm the practice of disavowal of marriage between two carriers of the sickle cell gene or marriage between a carrier of the gene and a full-blown person with SCD in some branches of these churches located in some other countries (Ezugwu, Osamor, & Wendler, 2019).

A study by Durosinmi *et al* (1995) reported that Nigerians generally accepted options offered by the prenatal diagnosis and acceptance of Post Natal Diagnosis (PND) with subsequent termination of an affected pregnancy. People of Nigerian origin in the UK constitute the highest population among the immigrant community in the UK. As they relocate to UK, they come with their values and ideas as accepted within their culture (Sturge. 2005: p.88). It is expected that with adequate education about transmission pattern of SCD and the options available for those who are affected, that trust will develop between patients, medical health provider and government; and patients' perception will change, and rational decisions will be taken (Clarke, 1991; Green & Statham, 1996).

This study which is to understand how SCD impact on the selection of romantic partner and reproductive decision making is expected to shed light on the attitudes of people living with SCD in UK towards genetic responsibility.

4.8 Socio-psychological burden of SCD

In the over one hundred years of history of SCD, researchers have focused mainly on the pathophysiological aspects of SCD with very limited research in the social and political dimensions of the condition. It is only in the last three or four decades that the attention has been drawn beyond the harmful impairment, to explore the harsh social constructions, meaning of illness in the wider society, the history and personal concerns the individual have to contend with in everyday living (Ahmad & Atkin, 2001; Anionwu & Atkin, 2001).

Annie (2009) suggested that the impact of SCD on an individual cannot be fully described with clinical manifestations of the disease alone without exploring the impact on social and psychological dimensions of living, challenging the medicalized presentation of the illness as if it were all physiology and pains of the illness. Other scholars also demonstrated that all domains of living are affected by chronic illnesses such as SCD (Barbarin & Christian, 1999; Helen Caird *et al.*, 2010; Thomas and Taylor, 2002). Different domains of life such as depression and anxiety in SCD (Belgrave & Molok, 1991; Edwards *et al.*, 2009; Udofia & Osekihuem, 1996); cognitive functioning (Hilton *et al.*, 1997); employment prospects and opportunities negatively affected by SCD (Barrett *et al.* 1988); discrimination and stigma experiences in SCD (Anionwu & Atkin, 2001; Maxwell, Streetly, & Bevan, 1999), SCD burden on academic functioning (Dyson, et al., 2021; Osunkwo, et al., 2021; Dyson and Atkin, 2013); impact on families and care-givers (Habeeb *et al.*, 2015); reduced quality of life (Annie 2005).

Oliver (1990) distinguished the impairment *disableness* of a chronic disease (which is the clinical manifestations of the disease or broken body such as a missing limp), from the disability effects, which is the societal-enforced oppression experienced by the individuals living with the condition. Kleinman (1988) argued that chronic illnesses impact the bearer through three dimensions namely, the clinical body symptoms, the personal lived experiences of the illness and the sociocultural experience due the sickness. The lived experiences of the illness can vary between people. SCD seems to affect individuals differently; for example, need for hospital admissions vary very widely or say, impact of hydroxyurea on individuals is idiosyncratic. The individuals who are severely affected and who are in and out of the hospital may be more 'disabled' by comments at workplace or in

the community than one who is hardly on admission and so can conceal their illness. Those individuals with stunted physical built may be more prone to 'abuse' by society than the one whose illness is not visible (Atkin & Ahmad, 2001; Dyson *et al.*, 2010). While medical intervention help relieve the clinical symptoms, it is powerless to address the social *disablement*. Studies abound that describe oppressive attitudes of some health professionals towards patients at the clinics (Atkin & Ahmad, 2001). Reeve, (2004) said of some of her participants narratives, "the existing literature about the difficulties caused to disabled people by prejudiced and/or unthinking health and welfare professionals. The concept of psycho-emotional *disablism* allows for full recognition of the way these relations with professionals, laced with power and control, affect and are affected by other forms of psycho-emotional *disablism* such as internalised oppression. The experience of patronising and prejudiced professionals is not just an issue for the individual to deal with but is an important dimension of disability caused by oppressive social relations which needs to be given more credence and attention" (Reeve, 2004: p. 7). There are numerous reports of health professionals who have accused the affected persons of substance abuse because of frequent trips to Accident & Emergency departments in the UK.

Some SMD critics argued that direct consequences of impairment effects can be disabling and do contribute to the negative attitudes of society (Shakespeare & Watson, 2001). For example, absenteeism from workplace or school due to ill-health. (Dyson *et al.*, 2007 & 2010; Anie *et al.*, 2002; Ballas *et al.*, 2010; Abuateya *et al.*, 2008). Boardman (2013) argued that the neat divide between impairment and disablement as is presented in SMD is muddled up by the "fluid nature of 'disability', 'impairment' and 'illness' means that they may be difficult to entirely differentiate, and indeed, life with a particular condition may involve a continual oscillation between all three states" (Boardman, 2013: p. 3).

At intersection of *disablism* due to impairment and *disablism* due to dominant social structures, selecting romantic partner can become problematic. For reproductive decisions, Dyson (1998) reported the burden borne by people with SCD as their identities of illness and belonging to ethnic minority group complicates the numerous reproductive considerations they must negotiate. The new predictive genetic tests offer opportunity to control and manage life world through making appropriate choices. Choices connotes the idea of autonomy being branded informed decision-making. The genetic screening programme is a preventative strategy, to rid the UK of SCD on the long run. Thus, the individual making the decisions is robbed of autonomous decision-making because being a *good citizen* denotes complicity with public policies and preferences.

This study seeks to explore how SCD impact on the selection of romantic partner and the reproductive decision-making of adults living with the disease in the UK. I have demonstrated that from literature, SCD is a chronic genetic illness whose disruptiveness involves both the clinical experience of the disease and the lived experience of its social construction.

4.9. Cultural Understanding of SCD

The NHS has funded several studies on impact of SCD patients' utilization on NHS resources for cost cutting purposes. (AlJuburi *et al.*, 2012). "The rising cost of healthcare places the health system in England under increasing pressure to reduce such inappropriate hospital admissions. The national confidential enquiry into patient outcome and death reports that a multidisciplinary and multi-agency approach is needed in the ongoing pain management of patients with sickle cell disease" (Green & AlJuburi *et al.*, 2012)

SCD is currently the most common genetic blood disorder in the United Kingdom. The possibility of eliminating new occurrences by responsible adherence to genetic health promotion strategies is goal for the medical fraternity, policy makers, and the wider society. The new genetic possibilities have attracted a lot of media attention, particularly the social media. With the publicization of genetic information, lay explanations, meanings and understandings emerged in the context of obligations at different milestone in life trajectory, such as being discrete about choice for partner selection and parenting to prevent future generations endowment with the SCD. Studies have identified variance in layperson interpretation of genetic information and the medical specialists. This is particularly evident in the interpretation of statistic probabilities in genetic transmission patterns (Parsons & Atkinson, 1992; Rowe & Wright, 2001; Etchegary, 2014). The life decisions about genetic risks taken by lay people based on such inaccurate genetic information commonly is at variance with the medical calculations, and such discrepancy may have important implications (Evers-Kiebooms, 1992; Edwards *et al.*, 2002). These inaccurate scientific facts mixed with cultural interpretations and converted to definite, descriptive philosophy held by society can influence the reproductive decision-making of individuals living with the condition (Etchegary, 2014; Parsons & Atkinson, 1992; Rowe & Wright, 2001). A great deal of the detailed information about SCD genetic risk is lost in the process of translating the facts from the medical geneticists to the public. The social construction of these obligations of responsibility, that is, the responsibility to know and manage one's own genome for

oneself and for others, label or stereotype those who are already living with the condition. Weiner (2011) noted that “an ethos of responsibility for self, family and society is encoded in clinical genetic practices and policies. In other words, genetic responsibility may be embedded in certain institutional or political settings” (Weiner, 2011: p.1761).

In UK, the medical model of disability culture assumes rational choices to be made to prevent SCD transfer to offspring if at risk. The social consequences are however, not taken into consideration (Atkin & Ahmad, 2001; Lupton, 1999). SCD risk defines an individual in the contemporary society, fundamentally shaping the lives of the individuals at both personal and societal level (Hallowell, 2006).

Normally, an individual would understand their *self* in terms of their auto/biography (Exeley & Letherby, 2001: p. 114) so, having to discover or be informed that one has an embodied risk that will be dangerous for parenting, will have an impact negatively on one’s self-identity and confidence (e.g., Pfeffer & Woollett, 1983; Exley, 1999a). Such branding isolates one from the rest of society. Though the individual belongs to the same group they may have always belonged to in society, yet the risk they are now diagnosed to possess classifies them outside the boundaries of peers, they become a sort of *outsider*. Embodying the SCD genetic risk potentially threatens the bearer in the private spaces, being incorporated into their everyday reality. The ordinary, everyday living social activities enjoyed by the normative culture, come under threat, as dominant medical structures *pathologizes* and subject the at-risk bodies to *surveillance* even at social spaces of partnership and reproduction.

Zola (1972) and Conrad (1992) had commented on the encroachment of the jurisdiction of medicine from solving pathological problems to involvement in social solutions as “more and more of everyday life has come under medical dominion, influence and supervision” (Conrad, 1992: p. 210). Zola (1972) termed it *Medicalization* of life. Conrad further argued that *medicalization* is an instrument of social control (Conrad 1992: P. 210). With the advent of predictive genetic screening and the use of an individual’s genetic information to predict and manage health and life course, the presence of medicine and its professionals at most pivots of life decision-making of people affected becomes inevitable. Vilhelmsson (2017) argued that “encouraging individuals to engage in preventive health activities... moves medical and health concerns into every corner of everyday life” (Vilhelmsson, 2017: p. 3). For this study, the impact of SCD, a genetic disease, on the selection of partner and reproductive decision-making of an individual living with the condition is explored.

In the UK just like all over the world, individuals are encouraged to implement these 'life strategies' for themselves, their kin and for others (Novas & Rose, 2000). These strategies are permeated with ethical responsibilities to society and a duty to make decisions that show selflessness and responsibility to *others* and society indirectly encroaching on personal human rights which is being addressed by personal choice-making (Kenen, 1994).

Contemporary studies of the target population in the UK shows an increase in SCD diseases awareness. Many forums of NGO support have been created, particularly in London where up to 75% of the target population resides. (AlJuburi, et al., 2012). This has enabled increase in the understanding of genetic information about the inheritance pattern of SCD which was only 25% in 1997. (Dyson, 1997). The policies implemented in the UK is hopefully meeting the needs of people living with SCD towards a more equitable healthcare for all citizens.

4.10. Conclusion

This chapter presented a literature review on the pathophysiology of SCD with its clinical manifestations and complexities. It described the histology of the RBC and the mode of changes that occur within the cells when an affected person is in crisis. The Clinical management of SCD and the self-management of people living with the condition in the United Kingdom are also illustrated in detail with some mention of upcoming high-tech therapeutic methods.

The global epidemiology and prevalence of SCD as well as in the UK is also presented. I reported that the history and distribution pattern of SCD has been found to depend globally on where malaria has been endemic and the countries where migrants from those countries emigrated to. They concluded that the mutation of *HbS* from *HbA* is due to natural evolution to survive infestation by *Plasmodium Falciparum* (Rees et al., 2010). The chapter also presented the genetic nature of SCD in terms of transmission to offspring of the affected individuals.

The Sociology of SCD was discussed; how it was discovered, characterised and how it became debated in the Western countries particularly in the United States and United Kingdom. The struggle to depoliticise it and make it visible to policy makers and researchers for better prospect of management in the UK was also presented. The understanding of the history and the struggle of the activists to get the policy makers in the west countries engaged in taking up the SCD as an important Public Health problem may lay foundation for understanding the *how* of the social construction of SCD; how it is perceived and understood in the societies may be relevant to this study. The improved life expectancy of

the affected people due to improved clinical management in the last few decades have made the psychosocial domains of life to become prominent. The lived experiences of individuals with SCD within the hostile social environment may be contributory to the difficulty they experience in accessing social services and support enjoyed by the mainstream population. This study is thus borne to fill in the gap that exist in literature about the impact of SCD on the selection of partner and reproductive decision-making of adults in UK living with the condition.

CHAPTER 5

GENETIC RESPONSIBILITY

With the amount of information out there now, the choices you make when you don't know something and when you do should be different

-Damaris

5.1 Introduction

In this chapter, I present the attitudes and motivations of the participants, who due to their experiences of SCD embodiment, sensed a moral obligation to act on the genetic knowledge they possess about the risk of transmission of the disorder to their offspring and make rational choices as they select romantic partners and make reproductive decisions. This is genetic responsibility, an essential factor influencing them to modulate the devastating consequences of SCD.

Their reasons for making the various decisions are also explored. From data, I explore how their experiential knowledge of SCD, and the associated social understanding of the disorder underpin their general attitudes and motivations. Also, how their various level of understanding of genetic options guided the depth of responsibility they are willing to take about managing their risk.

In the UK, all new-borns are screened to establish genotype (*HbSS* gene) for purpose of early medical intervention if affected. Individuals who may not be aware of their status when they came into the country, do get to know when they visit health facilities during a sickle cell crisis. A positive genetic test provides the individual with genetic information to make future informed decisions about life-course, particularly in areas of selection of romantic partner and reproductive decision-making.

The concept of GR coined by Lipkin and Rowley (1974), is the notion assumed in society that the at-risk individual has a moral obligation or responsibility to know their genotype so as to manage their own risk for benefit of self and for the sake of *others*, focusing particularly on ensuring disorder is not transmitted to offspring (Weiner, 2011; Etchegary *et al.*, 2009; Leefmann *et al.*, 2017). Quite unlike other medical tests, genetic test result has implications that goes beyond the individual, integrating other people's lifeworld and interests. Acquiring genetic information for purpose of alleviating the ruinous consequences of having SCD is considered rational because it is assumed to empower the person with the disorder to control their destiny rather than leave things to nature (Hallowell, 1999: p. 597).

From biomedical discourses, there are suggestions that refusal to act *responsibly* by preventing a child who is affected from being born is *morally* wrong (Hallowell, 1999: p. 599). However, some researchers such as Ross (2015) reported that affected persons experience socio-psychological tensions due to personal socio-medical factors that influence their decision-making as they balance morality, autonomy and responsibility.

Underpinning this life-course decision-making, is an understanding that the at-risk person is exercising autonomy, after being armed with the resources to make informed and responsible personal choices, without external interference.

The three dimensions of GR, which is to know about the self for self, for others, and to oblige others to know (Etchegary *et al.*, 2009; Ross, 2015: p. 37). This implies extending responsibility beyond *self* to *Others*. Accommodating *Others'* interests with one's interests could compound process of decision making; because the process shifts from being entirely autonomous, to considering the socially relational *Others* (Kenen, 1994). *Others* could refer to the partner, the unborn child, family or the wider society. Kenen (1994) suggested that the decision maker no longer exercises autonomy as an independent self but as an interdependent self, because the interests of significant others is superimposed on self-interests. According to Ross (2013), "genetic responsibility has become a key factor for understanding how genetic risks reshape choice, identification, and obligation within families" (p. 49). The moral responsibility gives insight about how, by whom and for whom choice is made.

The chapter explores the way genetic responsibility emerges in the narratives of the participants as they discuss process of selecting and selecting partners, and in their reproductive decision making. The stories of the participants will be discussed under the sub-themes below:

1. Attitudes and Motivations of Participants to GR
2. GR for sake of self
3. GR for sake of *Others* (potential partner)
4. Personal issues and responsibility for sake of *Others* (Offspring)
5. Factors impacting GR

5.2 Attitudes/Motivations of Participants to Concept of GR

All participants displayed strong positive attitude to genetic screening and all sensed moral duty to ensure SCD is not transmitted to offspring. It is a general discourse that all people will mitigate risk that will jeopardize quality of life.

Mary, one of the participants, said she was prepared not to have kids if she fell in love with someone with SCD.

“Yeah, I could marry someone who was SS or SC and we wouldn’t have kids. The odds were just too stacked up. So, because if I married someone with SS it’d be 100%... And then someone who was AS is 50% chance, so I think yeah, it would have been nice to get married, because you know everybody wants that companionship. But I think there are times when you have to make a logical decision, and I think 50% chance is a bit too high a chance. And I think personally, I don’t know about the person, this hypothetical person but I think personally, I would have been happy to make the decision not to have kids.

She felt the stakes of even 50% chance (actually chance is 75%) of having a baby with SCD would be too high with someone with the trait (HbAS) so, she will rather not have a baby. Like most other people, she desires to marry and probably have children. But if the child will have SCD, she will rather not have a biological child with this individual. Her lived knowledge of SCD and her understanding of genetic probability statistics reshaped her perception of life and options. She felt an obligation for safety towards the unborn child more than her desired motherhood. Her lived knowledge of SCD also motivated her to be rational in her decisions. She however mentioned the fact that the partner involved (‘hypothetical person’) will also have to have a say in the final outcome. It seems plausible that she will negotiate this personal stance early in the relationship.

Michael, another participant, also demonstrated the same feelings of obligation towards his offspring as he contemplated parenting. He stressed the importance of complete or accurate genetic information (GI) to assist in making informed decisions. He is also willing not to have biological children if Pre-implantation Diagnosis (PGD) is not possible. Rather he will adopt children.

“If I get with another lady I care about, with or without sickle cell trait or who doesn’t have sickle cell trait, it doesn’t bother me, I will marry her if she is comfortable with it. We are not illiterates. The genetic information is there to access, and should it be difficult to access maybe because of cost or something, then we can adopt a child.”

While he accepted that he would need to exercise agency to ensure his potential partner is not an at-risk individual, he asserts that there is a possibility that a partner he gets may be an at-risk person. In that case, he made it clear he will go ahead and marry such a person.

He would then explore all technologies available to see if he can possibly still bear a child that is not affected. If such technology is inaccessible or if the partner has full-blown disease, he will opt for adoption. It is however clear that just like Mary, every effort will be made to ensure an affected child is not brought into being. From his narrative, it is obvious he feels many at-risk people are unaware of the technical possibilities out there. And even if available, there is a possibility of cost which may make it inaccessible. For him, his choices do not need to be restrained. He can strategically manage his future at any convenient point of his life-course, that is, at point of selecting partner, or at point of reproduction. So long as he ensures SCD is not transmitted to offspring, he is being responsible.

David, one of the participants also concurs same sentiments, but has a different strategy to solve the problem. He said,

“These days I seek for Caucasians for relationships. That way, if children come, I am sure they will not have sickle cell. That is my current mindset.”

He feels he will be better off seeking partners in the safe zone where SCD is non-existent or rare. That way, he can save himself the painful decision-making first subjecting himself to external authorization and governance of his social space through biomedical surveillance (*gaze*) of suitability of the genotype of potential partner. Moreover, his decision to stay on the safe zone will ensure the offspring is not endowed with SCD. David certainly believes in being rational in making genetic decisions.

The behaviour of these participants exemplifies how people have parenthood instinct even before making decisions of selection of partner to bear children with. They felt an obligation to protect the unborn child from harm. Their choice of what type of life they want to live, has incorporated the interest of the life of *other* (the unborn child) into their plans. The welfare or interest of this significant *other* is engrained into their perception of self, with their lives being inter-connected with the lives of the unborn children. The welfare of the unborn baby motivated or shaped their attitude to the concept of GR.

Aaron, another male participant, argued intensely about need to know one's genotype and also the potential partner's for purpose of planning and managing one's risk.

“I think that would be very irresponsible. That would be a reckless way to live, you know, because if you fail to plan, you know, effectively plan, it will fail, you know, and the person will fail drastically, you know. Probably end up with a failed marriage, broken relationship with the partner, broken relationship with the kids, you know, because one hasn't been considerate enough, you know. So, I think that's a terrible thing. So, I think everybody should know what they're getting themselves into,

you know, beforehand. And you should make adequate planning and preparation for it, you know”.

That was an answer to a question of those who do not know their genetic status or who do not bother to ask their potential partners about their genotype. He called any at-risk person who does not plan ‘reckless. Aaron had a very difficult time getting a partner. He had many failed relationships which terminated at disclosure of his genotype. He felt a responsibility towards future offspring and called the process of genetic screening and selecting partner ‘planning and preparation’. He argued that failure to plan and manage life will lead to failure at many fronts of life. He believed that the “*planning and managing*” could be the difference between children being affected or not.

Damaris, a lady participant, concur that in the age of such technological knowledge, people should be purposeful about their choices of partner and reproduction.

“The choices you make when you don’t know something and now what you do know, are completely different. It’s not that I am opposed to those with sickle cell and the trait being in a relationship, it’s not that at all, it’s just that we are in a generation now that our generation should know that we shouldn’t be getting people who don’t know whether they have the trait or not.”

Damaris’ narrative flows with the normative stance that all people should know their genotype as well as genotype of potential partner for sake of self and sake of offspring. (Hallowell, 1999). Damaris argued that with the current options available for mitigating the disease, it is irresponsible not to act for prevention. She felt the sheer clinical consequences of SCD should impact the attitude of the at-risk person to make responsible choices. The attitude of majority of the participants was that everyone who is affected should be morally responsible as they make decisions of relationship and reproduction.

5.3 Genetic Responsibility for Self

Predictive genetic screening provides information about biological identity of an individual and so serves as a segment of risk management with regards to future life (Hallowell, 1999: p. 106). The first dimension of GR is to know own genetic risk for the sake of own’s health and wellbeing. Crawford (1977) said, “health is a duty... one has an obligation to preserve one’s own good health” Crawford, 1977: p. 669). Most of the participants exhibited behavioural agency for selection of partners and reproductive activities to mitigate the effects of their embodied risk for sake of health and better quality of living.

Solomon also felt affected individuals should ensure their potential partners are tested.

“All black people and Asians should know their status from birth. It is important. If you know what you are up against, then you can plan. But if you do not know, that is the problem. And no-one should take a partner’s word for it when it comes to status. Insist you both go to the lab and test so that there is no assuming anything. That way, you have all valid information.”

Solomon felt genetic information should be known from birth as it will be imbibed in the consciousness way before the process of engaging in life activities of selecting partners and parenting. In that way, an at-risk individual may automatically engage in risk averting agency when selecting intimate partners for purpose of own quality of life and well-being.

Mary also argued that the burden of SCD should generate a sense of responsibility towards self when it comes to life partnership for better well-being. She asserted that two SCD-affected couple will have a difficult life.

“So, if I’m SS and I marry someone who is SS, and we have SS kids, you know, how is that gonna work? Whose gonna look after us when we have crisis? [laughs] If the child has a crisis or the mom has a crisis? You know, I just didn’t think it was even, I’ve never thought of... Because sickle cell is hard enough when it’s one person in the family. Or two. But a whole family... Father, mother, two kids with sickle cell. How does that work? It was just not in the realm of my, when I think of possibilities, yeah. So, I’d rather an adopted child.”

Mary felt, as one with SCD, partnership with person who is also endowed with HbSS will lead to a difficult life especially if both suddenly fall ill. Mary’s embodiment of SCD, the physical, social and emotional burden which induces a disrupted living compels a pervasive obligation to mitigate further stressful life-course. In fact, she said she will rather adopt a child than bring a child with SCD into being if she has to partner with someone with the disorder.

Paul feels differently about reduced quality of life because of a partner who is affected.

“Yeah, even though some people would have frowned upon it the way I look at it, you are both suffering the same illness you understand it and as long as you are not looking to have any more children then I say why not?”

For him, once both understand what they both have, support will be easy and mutual. He complained about the social construct of SCD and how the members of the society tend to look down on people with SCD. So, for him, having a partner with SCD will eliminate that oppression. However, he did not imply that partnership with someone with SCD is a better

option, rather that it can be done. So, relationship is solely for sake of self. Should there be desire for parenting, adoption will be a good option.

For Deborah who had a very difficult life and relationship, she said when asked if she would support her daughter who has the trait to form a relationship with someone affected,

“I know it sounds strange, because I have sickle cell myself to say, no you can’t marry. But I think I know because I have been through it and I have been through you know, the family, the no, the taboo, everything and it hasn’t been easy, it would be a “no” for me unfortunately. Because why, why would she want to do that? You know? Why? Why would you want to put your life on hold? Why would you? I don’t know, I think it’s a difficult one, I’m thinking about it now, it sounds really nasty coming from me, but no, no, that would be, it won’t be worse that if you know that someone has sickle cell, no, no, no, no, no”.

Deborah in this narrative clearly reveal her stance that when selecting a partner, one has a chance to modulate the social and biomedical consequences of SCD on life course. While she has no control on the burdens of her embodied SCD, she can seize control when it comes to managing the way the future will go. When she asked the question “*Why would you want to put your life on hold?*”, her experience of the social connotation of SCD, the tremendous emotional labour imposed from social actors and her experiential knowledge of her embodiment was sufficient to warrant a termination of any at risk relationship. Not seizing control of risk management at the level of partner selection will mean embroiling in burdens of reproductive decision-making and engaging in problematic prenatal or post-conception genetic decision making. For Deborah, it is more expedient to avoid those oppressive routes.

5.4 Responsibility for Others- Potential Partner

The desire for having a romantic partner is one of the most fundamental of all human activities (Baumeister & Leary, 1995). Establishing a long-term intimate relationship which may lead to parenting demands an integration of the interests of the partner into interest of self (Slotter & Gardner, 2009). So, the identity of the significant *other is* incorporated into self. Romantic partners, as perhaps the closest of adult relationships, strongly impact the self-concept, (Slotter, Gardner & Finkel, 2010: p. 1). In the potential shared space of parenthood, an individual with a genetic disorder will invariably be forthright about their own embodied risk, since the outcome cannot be hidden, (whether negative or positive). Mary, a female participant described it this way,

“When you’re dating, and you’re living in separate places, you still have the, emmm, opportunity to hide and, you know, be off your phone. And

then you pick up your phone hours later after your crisis has passed away and say, "Oh sorry, my phone was switched off". You know, you can still tell all those white lies. But when you're sharing the same space, it's impossible. So, with time, you have no choice but to open up and they learn more about you and your sickle cell situation."

In a long-term relationship, there must be self disclosure. She had to come out straight with him once their relationship got serious. He had to be integrated into her self-concept. Like many of the other participants, Mary felt an obligation to be open to her potential long-term partner that informing him of her embodiment was *the right thing to do*. Being at risk of possible transmission of SCD to an offspring, she felt an inescapable ethical obligations and responsibilities to the potential significant *other* who wants to share life space with her.

Zipporah described her honesty about her SCD with her one-time partner who incidentally knew nothing about the condition. She felt an obligation to enlighten him about SCD by inviting him to go with her to support meetings as well as doctor's appointments. She said,

"I told him that I had sickle cell and... He wanted to know what it was. I told him what it was. Obviously, we went to that AA meeting (Alcohol Anonymous. She must have meant sickle cell support group meeting) then so during that period he got to know a bit more about it and then after that whenever I had appointments, he would come with me."

Weiner (2011) suggested that the new genetic technologies created "the genetically at-risk person obligations towards potential and actual kin, as well as a desire". (Weiner, 2011: p.1760). Many other participants like Ruth, felt their potential partners has the right to know and make informed autonomous decision about their relationship. She said,

"I knew I had to tell him early on. I've done this in previous relationships as well. I tell them early on. You know if you're not happy- just keep it moving."

Mary described the *emotional tension* when it comes to informing the partner. She realises that the dominant culturally belief is that her embodiment is "an attribute that is deeply discrediting," (Goffman, 1963: p.13). Mary's SCD is invisible because it did not affect her physical built and could choose not to reveal it to potential partners, and just pass as "normal." However, she supports the notion that it is the right of the partner to know even though it generates *emotional tensions*. The emotional tension is borne out of the cultural negative attitudes, ideas, and stereotypes about SCD in society. These shape the self-concept of individuals like Mary (Thomas, 1999a, p. 46). She said,

"When you meet someone and you like them, you know, you, then comes the dilemma of when to tell them. Cause it's kind of like coming

out of the closet. You know, then comes the dilemma of deciding, you know, when is the right time to have the conversation that 'I've got sickle cell'."

One of the male participants, Hosea, described his involvement in a casual but romantic relationship which did not convey this sense of obligation to disclose his embodiment to the partner. He said,

"Well, nothing serious at the moment. I mean I have been in long term relationships before but at the moment I am just dating and having a good time you know... I really don't think it is any of their concern at this point. If I was looking for something serious then maybe I would think of saying it but not now."

For him, only serious relationships deserve such disclosure of self. Even when asked about possibility of pregnancy of an affected baby he still did not feel that sense of responsibility to the partner or even the unborn child. He said,

"I do not know and that does not matter to me because I am not interested in anything serious... Well, if they become pregnant, I will just have to deal with it. I know there is a high chance of having a baby that has sickle cell if the mother has the trait but I will just deal with it when it happens. Hopefully, it won't, but if it does then I will."

From Hosea's narrative, it would seem the depth or quality of the relationship determines how pervasive the feeling of responsibility towards the partner is. A possible explanation as to why he may seem unbothered about the genetic risks he poses could be because he is not ready to settle down in a long term, meaningful relationship. In addition to this, he did not demonstrate any longing for children in his current state.

This will be discussed further in the next chapter.

5.5 Personal issues and Responsibility for *Others*- Offspring

The second dimension of genetic responsibility is to know about the self for the sake of *Others* (future children). The discourse in biomedical circle about genetic prudence is towards total prevention of SCD. Cultural standards suggest that a child is morally wronged if knowingly or carelessly it is allowed to be born with a health condition that will cause significantly reduced life choices relative to peers (Davis 1997, Ross, 2013). With result of genetic screening, categorising an individual as SCD-affected, government and society assume that a good citizen will have a moral obligation towards *Others* such as offspring even though such decisions are supposedly automatous. Advanced genetic technologies offer new possibilities of being able to employ some control to avert transmission of genetic risk factors, even though one cannot change the genes one is born with.

Abdullah *et al.* (2011) noted that partner selection is a vital decision any individual can make in their lifetime because of it completely affecting the directions their lives would go. All participants agreed *theoretically* that all people who are affected must have a moral sense of responsibility towards the health and well-being of future offspring and so choose a partner wisely. However, personal circumstances and social environment seep into the process of decision-making as the participants in this study got to the point of choice. Participants all demonstrated the enormous burden and emotional work they performed as they made important reproductive decisions, they felt convinced is best for their unborn children. Their concept of relationships and parenting, their reproductive and sexual lives were all shaped by their embodiment and social understandings.

Jonathan, a thirty-nine-year-old man, who was married twice, said to a question if SCD ever affect the way in which he formed romantic relationships which can lead to parenting.

“You must take things into consideration like the sickle cell issue- if you decided to have children with that person. Because I remember being told that if I was to procreate with another sickle person or a trait, then my offspring would suffer the same fate that I had which was full blown sickle cell and it’s something I didn’t really want to put my children through.”

Jonathan recalled being very sickly as a young person but only got to understand he has SCD when he became an adult. He was also counselled about the probability statistics of risk of endowing his offspring with the disease. His embodied experience of SCD generated in him an obligation to manage risk so that no future child is born affected. He reiterated elsewhere during the interview that people look at him negatively for always selecting romantic partners from among non-blacks though he is black. He explained that this was because of his determination not to have children who will go through his experience of SCD. His strategy is to select partner from ‘safe’ population.

“So, so that, that made me, look at I would say my relationships differently because I thought if I married a person who was of Caribbean descent or whatever, you know, with regards to them having a possible chance the disease then I have to be vigilant and make sure that I didn’t you know end up in that position where I was putting kids’ lives at risk by having children and, and having sickle cell as well.”

Jonathan further highlighted the fact that he desires to educate other affected persons the need to be rational about choice so that eventually the number of people suffering from SCD will reduce.

"I want to educate people so there'll be no, so that they make this conscious decision every time they want to enter relationships so that, you know, we can reduce the amount of babies born with sickle cell."

Hannah like many other participants also echoed Jonathan's concern,

"Like I said I wouldn't want another child with the illness. I will know that I would be putting the child through the same things I went through"

The social model conceptualised disability as a form of social oppression, rather than a medical problem, as if the impairment effects are neutral, an idea criticised by some disabled feminists such as Corker & French (1999,) Crow (1996), Morris (1996) and Wendell (1996). Many participants such as Hannah clearly concur with these feminists that the impairment effects do have a part to play in their experiences of disablement.

Amos, another participant also confirmed the fact that SCD impairment is part of the *problem* faced by those embodying the condition.

"Yes, I have to because, you know, the way I suffered I don't want to have a child sickle cell... So, I cannot, for example, go with someone with sickle cell, and plan a future. That's impossible and that's the first thing. Or with someone who's a carrier of sickle cell. That's not possible. I would not take the risk."

Deborah who recounted the most tortuous experiences among the participants, reported aborting affected foetus thrice in her perceived moral responsibility to her future child. She has lived her entire life with SCD with all the clinical consequences, the social abuse and emotional labour, she could not wish it on someone else. She was adamant that her offspring must not be affected when she discovered that her partner who said he has *HbAA* turned out to be a carrier (*HbAS*). Though she had always wanted to have her own biological children, she would rather not have children at all. Apparently, this was a relationship they both desired to stay in. He had been there for her when she went through her medical procedures; she reasoned they could still build a life together without children to avoid the risk, but her partner obviously wanted children:

"We had I think like four trials, no about two or three (IVF) and then, you know, none of them survived, so we had to leave that and then went the normal way, they you know, PBS way, so you get pregnant normally and then at 13 weeks they try, they do a test to see whether the baby has the S gene or not and if he does then, we terminate. Um, so I think I had about three terminations...before I had one, but by which time the relationship had broken down, you know, all of this about stress in the relationship. So that when I finally got pregnant and the child had only the trait."

She reported she had two or three IVFs which failed and then she resorted to engage in post-conception genetic screening. For that she had to abort affected fetus thrice before she

had a child who was healthy, with *HbAS*. She was one of the participants whose SCD was very visible, having had hip replacement, knee replacement and some eye surgery due to SCD. Her lived experiences of the condition generated the resolve in her to be ethically responsible. Deborah reported how she used to be so vocal in condemning her parents for going on to marry even as medical people they knew they might have children with SCD. She said she used to loathe her parents who had such knowledge for not managing or even avoiding the dangers associated with the risk. She said:

"I pretty much sort of hated them for it and I was really vocal about it, I mean, that's one thing about me, I'm very vocal and I was very vocal about it that how, especially when I'm sick and my mom is crying, I'm like, why are you crying? Because I don't get it. You're not the one in pain and why are you sorry, you caused it in the first place, so I don't understand that. Please just leave me alone, just get out of my room and I was that angry, you know. Nothing like that now, and I was really angry because I couldn't understand how they could... Knowing that this will happen who will go ahead and get married."

Her strong condemnation of her parents, who though they are medical professionals, still bore her, possibly impacted on her resolve not to repeat what her parent did. This is supported in literature where mothers with children who are affected have been blamed as irresponsible for bringing a child who is affected to being when armed with genetic knowledge of their risk (Hill, 1994; Jenerette & Brewer, 2010). She reported that based on her religion, she would not have supported termination of pregnancy but the genetic information she had as well as her experience of SCD shaped her decision. She was able to emphasise her privileged understanding and experience as enough guide to make right reproductive decisions. Like she said many times, only a person who has the condition can fully understand what SCD is.

Arribas-Ayllon *et al.* (2013) suggested that Genetic Information is "shaping the values, norms and expectations of individual identity as well as contemporary citizenship" and "changing ways in which we think of ourselves and our relations with others" (Arribas-Ayllon *et al.*, 2013: p. 2). Though genetic screening services offered to all persons who are affected is construed to be voluntary, the mode of offering the service does subtly exert pressure on the individual to use the service and comply positively with the recommendation attached to the outcome of the test. Hallowell (1999) argued that though reproductive decisions are supposedly autonomous, the lived experience of the decision process may not be quite so straight forward. This is because the individual is "being trapped by this knowledge and the responsibility it entails", their choices being constrained, (Hallowell, 1999: p. 598), as the

needs of 'others' come to be identified as hers. (Hallowell, 1999: p. 608). For Deborah, she understood prenatal diagnosis of SCD will inform what she does to the pregnancy, she said:

"I mean, using that I'm bringing faith into it as well and all this, you know, pro-life thing about, you know, shouldn't kill, thou shall not kill, I had no problems terminating pregnancies when it came to see, you know, oh that, that baby is affected and I kept saying to myself, if that is what will make me not to make heaven, then I am very well prepared not to make it. Because I just couldn't bear or have such things that I will bring my baby to the world with an illness... every time that I had an abortion, or I have to, you know, terminate pregnancy my partner will cry, so I got to a point that he couldn't, he wouldn't come with me again because it was stressful..... it's not an easy life and, you know."

"Making decisions about pre-natal diagnosis involves difficult and complex choices, in which couples not only draw on their understanding of the condition but also broader aspects of their cultural identity" (Atkins *et al.*, 2008: p. 2). Religion, for instance, gives a strong cultural identity, particularly for the ethnic population where SCD is prevalent in the UK, but Deborah's religion could not dissuade her from aborting the foetuses, being strongly persuaded that it was the right thing to do. Dyson (2007) argued that in the UK, due to the experiential knowledge of SCD, religion do become negotiable when making reproductive decisions around termination of affected pregnancy. Being known as 'at-risk' person with full genetic information, society constructs a perception that such a one is *lucky* to be armed with knowledge and ability to modify or avoid the outcome of the risk.

Another participant, Caleb, also said he used to blame God and his parents although he no longer does.

"There were times when I was on a sick bed and I blamed my parents, why did they decide to give birth to me with this condition. I blamed God, why did He give me this condition? So obviously as a child you would obviously get to that stage and you question a lot of things but as an adult, you learn to live with it, understand it and look on the bright side. As of today, probably over ten years now, I haven't blamed my parents that I have the condition because other people have something worse."

So, both Deborah and Caleb apportioned blame to *others*, (in this case their parents) for their being brought into being. Caleb unlike Deborah was able to exonerate the parents of the blame later as an adult because he realised, they did not behave irresponsibly when they had him since they were not exposed to the new genetic information.

For Ruth, her rejection by potential partner's family even though the partner was HbAA with no chance of a child being affected made her feel she could marry someone with SCT. She expressed some dilemma though as she thought it more deeply.

"Yeah I may have because I really liked him. I know in one of questions you asked something similar. So, this guy was the exception. He was like my rebound because my head was not screwed on tight, so I definitely would have. But deep down I knew it can't work even though I really liked him. Maybe at the back of my mind I was thinking we could just adopt- because I really liked the guy."

Her dilemma seemed to spring from the strong bond of relationship she enjoyed. This attest to the fact that decision-making for the affected people is not always a straight-forward issue. Agreeing theoretically that there must be a moral sense of responsibility towards the health and well-being of a future offspring did not preclude her deviating from this because of her love for this potential partner who she did not want to lose. During this segment of the discussion, she experienced dilemma or *emotional labour* as she tried to make a choice due to the risk they both had. Though she mentioned that she could opt for adoption, this was not a firm option she subscribed to at point of making decision. She said, *"Maybe at the back of my mind I was thinking we could just adopt- because I really liked the guy."* She had embodied SCD with all the pains all through her life and so knows the consequences. When asked if she would mind having a child with SCD, she reverted to the supernatural, she said,

"No, I wouldn't. and this goes back to my faith. I believe God will keep my child. He has given me this child for a reason. Regardless of what is wrong with this child. He knows I am capable and strong enough to look after this child. So, I don't see it as an issue. Maybe it's because I have sickle cell I don't know. I don't think I would mind..."

Ruth's decision to probably leave it to religion challenged the concept of GR. Some scholars had suggested that genetic information should cause at-risk people to appropriately manage their destinies instead of depending on nature. They consider it morally dubious to do otherwise. (Harris, 1998; Buchanan et al., 2007). Hill (1994b) reported in her study about reproductive behaviours of low-income African American women with SCD who, in spite of their adequate genetic knowledge, deviated from the expected rational thinking when it came to reproductive choice. She argued that "the SCD diagnosis threatened motherhood, an important cultural value among low-income African American women, and that they protected their reproductive autonomy by obfuscating SCD medical knowledge" (Hill, 1994b: p. 29). Cultural beliefs such as religion, societal/family values and other such strong social

factors may affect the reproductive behaviours of the at-risk individuals. Religion had no effect for Deborah though it did for Ruth.

Solomon is a pro-life advocate and will never consider termination of a foetus that is affected. He said,

“The last resort is the adoption if need be. We discussed everything and agreed to use any option available at any stage. But I bluntly told my wife I will never do any termination of pregnancy. If we do all we can to prevent giving birth to an affected child, and an affected baby still came, all well and good. I will never abort a baby, yes, that I will not do. My wife had a different view, maybe because she is a nurse.”

His reproductive preferences were in opposition to his wife’s and would rather go for adoption, but his wife opted for PGD for reproduction. The discordant views between the couple as they sought to make decisions in the context of their sense of obligation to their future child exerted some emotional pressure on their coupledness. Though an individual may have a preference, more often than not, choice will be affected by the preferences of the partner.

Ezekiel also echoed the same rhetoric,

“So, when we were pregnant with my first born the doctors, they were basically trying to get us not to have the baby. Saying that, due to risks they could potentially have sickle cell, tried to get us to have an abortion with her. We’re like, no she’s not doing it and at the end of the day he only had sickle cell trait. So, it would have been waste of a perfect life. The second time we just said, you know what, if the person has sickle cell then they have sickle cell, we’ll manage it at the end of the day, the child is a gift. When we found out my daughter had sickle cell, it was just a thing where we just have to manage her and by the grace of God, she had no issues at all... It’s a risk though, there’s risk with that. So, they said even if they do the test there is potential that she could have a miscarriage. Or there’s a possibility that it could cause brain damage or whatever to the baby. We weren’t taking that risk at all. So, we just said we’d find out... To me, I just don’t want to mess, take any risks with our children.”

Of note is the fact that both Ezekiel and Ruth were relatively healthy, having a milder form of the SCD when compared to Deborah. Their mild symptomology may have impacted on their mindset in terms of their willingness to bear a child with SCD. Ezekiel protected his reproductive autonomy when the clinicians advised them to terminate the pregnancies. He demonstrated his *right not to know* the genetic status of his future children twice. The first time, the child only had the trait, but the second child had SCD. He expressed concern that the test itself could cause a brain damage as well and so he was not willing to let it be conducted. Even though decisions are supposedly automatic, cultural practices do

assume that post-conception genetic tests should lead a *good citizen* to a primary moral obligation towards the *Other* (unborn child) by termination of pregnancy if positive for SCD. Reports in literature show that some people do not seem to reflect much on the consequences of the result because some have found it difficult or ethically problematic to terminate such pregnancies. However, when asked if he would have considered PGD, he said the technology was not available during his time of parenting. I suggest that his decision-making behaviour was based on his limited knowledge of genetic information and also on his desire to parent his child. Some studies have demonstrated that parenthood instinct can challenge rationality.

Theresa, another participant, who luckily had a baby with *HbAS*, says of her next pregnancy if she will consider PGD, she answered,

“Yes, why not? We were lucky to have this child without sickle cell. I will not deliberately risk it now. I will not... No, I do not want a child to go through all that. I will opt for IVFPGD if we are to have another baby. And if I am to get pregnant accidentally and the post-conception result prove the baby has sickle cell, I will opt to terminate it.”

When she was asked what she would do if her daughter wanted to date someone who is affected,

“Truth be told. I plan to encourage her to date only Caucasians not Africans. No, it is not that I do not like Africans, it is the reality of her genetic status. I have been through a lot. I will warn her very solemnly.”

Theresa's experiences as she tried to select a partner framed her perceptions and meanings of the social construct of relationships as well as reproduction for those embodying SCD. Her motherhood obligation and responsibilities to her daughter was demonstrated when she advised her to seek relationship within populations that do not normally suffer from SCD. Two other participants also mentioned using this strategy to ensure they do not select partners that could be risky for bearing children with SCD. Her reproductive conduct to exercise agency to abort any other pregnancy that is tested to be genetically affected was also borne from the understandings she gained from her experience.

The participants exercised multiple strategies to exhibit their moral obligation to their offspring. Many of them described a sense of responsibility towards ensuring safety for their offspring by not endowing them with SCD as they select partners, plan bearing children and in some cases where there are pregnancies, determination to save the unborn child from a difficult life through abortion. For Ezekiel, though, he demonstrated this obligation by refusing to agree with the abortion of their pregnancy. He said, *“To me, I just don't want to*

mess, take any risks with our children.” He exercised his autonomy of a *right not to know*. The medical counsel did not go well with him in the light of a possible brain damage due to the test. He resisted external authorization and power to shape, regulate and normalize his subjectivity.

Some participants demonstrated this responsibility by making decisions to completely abandon biological parenthood and rather adopt children in an effort to prevent bringing an affected child in to being.

Of note is that the strategies employed by participants in the study varied considerably depending on the circumstances of individuals in terms of body impairment and also the socially constructed meanings considerations. Societal construction and tolerability of the condition will influence the individual’s autonomy in decision-making. For example, some participants described changes in their reproductive behaviour in the light of availability or accessibility of improved reproductive technologies. Preimplantation genetic diagnosis (PGD) which allows early profiling of genetic embryo before implantation into uterus was very much welcomed technologies that many of them felt could influence their selection of partners for reproductive purposes. Majority of the participants made mention of this during the data collection.

5.6 Factors Influencing GR

Genetic tests not only provide the individual with guidance for decision making for own life course but also has implications for familial relationships. (Hallowell et al. 2003). This makes the decision around genetic results not as egocentric as the cultural presentation would have us believe. The social responsibilities towards kin and family compound the decision-making process as the interests in sustaining relationships with the kin is challenged. Thus, the familial nature of genetic information creates an ethical problem for the concept of informed consent. The biogenetic discourse around reproductive agency for individuals with SCD is about prevention while completely disregarding the sociocultural dimensions of the decision making. From the narratives, the participants draw upon many other experiences from interactions with family, community such as places of worship, society and often other challenging dialogs about their health in terms of medical or family advice which all build up to form personal understanding of the disorder and the genetic tests (Vahabi and Gastaldo 2003). These understandings and lived experiences of SCD formed the basis for the reproductive behaviours of all participants in the study. Though participants vary in their narratives of their attitudes and behaviour in respect of how to modulate the ruinous effect

of SCD, they all agree with the popular rhetoric of being morally responsible when it comes to making decisions about partner selection and bearing children.

The parenthood instinct of the participants after acquiring adequate genetic knowledge of how the condition is transmitted generated a typically strong moral feelings of responsibility towards their offspring. That may mean planning on selecting a completely non-affected partner (*HbAA*), utilize the new hi-tech genetic procedures such as Pre-Implantation procedures or as indicated by some participants, completely avoid bearing children. These participants claimed control or their autonomous right to decide whether to allow or not to allow a child with SCD to be born. For example, as earlier described, Ezekiel exercised control by deciding against the advice of the expert medical professional about termination of the two pregnancies. Ezekiel also reported how he and his partner, with whom he had two children, decided to terminate their relationship because they became discordant in their individual decisions. He wanted more biological children, but his partner felt it was too risky.

“It’s a thing where me getting sicker, you know, she didn’t want to get another child with sickle cell and I understood. You know, there’s a higher chance our kids would have sickle cell. Yeah. It was a thing where we had to, umm yeah, just basically had a decision now, you know, not to move forward. Because she was thinking of adopting. Me, I wanted my biological children. So, I’m not adopting a child. So, yeah, basically we mutually agreed that, you know what, it’s not going to work so why don’t we just move on.”

Paul on his part said he could accept to be in a relationship with another person who has SCD only on condition they are both agreed on not having children. He said such relationship should not be problematic since both understand the condition well and so may be able to support one another well. However, he called any attempt for such couple planning to have children ‘reckless’.

“Well it would be a no. There would be no discussion about that. That I think is reckless, that’s it reckless, being someone who is suffering from sickle cell I would not like to bring my child into the world with that illness and if you both have the trait or one of you has full blown or if you both have sickle cell it’s a crazy thing to do. You are opening that child to years of suffering, yeah, and why would you put someone else through what you’ve been through if you can help it.”

After losing his wife and multiple unsuccessful relationships, he decided to remain single. From data in this study, various personal factors seem to influence the behaviors of the participants in the way they made their choices around issues of selecting partners and reproduction. Thus, the varying personal circumstances of each participant complicate decision-making processes.

Nature of the Embodiment: SCD manifest differently among the affected population. Some people experience very severe form while some others have milder form. This explains why a few of the participants were only diagnosed with SCD in their adult years.

Mary who had a mild form of SCD said,

“If I did get pregnant, I probably wouldn’t even have tested to see if they had sickle cell and say Oh, do I wanna keep them, because then they’d be living, they’re existing inside me so I wasn’t gonna end a life because the child had sickle cell.”

The impact of lived experience of the impairment on the attitude of participants towards genetic responsibility is reflected in the narratives of the participants. From literature it is reported that personal experiential knowledge of a disease or experience of raising a child with the disease will motivate genetic screening and decisions (Ross, 2015). I suggest that the severity of the SCD symptoms do affect the level of resoluteness to make drastic choices of, for example, terminating an affected pregnancy.

Amos is the only participant who has Thalassemia, a variant form of SCD was asked if he would insist on a genetic testing of a partner, and if he would consider entering a relationship with someone full-blown SCD or SCT, his response was,

“Yes, I have to because, you know, the way I suffered I don’t want to have a child sickle cell. I must plan, I must plan...hummm. I cannot afford to marry someone like me and then have a child who will suffer like me... no way... So, I cannot, for example, go with someone with sickle cell, and plan a future. That’s impossible and that’s the first thing. Or with someone who’s a carrier of sickle cell. That’s not possible. I would not take the risk.”

Amos has been active in a SCD support group where information about SCD and information about GR is provided and encouraged. He made it clear that his experience with SCD has limited him in many ways in life, interrupting his education and impeded his career development. Therefore, he did not want a child to go through what he has gone through in life. His lived experience of the impairment motivated him to be ethically prudent.

Deborah’s narrative has been so much flagged in several parts of this report but hers vividly demonstrated how lived experience can impact on GR. She had a very severe form of SCD, with a liver transplant, hip replacement, less than healthy kidneys and a whole lot of other organ impairments so her experience with SCD was very harsh. This experience must have influenced her resoluteness in terms of genetic responsibility. I argue therefore that the more

severe the experience of embodied illness, the more likely the affected person will endorse the principles of genetic responsibility. Deborah said,

“At that point the whole thing just broke down and I’m like okay we are going to have to stop this, because there is no way. There’s no way you’re AS and I’m SS... I’m not going to have a sickle cell baby and we are not getting married for babies, we’re getting married for each other.”

She was willing to have the romantic partner and forego having children to avoid the risk of an offspring who is affected. Even with the hypothetical question put to her about what her reaction would be if her daughter falls in love with an individual with SCD trait or SCD, her response lends credence to my proposal that experiential knowledge of SCD will determine the resoluteness of one’s attitude to genetic responsibility.

Ruth’s SCD is a much milder form than most of the other participants. Her mild experience of SCD may have influenced her attitude as seen in the following statements.

“No. even when we are talking about having children at some point, SC has never been an influencing factor at all. We have always decided that we will wait after some time then have kids. But with regards to the anaemia, it has never been an issue.”

“But if I had a child here, I am not going to be worried. Because there are so many facilities that my child would be okay. Perhaps I’m thinking this way because I don’t have a severe case of SC. And I haven’t come across people that do have severe cases. Medicine has really advanced”

Definitely, Ruth’s mild experience of the SCD symptoms made her more liberal about obligation towards offspring. She had access to knowledge about advanced technologies and intends to use it if she sees the need without fear of costs.

Zipporah lamented that the clinicians led her wrongly. First, they tried to persuade her to terminate her pregnancies because of her SCD using strong words and later, according to her, they proceeded to remove her uterus without her consent when she was barely 28 years old. Now she is full of regrets because she cannot have a child in her new relationship.

“You start realising that this people do not know everything. Especially with my last child when they told me that I should have an abortion. They didn’t say have an abortion, they said we strongly recommend that you terminate.”

“Even after the second one, they said I shouldn’t get pregnant again but I found myself there again at which time because of my womb they put me on the coil and all that kind of stuff. They just put it in and that was that, oh I forgot about that. Anyway, when that was removed, they had to take out my womb and all of that but now I realise that I should have never had my womb removed because now I suffer from menopause. I

didn't know that when you have your womb removed you suffer from that."

While Zipporah's account cannot be verified (beyond the scope of this study), there were cases in the recent times where disabled people have been pressured to sterilisation through needless tubal ligations and hysterectomies (Ross, 2013; Rowlands & Amy, 2018). Zipporah felt that her right to make a reproductive choice autonomously like other people in society was denied through subtle discouragement by the medical doctor (Kallianes and Rubenfield 1997). Jones, (2010) argued that unrestrained and complete access to genetic knowledge is crucial for making a genuine reproductive choice. (Jones 2010). People with genetic disorders who are or contemplate parenting are always engaged in discourses about risk and counselled overtly or covertly about best ways to avoid risks associated with their reproduction (Hallowell 1999, Thomas 1997). As an individual with SCD, the cultural setting of the clinician as the expert and she, Zipporah, as a passive or docile subject makes her incapable of making an informed decision about her reproductive choice without subtle control. Goodley (2010) suggested that this type of relationship confers a "relational form of *disablism* embodied through experiences of..." "infantilization, patronising attitudes". I suggest that in line with literature, the clinician will influence the decision-making of the individual towards the expected social outcome (Morden, Jinks and Ong, 2012).

Cultural setting including religious beliefs of participants. The cultural setting of the participants, for example, religion do influence their decision making. About three of the participants mentioned their opposition to termination of pregnancies.

Ezekiel said,

"When we found out my daughter had sickle cell, it was just a thing where we just have to manage her and by the grace of God..."

He demonstrated passive attitude, relinquish control of the future to God who he seems to believe can take care of life-course. Thus, he absolved himself from active exercise of agency to ensure control of risk. Since he learnt to manage the symptoms and pain, he indicated that should his offspring be affected, they will also manage it. He did not consider the fact that managing risk for self and *Others* requires some deliberate resoluteness.

Ruth's SCD is milder than most other participants because she said she has never been transfused with blood, been in hospital on admission only once in five years and length of stay in hospital never more than two days at a time. She said,

“Yeah! I personally don’t believe in stuff like that. I just believe that whatever God wants to give me, let him give him. He gives good gifts- no matter how much people may stigmatise you for who you are. He adds no sorrows to His blessings. I believe that children are a blessing from God- so my first point would always be the natural way of conceiving.”

Definitely, Ruth’s mild experience of the SCD symptoms made her more liberal about her obligation to protect her future children. For her, there was no need to do a post-conception test. This means that she did not regard the result of the post-conception test as necessary as she cannot terminate a life.

Knowledge of Genetic Information. Level of knowledge of genetic information and technological possibilities did affect the decisions made by the participants. There is evidence in the narratives that some participants had only partial knowledge about their condition. The researcher noted that sickle cell trait and sickle cell disease were sometimes used interchangeably among the less educated and older participants. The university-trained ones did not exhibit that anomaly. The availability of high-tech technologies of Pre-implantation diagnosis (PGD) that make it possible to implant only unaffected foetus into the uterus, influenced some discordant couple not to terminate their relationships. In the UK, there are limits to what genetic capabilities and resources can be easily accessed through the NHS by people living with SCD. While pre-natal screenings are routinely done for at-risk conception, In vitro fertilization (IVF) is not routinely available. More difficult to access is the PGD process. Some participants were totally ignorant about this possibility. Many have hazy ideas, but the well-educated participants appear to be well apprised about the advanced technology.

Aaron and his wife have master’s degrees in their disciplines and were adequately informed about PGD which they accessed for one of their children.

“So, when we got married, we were going to do PGD IVF obviously, you know. And that’s what we’ve always said to all the antagonists, the church, the parents and all that. So, and we did a couple of fact findings before then, and which all seemed to indicate that it was a possibility, and hence we decided to go ahead. Because if we didn’t think it was possible, we would have just said, “Okay”. “Let’s end it”. Like I ended the rest of, well the previous ones ended.”

From Aaron’s quote above, they would have terminated their relationship if there was no such reproductive technology. Earlier before marriage, he took his girlfriend to the doctor to

ensure they both accessed appropriate information. He was resolute about future children not having SCD, so he sought out all needful information. He never contemplated adopting a child. He wanted his own biological children. He narrated the extensive consultation he had with his doctor before trying PGD. The very complex process cost them sixteen thousand five hundred pounds (16,500.00). Unfortunately, it failed, and they had to conceive naturally, a pregnancy which resulted in a baby with SCD. A few years later, they were introduced to a less complex method of PGD, and they succeeded. Of note is fact that they were not aware about the very expensive and complex nature of PGD before they embarked on it in the first attempt. Church *et al.* (2007) suggested that “complex invisible work is performed by disabled people in every day/night life” (Church *et al.*, 2007 In Liddiard, 2014: p. 4), as they try to mitigate the effects of their subjectivity. Considering all the efforts that went into his ensuring a child with SCD is not brought into being, I suggest that Aaron and his wife subjected themselves to ‘complex works’ of seeking, asking, and researching for information to be able to ensure he conforms to his moral obligation as a parent to his future children. I propose that detailed genetic information should be availed to all persons living with SCD to enable informed decision making at the level of selecting partners and during reproductive decision making.

Zipporah, a participant of Caribbean origin who suffers from a severe form of SCD which made her unable to hold down a job, complained bitterly about not being educated about genetic technologies available. She is not educated beyond secondary school and the last time she worked; she was a cleaner in a large store. She is not in any relationship although she desperately desires to start a family. She heard of the PGD option only during the interview and complained bitterly about lack of genetic information. In her words,

“And the thing is, at the age I am now, no one has sat me down and talked to me about fertility issues. I actually feel quite cheated. You know I still want to have children, I explained to them that I still want to have children and yet no one explained to me what the options are in terms of if I didn’t meet someone who is AA (HbAA) so as far as I know, all I know is that there is a 75% chance that my children would have sickle cell so I can’t take that risk. No one has ever sat me down and told me about what you mentioned, never... I think you need education; I think you need to know that. Because even I myself even though I am well read up on sickle cell did not know the PGD IVF thing in the fertility field, I did not know that. So, if people knew that it is not the end of the world because even me, I had sort of taken that no to AS, no to SS kind of route because I wouldn’t want to have a child suffering... If people knew their reaction would be different.”

Obviously, the hope of being able to have a child who is unaffected with a partner who is at risk genetically would influence the decision-making process. The participants that regularly attend SCD support groups seem to understand genetic information and concept of genetic responsibility better than those who don't; and it seems the knowledge gained from those meetings influence their decisions. Zipporah could not attend these support group meetings regularly because of her ill health. Damaris one of the participants argued that all persons entering relationships have an obligation to know their status and be genetically responsible. She said,

"The choices you make when you don't know something and when you do know, are completely different. It's not that I am opposed to those with sickle cell and the trait being in a relationship, it's not that at all, it's just that we are in a generation now that our generation should know that we shouldn't be getting people who don't know whether they have the trait or not."

Rebecca also concurs with Damaris when she said,

"Be sickle cell aware, there are sickle cell support groups and that is what we are there for to give you information, so you can make conscious decisions, mull things over before you go in both feet first. You might not even mind having a sickle baby despite the pain the child might go through and if you really want a sickle baby why not adopt one. People just need information because when you have reached an adult mind, you are capable of making decisions so make your decisions but be informed."

Another participant, Theresa said,

"I have thought about what the doctors are saying and I think I agree with them. Even at the sickle cell society, that is what they are saying. It is better to be responsible in choosing a partner, if only because of the oncoming child... If all people with sickle will avoid this, soon, no-one will have the disease in the country. This is what they are saying. It is a fact, not because of race."

These three participants attended support group meetings regularly and seemed to have grasped some level of genetic knowledge. For them, genetic information is empowering. They understand the information so well that Theresa could say, *"It is a fact, not because of race."* That comment is underpinned by the long socio-historical accounts of racism against the black people across Europe and America and the political history of SCD, that created mistrust in governments' policies and intentions. Most people in those black ethnic communities believed the conspiracies that those policies were implemented to annihilate black people hence Theresa clarified the benefit of genetic responsibility with *"not because of race"*.

Emotional bond with potential partner. Other factors that can affect reproductive behaviours extracted from the narrations of participants is the strength of the bond between a couple. This was typified in the narratives of Ruth. Her expression about a potential partner she really liked confirms how emotional bonding with a partner who may be risky can affect a resolve to be responsible.

“Yeah I may have because I really liked him. I know in one of questions you asked something similar. So, this guy was the exception. He was like my rebound because my head was not screwed on tight, so I definitely would have”

David, a well-educated participant, narrated that he was in a reciprocal love-relationship with a lady and expected they would just take the SCD as one of the challenges of life. He recounted how this lady abruptly terminated the relationship as advised by their pastor though he pleaded with her that they can seek for a solution *“because life is always throwing challenges”* He felt the love bond could take them to seek solutions, even if it may mean they do not have children, or they can engage the PGD methods. The emotional effect is obvious on his relationship and reproductive decision making.

5.7 Conclusion

This chapter illuminates the theoretical stance of all the participants with regards to genetic responsibility. They all concur with the medical professionals and the wider society that there is a moral obligation by people who are affected to acquire genetic information for the purpose of managing their embodied risk for sake of self and their offspring. Most of them categorically said they will rather select romantic partners that are not affected in order to avoid having an affected child. The narratives also reflect the ways in which autonomy to choose a partner or make reproductive decisions is constrained by practices of governance and surveillance.

A number of them referred to their lived experience of SCD, the bodily pains and the socio-psychological effects being important motivation to make choices that will safeguard their future children from being affected. However, their narratives depict the difficulty of finding partners that are *HbAA*. They feel they have a right to romantic partners just like everyone else in society which is quite contrary to some cultural thoughts that people with disability or abnormal bodies are asexual or unfit to be parents. (Hwang 1997; Palombi 2012). Three of

the participants relinquish this right and decided to be single because of the emotional oppression they experienced from society as they seek to find partners.

This chapter also highlights the varied strategies they developed to achieve this aim. Just like Aaron put it, an individual with SCD needs to be intentional about selection of romantic partners and reproductive activities because of the consequences that may result from careless living. He said, 'if you fail to plan, the person will fail drastically'. Another participant concurred that genetic knowledge should inform the reproductive decisions made by people who are affected. Two of the participants, for example, decided to select romantic partners from Caucasians among whom they reckon SCD is not prevalent. A third participant also said she will influence her child to select Caucasian partner so as to avoid SCD. That way the possibility of being engaged with partners at risk will be remote. A number of participants made decisions not to have affected individuals as romantic partners. They opined that once an individual is aware of own status, efforts must be made to have that consciousness and mitigate any possible romantic relationship with another affected person. Solomon, one of the participants said it is mandatory for all black people to test and arm themselves with their status information. He called it 'reckless' living not to be sure of one's status as well as the genotype of a potential partner. Four participants said they can marry anybody even if they have HbS, but they are open to adoption instead of having biological children once there is a risk. An assumption most of them made is that though they embody SCD, that does not prevent them from engaging in intimate relationships because they felt they can control the outcome of the relationships by making rational choices. The participants understood that their obligation to safeguard their children is autonomous so no one should be forcing them to make such decisions. Most of the participants generally demonstrated instinct of parenthood to protect offspring from harm, even though their decisions did not change their own already problematic body.

Two of the participants complained about their autonomous right to make reproductive decisions being challenged by medical professionals who tried to influence their reproductive decisions. Ezekiel, one of the participants demonstrated how he resisted the counsel to terminate two pregnancies. Though one of the pregnancies resulted in having a child with SCD, he did not regret his action. For him, his parenthood instinct to protect the child from harm was more important. He, like one other participant, took control of their future life-course, using their personal knowledge of their embodiment to make their reproductive choices rather than the view of the medical fraternity. Zipporah for example regretted listening to her medical professional who persuaded her to undergo hysterectomy

when she was younger so as to prevent her having children who may be affected. Her current knowledge of the possibilities even though she is embodied with SCD made her regret such procedure.

Of note is the case of Hosea who at the time of interview was in a romantic but casual relationship. His attitude to the relationship even if it led to an affected pregnancy, was non-committal. He did not feel any obligation to manage the risk nor was he bothered if the outcome of the relationship is an affected pregnancy.

From data, there are varying levels of genetic knowledge which can inform responsible behaviour in terms of selection of partners and reproductive decision-making. Among the participants, there seem to be a disparity in the level of knowledge of Genetic Information they have. The university-trained ones seem to access higher level of technical possibilities more than the participants with low educational status. Hence in terms of informed decision-making, the highly educated ones seem to be at an advantage. The well-educated participants like Aaron knew about the Pre-implantation Invitro fertility diagnosis so he with HbSS was able to marry his partner who is HbAS. He ensured his girlfriend and himself accessed appropriate genetic information from the doctor about genome possibilities. He was determined not to bring a child with SCD into being. About four other participants said they were unaware about the new technology. Of the participants who are not very educated, those who attended SCD support groups seem to be better apprised about new genetic technological procedures. Damaris and Rebecca who attend such meetings said available technological procedures should influence reproductive decision-making and that all persons entering relationships have an obligation to know their status and be genetically responsible.

In line with literature reports, data reveals that there could be a discrepancy between theoretical stance for genetic responsibility and actual decisions made when affected people face the reproductive decision-making. Also elucidated from the data of this study is the fact that many factors and circumstances in the lives of the participants do challenge their natural obligation to their offspring and kin. The narratives highlight the complexity that exist in reproductive decision-making, whether at the level of selecting partners or at parenting level because some social issues compete with the moral obligation to prevent transfer of HbS to future children. In other words, life situations may make reproductive choice to change. For instance, an individual who is committed to make choice responsibly may be in emotional relationship with another at risk individual and so abandon a formerly held stance. Ruth, one of the participants was willing to marry an at-risk person because she liked him

very much and was willing to opt for not having a biological child. Some of these social factors elucidated from the narratives of participants are cultural beliefs such as religion. Three of the participants said they will never engage in abortion of a foetus who is affected. Ezekiel talked about relinquishing his fate to God rather than abort a baby. Ruth also will not abort an affected pregnancy. Of note though is the fact that Ruth who has a milder form of the disease, never had a blood transfusion and is hardly on admission in hospital was not so against partnership with a person who is affected. I suggest her stance may be because of her mild lived experience of SCD. Deborah on the other hand who suffered the most severe form of the condition commented that though because of her religious stand she would not normally terminate any foetus, but her severe experience of SCD influence her decision to terminate three affected pregnancies.

Another factor that can influence individuals from being irrational in their reproductive decision making is the emotional bonding between two people who are affected. Ruth and David both narrated such experiences. They were willing to obfuscate their genetic knowledge to marry the potential partners. David mentioned that other solutions and options can be sought for such as adoption instead of having biological children.

In all, they demonstrated their autonomy as they made decisions around these arrays of reproduction decision making. In some instances, they resisted the dominant attempt to compel them to absolve their autonomy rights of making their own decisions according to the meaning they ascribe to themselves as well as their identities. The older participants who were not categorised as risky when they were involved in forming of relationships and also parenting did not experience any of the feelings of obligation or responsibilities apart from the normal parenthood instinct experienced by all peoples, able-bodied or not. The dilemmas experienced by adults living with SCD at point of forming relationships or at level of making reproductive decisions were completely absent in the life-course of these elderly participants.

CHAPTER 6

STATUS DISCLOSURE

“People generally didn’t think that you could live life and the moment you would say I have sickle cell; it will be sorry I am AS; I am not going forward with this”

~Rebecca

6.1 Introduction

This chapter focuses on the impact of SCD status disclosure on the selection of romantic partners and reproductive decision making of adults living with SCD in the UK. The participants described their disclosure experiences with the prospective partners, friends and in some instances, families, as they seek to settle down in family. Liddiard (2013) and Wood (2007) defined self-disclosure as sharing of deep and intimate details about self to another person, a sharing that can build or dismantle the relationship.

In this study, self-disclosure will be limited to genetic status disclosure. It refers to at-risk individuals, feeling a perceived need or being ethically obliged to divulge their genetic status to potential romantic partners despite possible negative consequences of such disclosures. Such consequences may include termination of relationship, emotional pain due to shaming and rejection, feelings of being diminished in the eyes of *others* or even reduced social status (Klitzman & Sweeney, 2011). Green and colleagues investigated disclosure of BRCA/1/2 to potential partners and said the individuals were motivated by *the* awareness of health implications for partners and also for a successful relationship, deep information about self must be shared (Green *et al.*, 2003)

This chapter also presents the dilemmas many participants faced when planning the disclosure. Nearly all participants (N=23) experienced negative responses from at least one potential intimate partner in their lifetime. Some narrated their painful ordeal while others seem not to be overly disturbed by the negative responses. All participants agreed that status disclosure must be made to the potential partner if the relationship is a serious one. Some of the participants believed that disclosure must be strategized to produce maximum benefit. The various aspects will be elaborated upon later in the chapter.

The findings from the participants will be discussed under six sub-themes as listed.

- 1) Attitudes of Participants to Self-Disclosure
- 2) Whom to make disclosure
- 3) Non/Disclosure for lack of awareness
- 4) Strategies employed for disclosure

- 5) Impact of Family and Friends on disclosure
- 6) Outcome of Disclosure

6.2 Attitudes of Participants to Genetic Status Disclosure

From the data, gender did not seem to have any impact on disclosure. All participants sensed ethical obligation to make status disclosure to their partners so as to enable them to make informed decisions about managing their risks. Both male and female participants expressed being motivated to disclose by their lived experiences of SCD, genetic knowledge of transmissibility of the disorder to offspring as well as the fact that the partner has a right to know.

Micah, one of the male participants was of the opinion that disclosure is a must. He said emphatically,

“Oh no, I must disclose my genotype, and also know that of my girlfriend. Why bring a child into the world knowing they are going to have sickle cell? If they are AS, if they meet someone who is AS and they are carriers then there is a one in four chance the child is going to come out with sickle cell.”

Solomon, another participant has this to say when asked about people who do not disclose their status or who do not even know their status,

“Reckless, reckless. All Black people and Asians should know their status from birth. It is important. If you know what you are up against, then you can plan. But if you do not know, that is the problem. And no-one should take a partner’s word for it when it comes to status. Insist you both go to the lab and test so that there is no assuming anything. That way, you have all valid information.”

So, across board, all the participants were of the opinion that disclosure must be made to serious potential partners and genetic testing must be done. Solomon demonstrated very strong opinion about all populations among whom SCD is prevalent to know their genotype for risk management around selection of romantic partner. The genetic status of the potential partner can become an important information about suitability of partner for parenting because of possible long-term implication for his offspring. He apportioned moral judgement and blame to couple who do not know genetic status before starting a relationship when he called it *reckless*. He felt that a person with SCD may not be able to change own embodiment but should be diligent to ensure illness is not transmitted to future generations (Kessler *et al.*, 1984). Deborah presented a tragic but common occurrence. She asked her partner about his genotype. He said he is *HbAA* obviously because he is hardly

sick. Deborah did not insist that he goes for screening again to confirm his genetic status. Unfortunately, after firm establishment of their relationship, she discovered he was a carrier.

“He knew that there was no way I was going to have a sickle cell baby, he knew that, you know, I was only going to marry an AA and he did say he was AA, even though things turned out to be different, um, so yeah, he did know early on.”

Obviously from her case, knowing and disclosing one’s status is one thing, also ensuring that the status of the partner is known is quite another. Terminating a relationship when it is well established can be very difficult.

Zechariah believes it is necessary to encourage partner to test and disclose. He figured an informed decision could prevent heartbreak later like in the case of Deborah:

“I mean that’s one of the reasons why I always make sure they know that I have it. If I ever met somebody who don’t know that they have it, I always try and encourage them to go and find out especially if it’s a serious relationship.”

For Zechariah, disclosure of his genotype and also educating potential partners who are ignorant about their status is a necessary component of process of partner selection. Most of the participants recounted that their motivation for ensuring they do not transfer SCD to their offspring is borne from their experiential knowledge of SCD rather than from the instruction of *Others* such as medical professionals or family.

Genetic responsibility is a vital factor influencing people who embody SCD to sense an obligation to make a disclosure to a potential partner. Zechariah and Solomon were middle aged men who also had tertiary education and so well informed about genetics and its reproductive implications. Their embodied knowledge as well as their experiences may have informed their inflexible resolve about disclosure and ensuring potential partners test for genotype. Deborah embodied very severe form of SCD, both socially and physically and was very determined not to transfer HbSS to her future child. But she was much younger and inexperienced about life than Solomon and Zechariah were, hence, she easily believed her boyfriend when he said he was *HbAA* and did not insist he double-checked his status. This is quite in contrast with earlier studies among people with SCD which reported that reasons for not knowing partner’s status were because of uneasiness and sensitivity of asking their potential partners to test and a lack of awareness of the necessity and availability of genetic screening (Asgharian *et al.*, 2003; Hill, 1994). I suggest that as public education about genetic screenings and nature increases, lay people get better understanding of the issues and also get acquainted with the processes and purpose. A

well-educated society will produce individuals who being at risk are more at ease with making informed decisions and choices. Disclosure of their genetic status was one of the reproductive agency strategies participants employed to ensure they did not bring their offspring into being with SCD to suffer all the experiences of physical, emotional, and stigmatizing situations.

6.3 Whom to Make Disclosure

Christensen (2011) suggested that “each person ‘owns’ his or her private information... it would seem careless to trivialize these ‘possessions’ by freely giving them away to relative strangers” (p. 3). One’s own genetic information is personal information, more so as it defines one’s identity. Deciding to make a disclosure or not depends on how much trust the discloser has in the recipient of the information and what the discloser expects to gain from the relationship (Christensen, 2001). In other words, disclosure is made with the hope for a reward of increased intimacy and to help move forward with the relationship.

Most of the participants in this study agree that disclosure should be made only in serious relationships and not casual relationships. Self-disclosure is a boundary regulation in the maintenance of privacy and individuals control the kind of relationships they want through the adjustment of the “boundary” of self disclosure (Derlega, & Chaikin, 1977). Several of the participants are confident and educated people with some level of self-esteem even though they live with SCD. Scholars suggested that chronic illness can be an attribute that is “deeply discrediting” (Scambler, 2009; Goffman, 1963). These participants therefore would not divulge such personal information in a casual relationship. They all feel it is important to disclose genetic status to potential romantic partners they intend to share their lives with, even with the risk of rejection. They are agreed that such obligation outweighed the fears of termination of relationship. Caleb and Jonathan expressed this feeling of disclosing status only when the relationship is serious. Jonathan said:

“I don’t think it’s something that, you know, you don’t really go for a drink and you know meet a girl and say you have sickle cell... I think it’s, it’s really only important if you get to stage of like I say you must be having a family later on during the relationship rather than when you first get together.”

Mary also concurred that even if one does not want to share one’s status in a relationship that is not serious, a serious relationship such as co-habiting (such as marriage) warrants a disclosure.

“...You know, you can still tell all those white lies. But when you’re sharing the same space, it’s impossible...”

Mary had mentioned how she often pretends all is well with her boyfriend who later became her husband even when she is having some pains and discomforts. However, she argued that many of those pretences may not be possible once one is in the shared space in a marriage. Thus, she suggests it is mandatory to make a disclosure to a potential partner with whom one plans a long-term relationship such as in marriage.

Hosea mentioned that he is in a *casual* or unserious relationship and when he was asked if he has made a status disclosure, he said,

“Oh no I don’t. I really don’t think it is any of their concern at this point. If I was looking for something serious then maybe I would think of saying it but not now.”

Even when he was asked if he considered that an affected child can be conceived, he maintained he will not make any disclosure because the relationship, though intimate and romantic, is not a serious one. This suggests that motivation for some participants making a disclosure is their perceived seriousness of the relationship. As suggested by Christensen 2011, participants considered their genetic status a very important and private information that cannot be trivially flung to a casual romantic partner (Christensen 2011: P. 3).

6.4 Non/Disclosure for Lack of Awareness

A few of the participants who were older did not make any disclosure to potential partners when they were forming relationships. Eve is a 56-year-old participant of Caribbean origin, who was very sickly all through her life. She explained that her SCD was mistaken for rheumatism pains by her mother when she was growing up because there was a complete lack of knowledge about SCD. Even when she grew older in the UK and was diagnosed with SCD, there was still no awareness about the genetic nature of SCD or its implications on future offspring in her community when she started engaging in romantic relationships. Definitely, in the medical circle, SCD was already known considering the age of Eve but as far as she is concerned, there was no public knowledge or any counselling then. She said of status disclosure:

“No, it was not an issue. I did not know all about those things then, about testing before marrying or anything like that. It was non-existent in those days. I am talking about over 30 years ago. No-one talked about genetics or screening and all those things. I just keep appointments in the hospital for check-up. That is all.”

Jonathan, who is also a middle-aged individual, grew up in a “White populated area” and knew he had SCD but had very limited genetic knowledge of how it is acquired or its effect on future children. He disclosed his condition to his partner who later became his wife. She too was ignorant about it then:

“You know obviously my wife and I got married didn’t know much about sickle cells. And I guess sickle cell let’s say it was something that no one probably even understood or even knew existed back then. So, I wouldn’t say it affected me in that way.”

Another older participant, Micah, knew he had SCD but was not exposed to genetic information regarding transmission of *HbS* to future generation. For his first serious relationship, he mentioned his status to his partner:

“Yeah, I told her I have sickle cell. I don’t think she knew really what it was... it could have been maybe 6 months or a year (into the relationship).”

The society in which these participants lived were totally uninformed about SCD or its transmissive nature. These older participants were sickly, and all bore the body burden of SCD, but they and their partners were unaware about its transmissive implication to offspring. The two participants who made genetic status disclosure to their partners only did so to let them know about their frequent ill-health. SCD did not impact their forming relationships because society did not have any understanding about SCD or create any stereotyping about their condition.

The NHS in *The UK Strategy for Rare Diseases*, (Department of Health and Social Care, February 2019) formulated and promoted genetic screening policies to enable people who are affected make responsible choices of romantic partners for reproduction. The NHS hoped this strategy will ensure the at-risk people make choices to avoid transfer of *HbS* to future generations for improved public health. These predictive genetic screenings unintentionally created a split in society as affected individuals become viewed as possessing undesirable attribute which makes them in *deviance* from the rest of the society. Most of the studies on chronic illnesses upholds the dominant cultural understanding that illness is *abnormal*, inherently negative, and a personal tragedy (Campbell, 2005; Campbell, 2008; Thomas, 2007). With the unfolding of the transmissive nature of SCD as a genetic condition to the public, the bodies of people with SCD became considered as *dangerous* and problematic. These meanings allotted to SCD generally created marginalization, labelling and stigma in society. These meanings and reactions from an individual’s social

environment impact on self-concept of the individual. Exeley and Letherby (2001), argued that “self is understood by a person in terms of auto/biography” (Exeley and Letherby, 2001: p. 114). An individual who embodies the *undesirable* trait which is promoted publicly to be dangerous for parenting, will not only have their self-identity and confidence impacted negatively (e.g., Pfeffer & Woollett, 1983; Exley, 1999a), but also may be perceived as ‘less’ in social relationships with others. “Illness may threaten a woman’s self-worth and jeopardize her ability form intimate relationships” (Hoskins *et al.*, 2008). The ordinary, everyday living activities of romance and making family, enjoyed by the *normal* people in society, become problematic for the individuals as the authorities and the rest of society *pathologize* their bodies.

The above mentioned three participants did not experience any problematic disclosure to their partners because there was no genetic knowledge in society nor was any public meanings attached to their ill-health. Afterall, there could have been many sickly people from any other conditions, but those sicknesses did not define them. In case of Eve, her mother and her society thought she was suffering from rheumatism. Although rheumatism is majorly suffered by old people, society could have just called it early rheumatism. Nobody dies from rheumatism after all. I suggest that the problem experienced by other younger participants at the point of disclosure was not because of the embodiment of SCD alone but because of the creation of the genetic category in society of *affected/non-affected*, *normal/abnormal*, which classify them as unfit for certain societal functioning such as parenting. The biomedical and cultural meanings created the social problems around these life activities for the individuals.

In contrast to the medical model, social model of disability does not locate disabling social problems “in the head and bodies, the psyches, of disabled people” (Goodley, 2011: p. 716), but in the normative society’s understanding and attitudes. The involvement of the government with policy development and implementation wielded some form of credibility to these meanings of the normative culture about unacceptability of the condition. This may covertly exert some political *power* on the individuals to make decisions that will completely avert the “tragedy”.

6.5 Disclosure Strategies

From the participants’ interviews, it seems many of them felt disclosure of genetic status must be strategized. Reports from literature also corroborated this sentiment that disclosure does invoke some complex internalised pressure in the persons making the status

disclosure. Klitzman and Sweeney (2011) argued that “dating situations are critical to the possibility of establishing an ongoing supportive relationship... and of having children” (Klitzman and Sweeney, 2011: p. 98). They suggested that it is during this early part of a possible relationship that both two individuals assess each other and make decisions if such life investment into each other’s lives was worth it. The individuals at this stage face the dilemma of “whether, why, when, how, and what to disclose” (Klitzman and Sweeney, 2011: p. 98). These are disclosures made voluntarily. Voluntary disclosure denotes the plans of the person with the SCD to deliberately divulge their own genetic information to their partner. The internalised pressure is borne from the knowledge that the implications can be positive or negative.

Mary is a young woman who got married just three years before the interview. She does not yet have children. She felt that there is a right timing for disclosure to potential romantic partners.

“When you meet someone, and you like them... then comes the dilemma of when to tell them. Cause it’s kind of like ‘coming out of the closet’. You know, then comes the dilemma of deciding, you know, when is the right time to have the conversation that ‘I’ve got sickle cell.’”

Many studies in literature had also described *disclosure* as the process of “coming out of the closet” (Davidson and Henderson, 2010; McRuer, 2006; Sherry, 2004; Swain and Cameron, 1999). Mary’s narrative of disclosure being like “coming out of the closet” correlate with Christensen (2011) that disclosure is a private and personal information that many people will not want to fling out to just any casual person

She further narrated,

“And, you know, but later on in life, I think it became a deliberate thing. I had to plan when to tell people, and I realized that, you know, you don’t just hit people on the head with it, on your first date... At the same time, you don’t wait until, you know, the invitations are printed before you come in. You have to, sort of let them get an insight into you, get to know you as a person, possibly, start caring for you before you make that kind of, in quote confession... It’s just a time when you feel... comfortable with each other... They care about you a bit... If you let them get to know you just a bit, then they can see you rather than see the disease.”

She explained that there is a right time for disclosure which she learnt after some failed relationships due to wrong disclosure timing. She argued that in the past, she used to be casual about disclosure. But she later realized that disclosure should be handled with care, it needs to be well planned. She opined that a premature disclosure before the potential

partner has become well acquainted with the individual will likely lead to failure but when the couple are well acquainted with one another, the decision-making of the potential partner will not be based on the genetic status alone but also on the totality of who she is.

Like Mary, some of the participants suggested that there is a right time for disclosure in a dating phase, it should not be too early so that decision making of the potential partner is not solely based on the impairment condition and must not be too late to avoid emotional upheaval if relationship must be terminated. However, most of the participants believe that early disclosure of status to partners is the best strategy for the sake of their significant *Other* and for themselves as protection against undue heartache in case disclosure results in termination. Many of them narrated multiple relationships that terminated after disclosure and thus they learnt that it was important to strategize disclosing.

Damaris narrated an experience this way,

“The first date I had looked quite mannered. We were both in uni at the time. Same city different unis So back then, I had already made up my mind that I will tell any potential boyfriend that I have sickle cell, so they could have the time and space to make up their mind whether they want to continue with the relationship or not. So, I did that on the first night. At first it seems he didn’t mind, you know. But as the evening wore on, I noticed that his countenance had changed, and he ended the date earlier than we had planned. He said he just remembered some homework he needs to submit as the deadline is that evening. So that was it. Evening done. Relationships are such a pain.”

Damaris explained that she felt an early disclosure was the right thing to do but her experience with that date made her change her mind about early disclosure.

She further said in her analysis of what happened that day, when asked if she felt her disclosure was the reason for termination of date:

“Absolutely! He just ran. He didn’t give me a chance to explain anything to him. He ran like what am carrying is contagious and must be rid of me at all cost.”

Her date literally walked out on her, so she changed her strategy. She concurred with Mary on the need to strategize, allowing for some period of fully getting to know one another so that decision on whether to continue with the relationship will not be based on the impairment alone: For the next date she said,

“Because of my experience in uni, I decided I was only going to tell them about my SCD after we have known each other very well. So, I waited for about nine months. I think I was nine months into the relationship before I

told him I had SCD. I was nervous, you know because of my past experiences and all.”

Most Participants however felt differently. They argued that the pains and hassle of an established relationship should be minimised by early disclosure. Paul, for example said,

“Oh, she knew from day one cause I’ve always had this principle, it’s better you tell the person at the beginning than tell them later... I have always lived by a principle, what I always do the first time I meet somebody who I am interested in I always tell them I have sickle cell. I find that it’s better you tell them at the beginning than you tell them later and they start to pull away from you. So, they know from day one what they are getting into. So, I have always brought it up in the first evening that way they have a choice.”

Hannah was also of the opinion that it is better to disclose to potential partners early so they can decide whether to continue in the relationship. She expressed it this way:

My first rule is to tell them about sickle cell and that I have sickle cell... Right from the beginning.”

In a similar manner, Ruth also expressed the same view of early disclosure to avoid needless hurt:

“I knew I had to tell him early on. I’ve done this in previous relationships as well. I tell them early on. You know if you’re not happy- just keep it moving.”

Hosea said it this way:

“From the beginning. Obviously, given my status, it has to be one of the first things I declare before things get any serious, you know. So that we don’t get half-way, and when emotions start to kick in and then you now start declaring it, you know. I think at the earliest time possible before emotions start to rise, lay the cards on the table.”

For these participants, they had to decide on what is most important to them; whether the experience of excruciating pain from rejection when relationship has progressed well or the possibility that the relationship will not be terminated if the potential partner is allowed to be better acquainted with who they are before being confronted with the reality of their genetic status.

Micah relays his experience about a self-disclosure:

“I remember I met one girl, I was quite young then that was in my 20’s, I told her I had sickle cell and never saw her again... Never saw her again, and she was a black girl.”

Micah highlighted the race of this girl possibly to demonstrate the fact that disclosure of SCD will always impact the decision-making of a potential *Other*, irrespective of race. Society's understanding of SCD is that it is a 'black person's disease', and Micah's expectation was that of understanding and tolerance since the potential partner is also a black person. His experience made him decide he may be better off to seek partnership among white population since SCD is not prevalent among that population.

These participants presented the disclosure point as uneasy and oppressive. The cultural attitudes that view the affected as people to be avoided as romantic partners if parenting is being considered make the disclosure point critical in the survival of the relationship (Link & Phelan, 2001; Goffman, 1963). Reeve (2002) suggested that such an internalised oppression felt by the disabled is *psycho-emotional dimensions of disability*. Damaris' experience of abrupt termination of a potential; relationship because of her embodied SCD was emotionally disabling and did affect her self-concept (Reeve, 2002: p. 495). For the next two relationships Damaris decided to delay disclosure until they were better acquainted with one another.

Ruth narrated her disclosure experience

"He came to the hospital with some soup as he was sat there the nurse came in. You know she would read your file? It was s annoying... She read out my date of birth and said... 'You have SCD...' And I was like 'yes'. So, she asked me some other questions and then she left. And I felt so embarrassed."

She was embarrassed because the status disclosure was involuntary and unplanned. She felt the nurse was not discerning or respectful of her privacy when she indiscriminately announced her condition in the presence of a visitor. Michael also had an unplanned for disclosure by nurses while a girlfriend was visiting him in hospital.

"I was unwell and could not go for practice, so she came to see me in hospital and heard the nurses mention sickle cell. After I left the hospital, she asked me, and I told her. Surprisingly she started crying. It was so embarrassing for me. I mean..."

Disclosure of a genetic status is expected to be autonomous. The lack of respect for privacy contravenes the principle of Human Right in the UK. Though not the focus of this study, there are research reports in literature that addressed this phenomenon. All participants who reported this experience narrated being very embarrassed when clinical staff made such public disclosure of their embodiment. I suggest that the embarrassment of such unplanned

involuntary disclosure which caught them off guard demonstrates an aspect of *disablism* which will be discussed in detail in the subsequent chapter on *Stigma*.

Theresa claimed that her SCD was visible because she had the characteristic stunted growth as well as a knee replacement. She walked with a limp. Goffman (1959) suggested that the body, intentionally and unintentionally, communicates social information about us to the *others* (Goffman, 1959; p. 1). Theresa affirmed that her potential partner knew right from when they met and became friends that she had SCD. This is also a form of involuntary disclosure because her SCD was visible right from the onset of their relationship. The potential partner's perception of the condition might have been influenced by the cultural meaning given to the ill-health and that could make him have a psychological 'power' or 'edge' over Theresa as they contracted a romantic relationship. Reeve (2002) argued that "having an impairment which is immediately visible presents the observer with privileged information and therefore power, about that body. This *gaze* is influenced by the stereotypes and prejudices about disabled people and so the power of the *gaze* is intimately linked and nourished by knowledge from within the social domain" (Reeve, 2002: p. 499). Though the relationship progressed, she discovered it was not for real. She was being taken advantage of. She said,

"Later one of his classmates confessed to me he said he was relating with me because of my British status. Even if he married me, he will seek a divorce once his British status stabilizes. I was shocked. That was the end of that relationship."

David narrated his experienced of a disclosure:

"I met a girl in the factory who I felt liked me. I was only 18 then, she was probably about 20. I asked her for a date which she conceded to. But just an hour before we were to go for the movies, she called to cancel it. When I asked her why, she said my closest friend in the factory told her I have sickle cell and it is better she does not start any romance with me. That is how that first relationship ended."

David's experience is an involuntary disclosure made by a friend at workplace. He was also embarrassed by the attitude of the potential partner as this was his first date. He was discriminated on by the social friend. While involuntary disclosure may be deemed not fair, it does save the participant from the dilemma of having to plan a disclosure, Involuntary disclosure tends to be easier than having to knowingly plan a disclosure. Morris (1991) argued that any disabled person is aware that a public genetic disclosure is demeaning

since “the public world will be dominated by stares, by condescension, by pity and by hostility” (Morris 1991: p. 25).

Hosea did not disclose his status to his girlfriend for three years for fear of rejection:

“At the time I didn’t believe it was necessary to share that I had sickle cell with her. Especially the first two years. So sometime during the third year I told her. She was very upset that I hadn’t told her earlier and she said she couldn’t be with me anymore... Yeah that’s why she broke up with me because she said that I was not honest with her from the beginning.”

She could not trust him again. Concealment of impairment status is emotionally laborious according to Church *et al.* (2007) who posits that people with impairment often perform “complex invisible work” to “stay corporately viable” in the normative public. He further explained that these types of “work included hiding impairment and its effects;” particularly in the private sphere of intimate relationships (Liddiard 2014: p. 4; Exley & Letherby, 2001: p. 115). Wong (2000) described these types of (emotion and other) work employed by the disabled in reproductive and sexual space as “work has become an umbrella code that encompasses both the barriers’ women face and the agency they exercise in dealing with them” (Wong, 2000: p. 303). The concealment breeds distrust and does not foster a relationship.

Another participant, David, also experienced this and lost a relationship. He had experienced two painful terminations of potential relationship due to SCD. He deeply wanted a woman as partner. However, he feared disclosing his status to her for a period of one year. He had many opportunities to disclose his status because the woman had a sister with SCD, and she often told him about her sister’s SCD crisis:

“No, so, that was the problem. At the time I was afraid the relationship will terminate again so, I just did not want to share that I had sickle cell with her. One day, when we were talking about her sister again, I slipped and mention that I do experience the symptoms she was talking about. It was a mistake, a grave mistake and I paid for it. She was very upset that I hadn’t told her earlier and she said she couldn’t trust me again.”

Some participants talked about their experiences of deliberately delaying disclosure because of fear of losing their partners. Thomas 1999a conceptualized the danger of concealment, if the individual is hiding an impairment and is later discovered. She called the unsettling emotion borne by the fact that the genetic status will eventually be known “the negative psycho-emotional aspects of concealment” (p. 55). She explained that it throws

the person with impairment as being dishonest and that can negatively affect or stall the budding relationship (Thomas, 1999: p. 55).

Solomon pointed out that from his experience, getting through the stage of disclosure successfully does not imply that all is well. He explained that there could still be hurdles to overcome:

“Well, because of my first experience, I had this attitude of telling them early so if they do not want to, they can just move away, but even that did not work. They tell you they will convince their parents but when the time comes, they inform them.... and the relationships fizzle away.”

Morris (1991) described how each person’s intersection with the normative public is challenging.

Solomon’s narrative demonstrated the fact that for many of the potential partners, the opinions or choices of *Others* such as family members, friends, clinicians or community leaders such as church leaders do influence the outcome of disclosure. His experience corroborates with concepts of Thomas (2009) as people are relational identities (Thomas, 2009). That will be elaborated upon late in this chapter.

The different strategies of disclosure described by the participants include voluntary and deliberate disclosure which can be done very early in the relationship or at a strategic time when the persons making the disclosure are convinced the potential partners are well acquainted with who they are and can make an informed decision about whether the relationship is worth it or not. Another type observed from the data is the involuntary disclosure when the individual’s status is either accidentally revealed to partner through a clinician or in some instances, disclosure is made by a member of the society such as a friend or colleague. Another involuntary type of disclosure is when the disease is visible, and the affected person does not need to disclose. There is also a deliberate delayed disclosure which very frequently occur when the affected person is not courageous enough to disclose for fear of losing the partner. Invariably, the partner casts this as a concealment and it breeds distrust. One case of concealment was because the participant considered the relationship as casual and so does not want to make a disclosure.

Although it is beyond the scope of this study, I noticed that most of the male participants prefer early disclosure while the female participants opted for more strategically delayed disclosure.

6.6 Impact of Family and Friends on Disclosure

Solomon said,

"I don't know. Sickle cell is a big issue. And you know it is not even the girls, it is mostly the parents. I have had horrible experiences that nearly made me go mad. I am from Nigeria originally. Sickle cell in Nigeria is an anathema. Don't mention it."

Solomon argued that oftentimes disclosure does not end with the potential partners alone. *Others* in society such as family members are usually part of the disclosure process, because their opinions matter. Thus, even if disclosure was successfully performed with a potential partner, in many instances, the final outcome may only be known after disclosure has been made to the family. He narrated how his first marriage got terminated because the mother-in-law refused to accept the relationship, though his wife, (HbAA). was fine with his status of HbSS. The traditional aspects of the marriage were started before his partner's mother knew of the status:

"I think it was the morning of the introduction that she mentioned my having sickle cell to the mother. The parents shouted and said their child cannot marry a Sickler. That did not filter down to me then because my parents were already on their way with some family members to visit her parents. The visit was okay although my mother felt they did not sound as enthusiastic as they expected. It seems everything was hurriedly done."

From then on, the mother became very antagonistic to the relationship. Though they married privately, the harsh attitude of his in law eventually led to the divorce.

Reports abound in literature about the impact of the opinions of family members, friends and associates on decision making process of partners of people with SCD at after disclosure. While this is also discussed in the next chapter under *Stigma*, the prevalence of negative stereotypes of disability, deserves to be mentioned here as well.

Most of the participants, particularly those originally from West Africa, experienced the impact of potential partners' families upon disclosure of their status.

Aaron experienced at least two terminated relationships before meeting his wife because of family's attitude to SCD. In trying to illustrate this, he said:

"I think things only start to change when friendship, when things go beyond friendship, and then you go into relationships, and, and, even at relationship level, it still doesn't really pose an issue until relationship decides to go a step further, you know, and then you start to think about having a life together, you know. And by the time the, the other person then informs their family that, 'Oh,

this guy is em ...', 'I'm looking to settle down with him, and by the way, he's got sickle cell' then a totally different drama starts."

He described the impact of family on status disclosure as "a *totally different drama*." In which case, being able to go successfully through the disclosure stage with the partner does not necessarily mean all is well. He narrated how he met his wife and discovered she has *HbAS*. He advised her to let them terminate the relationship, howbeit very painful, even when she said she will persuade her folks, because like he said:

"I can already picture where the whole thing will get to...'.If you think you can see this through...' you know. Because the previous girls, that's how they told me that: Oh, they were going to see it through. They were going to make sure that they convince their folks, you know. You know when someone is in love; they believe that they can move the world... But eventually they went to have the fight with their parents, and blah blah blah. Eventually they still came back and said, 'I'm sorry', you know. I couldn't win the battle.' So, it's goodbye, you know."

Damaris narrated her experience,

"The uncle had asked him what was wrong with me and he told him I had SCD. His uncle didn't take it well at all... He insisted that my boyfriend should go for screening immediately. Okay so my boyfriend ended up going for a screening and uhmm, it came out that he had the trait. That he was AS not AA as he had thought. When his uncle found out, he told his mother. And that was that. It was so horrible."

She had a painful experience with her potential in-laws. Her relationship was well received by all in the family but when the partner disclosed her genetic status to his uncle, '*drama started*' using Aaron's language. Thus, Damaris' boyfriend could not continue with the relationship and had to terminate it since his partner's mother was against his marrying someone with SCD.

To curb family interference, Mary made an interesting suggestion that status disclosure should be a private thing between the couple.

"You know, you can both decide to, to keep it to yourselves. It's not something to, that has to broadcast, you know. It's something very personal to you. Why does the whole world have to know about it? It will only create problems, so yea. You can choose to keep it between both of you."

Fortunately, she did not experience a very visible antagonism from her in-laws when her then-fiancé disclosed her status to his parents. Perhaps counsellors can include this as an option which potential couples can adopt, keeping the information between the couple only.

Though not within the scope of this study, ethnicity seems to play a part in issues of disclosure. There seems to be a great difference in the way partners of persons of West African origin and those of Caribbean origin responded to disclosure. The Caribbean seem to be independent in their decision-making at disclosure more than the Africans. None of the participants of Caribbean origin mentioned involvement of any family member in the decision-making processes in their narratives. Meanwhile, all participants of African origin stated this phenomenon without being prodded in their interviews. Hopefully this will be studied further to understand the reason for the difference. SCD is normally prevalent among minority populations in the UK and the cultures of these populations in the UK are often extensions of the cultures in their countries of origin. For instance, Africans especially West Africans, are very dependent on opinions of their families and communities, particularly parents when it comes to consent and decision-making about marriage and reproductive choices. (Jegede, 2009).

6.7 Outcome of Disclosure

Disclosure of genetic information to a potential romantic partner poses a number of challenges to people living with SCD. It remains a critical point of make-or-break of the relationship (Wood, 2007 In Christensen, 2011). All participants acknowledged the dilemma they experienced as they plan to make a disclosure to their potential partner. The dilemma is internalised tensions which Thomas (2007) suggested is psycho-emotional *disablism*. The lived experiences of participants are littered with ableist imposed oppression, pain and stereotyping (Klitzman & Sweeney, 2011), thus, creating a consciousness of their broken bodies and broken self-concept (Liddiard, 2014; Paterson & Hughes, 1999).

Individuals without SCD exercise these rights in their privacy without any restriction or need for application of any ethics. For the participants, there is a sense of encroachment of the societal norms and beliefs into the practice of their citizenship, particularly in the private space of selecting partners. The participants' private preferences/decisions are, as it were, up for scrutiny by the ableist public with medical surveillance, social policies and debate (Plummer, 2003). Thus, disclosure becomes like an examination the individual works hard to pass. This can be explained by stories of the interactions some participants had with parents of their non-SCD potential partners at the critical point of disclosure. They perform "telling, hiding, keeping up, waiting, teaching, networking, negotiating" (Church *et al.*, 2007: p. 10), in an attempt to convince them to allow the relationships to continue.

As mentioned elsewhere, places of worship (churches or mosques) which are powerful segments of the community that shape the norms and understandings of a society become transformed into policing of bio-sociality policies that label these individuals as *abnormal*, cause them to make disclosure and abide by the patriarchal medical recommendations.

Gender did not make any difference to the dilemma faced at point of disclosure or impact the outcome. Both male and female participants narrated failed and successful disclosures. As reported earlier in the chapter, a few elderly participants, such as Eve narrated that having little or no genetic knowledge when they were engaged in selecting partners or making status disclosure did not affect selection of partners. They reported being very sickly all their lives but, for those who knew they had SCD, disclosure did not impact on their relationship forming.

She remarked laughingly when asked if she made any disclosure to her other romantic partners,

“There was nothing like that. In both cases, I thought marriage will come up, but it never did. No disclosure of anything. Just friendship and then romance and then baby.”

Some participants who knew they had SCD, narrated stories of partners who did not know what SCD was when they made disclosures. These partners remained supportive and took it upon themselves to conduct their own research in order to be more enlightened about it for purpose of supporting their partners. Zipporah said:

“I was sick. He couldn’t understand why I was so sick... So, I told him that I had sickle cell... He wanted to know what it was... He got to know a bit more about it and then after that whenever I had appointments, he would come with me... He used to pamper me.”

Amos and Jonathan reiterate how their partners made deliberate efforts to educate themselves to be able to assist and support them. Jonathan, for instance said:

“I disclosed to her... She had to obviously do a lot of research and find out about the disease to be able to obviously support me at home. If I need any help while I’m in crisis, yeah. So, a lot. She knows a lot if I’m not well and you know before she didn’t have a clue. Now she knows you know, and she can tell, to be honest when I’m going to probably end up in hospital. That happened, like over the years, because of the knowledge that she’s gained while she’s been with me of the disease.”

When disclosure is successful, the participants report enormous support from their partners. Some participants reported negative outcomes when they made status disclosures to their potential partners. Theresa, for instance, narrated one of her experiences of disclosure to

one her potential partners. Though her boyfriend seemed to accept her condition and relationship continued, she later got to know he was only taking advantage of her British citizenship. When his plan did not work out, he terminated the relationship. She said of her experience:

“He bloated out at me ‘you should be grateful you have me as a boyfriend. Even my parents are totally against this relationship with your sickle cell. You better be careful.’ Wow!! Something died in me that day.”

Theresa’s experience is a classic example of being stigmatized. I elaborated on this extensively in the chapter devoted to discussion on Stigma. Contrasting Theresa’s experience with Ruth whose SCD was not visible because she said her SCD was milder than most people as she is hardly in hospital. Nevertheless, she decided to disclose early in the relationship and discovered that her partner did not even know his status at that time. Fortunately, he tested *HbAA* before they married:

“When I told him, he was surprised. He was like, ‘are you sure? You don’t look it.’ And the thing is- this is exactly what I was going to say before. He didn’t think I look it and he thought I was quite strong, which I am. Because I don’t think my SC is severe. I mean I can’t remember the last time I had a crisis. So, he has never experienced me with a crisis. I have not had pain in a long time and I think that is just being blessed to be honest. He had this mindset of ‘it can’t be, she really isn’t sick. So, its fine with me it won’t be an issue’”.

Thomas (1999a) posits that when illness is not visible, the power of the disabling “gaze” is reduced. This implies that the individual who is affected has the prerogative to disclose voluntarily. Disclosure of non-visible but serious illness can sometimes be more unsettling in a social relationship than the visible ones. The interaction can become disrupted, as the partner display doubt and scepticism. The dominant cultural assumption is that once impairment is hidden, one is healthy and non-disabled (Davis, 2005). Ruth’s partner expressed doubt and scepticism. She received this positively that her embodiment was a non-issue to him.

Michael narrated a painful disclosure experience he had with his potential partner who was a well-known friend right from school days and whom he started dating just a few weeks before relocating to the UK. She suggested he informed his family to initiate marriage proposal to her family before he goes abroad, so he did. Just three days to his departure, he decided to make a disclosure of his status to her:

“I gladly asked my mother to organize a proper visit to her family. Just that evening as this was being planned, I felt I should let her know about my status. So, I told her... She shouted ‘Really?’ I said ‘yes’. Her countenance changed completely. When I asked her why, she said she has a cousin who has that problem and so she understands it. We parted that day with such somber mood. Honestly, I still did not take it seriously. The next morning, she called me and said she wants to call off the relationship. I could not believe it. I think the excitement of my relocating to the UK helped me cope with the disappointment.”

Michael’s disclosure immediately stalled the relationship. His potential *other* was not going to even consider continuing with the relationship. He did not even know her status or what was so repugnant about him. He acknowledged the enormity of his condition and felt status disclosure is necessary but somehow expected his long friendship to save the relationship. The attitude of the potential partners after disclosure can be unpredictable as they vary widely from person to person. In some instances, as in the case of one of Mary’s friendships, the potential partner seemed to support but later the relationship fizzles away. She said:

“I decided that night to make a disclosure. I was really scared I’ll lose him. When I did, he took it calmly and said, ‘is that all’. So, we continued but before long, I noticed his communication diminished and he abandoned me.”

David’s experience is similar to Mary’s. In one of his relationships, he argued that the woman may not have fully understood what SCD is and so was supportive. Immediately she understood it all, she retracted her steps. She was probably influenced by associates, colleagues or family. Basically, attitudes and support after disclosure border on negative behaviour such as stigma and stereotyping, but sometimes on positive attribute such as compassion and acceptance.

Christensen (2011) argued that self-disclosure when successful do promote longevity and quality of friendships. Caleb was lonely when he relocated to the UK so that bonded him to his partner who later became his wife. His experience of loneliness and aloneness in the new environment of UK created a ‘cosiness’ or intimacy with the newly found female-friend. It was relatively easy for him to make a disclosure of his genetic status. Their closeness and intimacy fostered trust and compassion so they could afford to be vulnerable to one another. In the words of Caleb:

“I think the very first person I told I had sickle cell was my wife... Now she knew I had the condition during the first year of our relationship, in fact within a couple of months and the reason for that is because when I came to the UK, I

came alone so I knew nobody so she was virtually the only person that I had a very close relationship with.”

Family, friends church and other associates do play enormous role on outcomes of status disclosure. In many instances in this study, their preferences can override the decision-making process of the potential partners of the person affected.

Damaris, an immigrant from Nigeria reported that her boyfriend’s mother was the source of the termination of their relationship after disclosure,

“Oh, she (boyfriend’s mother) made him break up with me. She didn’t like the fact that I had SCD. That was a done deal for her. He tried to reason with her for some time, but she had her mind made up.”

For one of Aaron’s failed relationships, after status disclosure to the family of the potential partner, the response was,

“‘You either marry him and loose us’, you know, or ‘You keep us and loose him’. And obviously it wasn’t a walk in the park for her, it wasn’t an easy decision, but she had to come to, and eventually come to a decision that it had to end, you know. And I was terribly heartbroken. I was terribly heartbroken. I was terribly heartbroken. Terribly heartbroken.”

Aaron had had a difficult struggle to select a romantic partner before eventually meeting his life partner. His case will be more elucidated in chapter discussing Stigma. In the successful relationship he eventually contracted after so many failed attempts, he decided to literally ‘bring it all out’ in the open and be completely transparent to the potential partner since he has decided to get married to her. His self-disclosure plans included taking his girlfriend to his doctor so she can be exposed to all the health problems, genetic possibilities and any other thing she may want to know. This gave him a sense of ‘rest’ from the emotional work of concealment while his partner who received the highly private information felt Aaron can be trusted. This reciprocal goodwill feeling towards one another drew support from his partner. In his words:

“Then on my next appointment to Dr Jacob, I took her with me. I said, ‘Every question you want to ask, ask Dr Jacob’, you know. ‘Whatever it is you want to know.’ So, she asked Dr Jacob all sorts of questions and he answered all the, all her questions objectively, of course, you know. Professionally, you know. So, she was rest assured that she’s met my consultant, he’s demystified the whole thing to her, and she was ready to carry off with it. So, I didn’t hide anything... I took her there and said ‘Look, this is me. This is my consultant’, you know. ‘Do you still want to proceed?’ She said ‘Yes. Okay. Let’s see. Let’s go on.’”

He made himself vulnerable by taking her to his doctor and also free her to make an informed decision about the relationship. All the participants agree that disclosure must be made to a potential partner.

Some participants also reported positive disclosure outcomes as their partners responded with empathy, love, and support. Elsewhere in this chapter, I presented Mary's detailed account of her disclosure process and the positive response from her partner and his response of love. She went further to show the continuous support of her partner who is now her husband in the following narrative.

"Sometimes he even annoys me, 'Are you all right? Are you all right?'... He takes my silence for, 'Oh, she's in pain and she's not saying it...' But he feels like, 'Oh, is something the matter?' So, there's always that constant 'What's happening? Keep me updated', you know. Sometimes he apologizes for 'Oh sorry I'm asking you, but are you all right?' That kind of thing."

Her husband has become acutely aware that she may suddenly fall ill. Through his love for her and acceptance of her condition, he pre-empts these occasions by constantly checking on her. Mary's experience proved the point made by Christensen 2011 that self-disclosure can enrich a relationship (Christensen, 2011). She painted a picture of time of her disclosure very intimate and romantic and that there was an improvement of her relationship post-disclosure. There was acceptance:

"And I think, I remember we were lying side by side. I told him... Yeah and I told him, and he was just like 'Oh...', you know, 'It's okay. It only makes me care for you more, or love you more', ...But he took it in stride. He didn't worry too much about it."

Negative experiences of the outcome at disclosure level to many potential partners elicited anxieties, pain and questioning of their self-worth and desirability. Some of the participants like Theresa and Deborah decided to stay single instead of continually experiencing painful cycle of disclosure and rejection. Thus, it is not just the disclosure encounter itself that is disabling, but the uncertainty of not knowing how the potential partner will respond to the status news.

6.8 Conclusion

This chapter investigated the impact of genetic status disclosure on the process of selecting romantic partners, and on the reproductive decision-making of adults living with SCD in the United Kingdom. The chapter also highlights the attitudes of potential partners to the individuals making the disclosure. The socially constructed responses of the partners in terms of support or non-support after disclosure are also elucidated.

Data reveal that all the participants reserved the right to select partners for romantic relationships and parenting, as normal part life course activity. However, there is a consensus among all participants that persons with SCD should sense an ethical responsibility to make a disclosure to partners as part of the process of ensuring that *HbS* gene is not endowed to offspring. As reported in some studies, they also felt the disclosure must be in serious relationships and not casual ones, (Klitzman and Bayer 2003), because the genetic status information is private and deeply personal. One of the participants portrayed carefree attitude in a situation of involvement in a casual relationship that was romantic and sexual. This might be because he was not yet ready to make a family at that time.

An important finding in the study was that many participants felt status disclosure is a critical point in the process of selecting partners because of the possibility of termination of the relationship (Klitzman & Sweeney, 2011). They felt disclosure must be planned strategically for optimal positive result. However, their individual strategies vary. The strategy each person adopted seem to be informed by past experiences of disclosure. Many of the younger participants argued that disclosure should be made early at the dating stage to avoid undue heartaches in case of termination of the relationship. Although not conclusive, I noticed that the male participants more than the female ones seemed to support early disclosure rather than the delay strategy. Some female participants suggested a fairly delayed disclosure as reported in some studies. One of the female participants, Mary, put this idea very clearly when she said, *"in most of my relationships, you know, initially, the earlier ones, I kind of tried to let it happen organically, like maybe something we kind of just talked and, you know, we got on the topic, and then I said: "Oh, by the way I've got sickle cell". And, you know, but later on in life, I think it became a deliberate thing. I had to plan when to tell people, and I realized that, you know, you don't just hit people on the head with it, on your first date or your second, and say "I've got sickle cell". At the same time, you don't wait until, you know, the invitations are printed before you come in. You have to, sort of let them get an insight into you, get to know you as a person, possibly, start caring for you before you make that kind of, in quote "confession". And I think for me that's the fine balance"* So, they propose a strategic right timing for disclosure. The argument made by those who prefer early disclosure highlights the dilemma they faced as they weigh what is more important, to suffer a heartache by delaying the disclosure or to risk potential partners making decisions based on their (individuals with SCD) embodiment. The positive dimension of the delayed disclosure, they reasoned, is that the potential partners get well

acquainted with who they are notwithstanding their impairment and they, the potential partners, can make an informed decision whether the relationship is worth it or not.

The study reveals many types of disclosure the participants made. Some were involuntary in nature. For instance, some disclosures were made accidentally by hospital staff during visits by potential partners when they were sick. Some other involuntary disclosures were made by friends or colleagues in society in a stigmatizing attempt to encourage the potential partner to terminate relationship. Other involuntary disclosures involve the visibility of the SCD in the participants. In other words, their physique is affected by the condition so that the potential partner knew from onset of relationship about their impairment. The voluntary and deliberate disclosures done very early in the relationship seem to be popular with the male and younger female participants. There is also a deliberate delayed disclosure which two participants reported they made because they were not courageous enough to disclose for fear of losing their partners. Data reveals, in line with reports in literature, that the partners cast this as a concealment and so develop distrust for the person with SCD. One case of concealment was because the participant considered the relationship as casual and so did not want to make a disclosure.

It is noteworthy to mention the experiences of older participants who formed romantic relationship when there was a dearth of genetic knowledge. There were some participants who reported that their relationships were not impacted at all by SCD. Even though these participants were sickly, there were not social stereotyping of *HbSS* in society thus, the individuals who was affected received compassion and support. One of the participants, Eva, said she never made any disclosure since she did not know anything about the genetic nature of SCD.

The attitudes of the potential partners in terms of support or non-support for the affected after disclosure also featured clearly in the study data. Christensen (2011) and Wood (2007) suggested that self-disclosure, when well received, can add quality to intimacy in a romantic relationship and generate robust intimacy in the relationship. Some of the participants narrated high quality relationships which is exemplified by strong support, care and compassion from their partners after a successful disclosure. Most participants narrated some failed disclosures as their potential partners terminated the relationships after disclosure. These experiences of rejection experienced at one point or the other by the participants demonstrates varying levels of psycho-emotional pressure as they made disclosures. They all have a consensus that SCD has cost them an enormous '*loss of life*' (Charmaz, 1983).

Another theme that emerged from the data is the involvement of family, friends, clinicians and other segments of the society in the process of status disclosure. (Klitzman 2010). Many participants narrated that disclosure in some relationships did not end with the potential partners. In other words, even after disclosure has been made to the partner, there were still the hidden disclosure that the partner will have to make to these extended relations whose opinion did impact the final outcome of the relationship. This seemed prevalent among the persons of West African origin as compared to the ones of Caribbean origin. This is however not within the scope of this study.

The next chapter is devoted to the theme of impact of stigma due to SCD on the selection of romantic partners and reproductive decision making of the participants.

CHAPTER 7

STIGMA

“You either marry him and loose us’, you know, or ‘You keep us and lose him’. And obviously it wasn’t a walk in the park for her, it wasn’t an easy decision, but she had to come to, and eventually come to a decision that it had to end, you know. And I was terribly heartbroken” ~ Aaron

7.1 Introduction

The focus of this chapter is how from the narratives of the participants, SCD-associated stigma impacted on their selection of romantic partners and reproductive decision-making. Participants in this study reported varying levels of discrimination and stigma experienced from various segments of the society as they select partners and also make reproductive decisions. They narrated stories of anxiety and tensions as they subject their bodies to *medicalization* to ensure genetic compatibility with the potential partners during the process of selecting partners. In some cases where their relationships were already stable, they encountered oppressive disavowal from social actors such as potential in laws, organizations in society like places of worship, associates and in some instances from the potential partners themselves. Another category of source of oppression the dilemma encountered at disclosure when trying to establish a relationship, making decisions around pre-conception testing or termination of affected pregnancy and coping with the dehumanising attitudes of the general public because of their embodied disorder.

Predictive genetic screening constructs a gendered society of *normal/abnormal* bodies. The genetically ascribed label of ‘risky for transmission of gene to offspring’ is understood culturally as body being “dangerous” and unfit for reproduction (Kavanagh and Broom).

The key societal actors such as clinicians, potential partners and their families, members of their places of worship and many other lay people in the society consider the individual deviant from the accepted requirements of normal body (Beatty, 2018; Waskul and Vannini 2006). The constructed cultural meanings define the individual’s identity within the broader social, cultural and community settings, and their self-concept is tainted. This concept was referred to by Goffman (1963) as “*Spoilt identity*.” According to Goffman (1997), the genetic disorder becomes an attribute that is “deeply discrediting... an aspect of the self that is socially devalued, that reduces the bearer from a whole and usual person to a tainted, discounted one?” (p.131-132). The reactions and attitude of society become the source of

discrimination and stigma experienced by the person. The biomedical discourse about SCD is prevention of genetic transmission at all locations of reproductive decision making. This include point of selecting partners, making decisions about parenting, engaging in a pre- or post-conception screening and terminating a pregnancy if foetus is affected.

Link and Phelan (2001) conceptualized clearly the difficulties persons with disability may experience during the process of seeking romantic partners and making reproductive decisions when they said, "by definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often un-thinkingly, reduce his life chances. We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents" (Link & Phelan, 2001, p. 369).

The thematic analysis of the data collected during the interviews with the participants are hereby presented. I identified the variety of ways stigma was experienced and explored the emotional work the participants performed to counter the stigma and 'manage' their personal dignity during the selection of partners and making of reproductive decisions. Participants presented their understanding and meanings they made of these interactions, various coping strategies to manage the stigma, through using avoidance, confrontation or simply learning to live with it. I suggest that their selection of romantic partners are locations for performance of emotional work due to participants' experiences of *psycho-emotional disablism* (Thomas, 1999).

Several themes and cues emerged such as tension and anxiety from disapproval and rejection, attribution of blame, experiences of disbeliefs from significant others, policing of behaviour by others, experiences of tensions during sex because of bodily pains. All these produced feelings of isolation, shame, guilt, fear, hostility, concerns for the future, and feelings of need for support.

The sub-themes that emerged from the narratives of the participants are 1) Stigma experienced from some authorised body such as a place of worship which is described as Structured/Institutional Stigma, 2) Stigma experienced from the Family of the potential partner, 3) Stigma from *Others* in society which includes the potential partner, friends and associates within the society. Other forms of Stigma experienced in unique locations such as in Sex and Intimacy as well as in partner's support system are also discussed separately. A phenomenon well discussed in literature is also discussed separately and this is Blame attribution by *Others*.

Eleven participants are married, seven are single, three are divorced while two are now completely uninterested in getting a partner.

The findings from the participants will be discussed under these sub-themes:

- 1) Structured/Institutional Stigma
- 2) Stigma from Family
- 3) Stigma from *Others* in society
- 4) Stigma in privacy of Sex and Intimacy
- 5) Blame attribution by *Others*
- 6) Stigma in Partner's support system
- 7) Resignation/Termination of relationship
- 8) Conclusion

7. 2 Structured or Institutional Stigma

Institutional/structured stigma refers to discrimination and stigma experienced by the participants from a body or organization within a community to which the individual belongs. Some disability scholars suggested that stigma not only stem from close relations such as family and friends but also from social institutions, clinicians as well as the general public. They reported that such societal stigma has negative consequences for individuals with SCD, including hindering their psychosocial wellbeing. (Bulgin, Tanabe & Jenerette, 2018). Aaron narrated his interactions with his place of worship about conducting his wedding. The church had wedding guidelines in relation with SCD.

"Yea. Because in our church where we got married, before you get married, the marriage committee, they would ask you guys to go to your GP with a list of screening to go and do, and the GP would send the result directly to them. So, you sign all the necessary paperwork, and get the GP to send the result directly to them. So, they would look at the two results, and then, then advise you accordingly whether they think they recommend or approve, or do not, you know"

For participants of Nigerian origin who emigrated to the UK, religion and faith leaders occupy important social and moral influence for life activities such as marriage (Ola, 2006; Asekun-Olarinmoye *et al.*, 2013). Aaron reported on the very difficult experiences of terminated relationships he had previously as he tried to select a partner. He related how, after many failed attempts to get a partner, he decided to remain single and was planning on how to settle into living as a single. He was however, introduced by some friends to the potential partner he eventually married. The church adopted the biomedical approach to SCD risk by refusing to allow a non-compatible couple to marry.

“And then GP did all the tests, and then sent the results to them. So, they got the results and were like ‘Okay. Every other thing is fine, but this genotype here and this genotype here doesn’t, doesn’t tally’. For that reason, they don’t recommend the relationship to go ahead. And then we started to tell them again about this IVF thing, that we were going to do IVF PGD... We started to explain, you know. It wasn’t a walk in the park...”

Aaron narrated his church’s intrusiveness through the activity of the marriage committee, advising him on partnerships allowed by the church. They showed him the church’s policy about the necessary requirement for conduct of weddings. The church’s ruling not to allow a *discordant* couple to be wedded in the assembly constitute a *directive* which contradicts human rights of autonomous decision making about selection of partner. Aaron and his partner were well informed about modern advanced technology such as PGD/IVF to conceive in the future, but the marriage committee were adamant that the church could not conduct the wedding.

Link & Phelan (2001) argued that “stigma is entirely dependent on social, economic and political power – it takes power to stigmatize” (Link & Phelan, 2001: p. 375). Aaron is originally from Nigeria, a first-generation migrant. He was always a member of that church and could not consider having his wedding anywhere else. Link and Phelan (2001) conceptualized the role of power or ‘authority’ in stigmatization. When an authority such as the church refuses to allow the wedding of two at-risk adults even though the couple had plans to ensure SCD is not transferred to their offspring then ‘power’ is being exercised to back up their exclusion and stigma.

When the couple insisted, they were referred to obtain parental consent from both sets of parents. The church leaders knew that Abigail’s parents (Aaron’s parents in-law) were very committed to obeying the rules and regulations of the church and the answer would be a ‘no’. “If stigmatized persons cannot be fully persuaded to voluntarily accept their lower status...direct discrimination can be used to achieve the same outcome.....if direct discrimination becomes ideologically difficult, other forms of sophisticated structural discrimination can achieve some of the same ends” (Link & Phelan, 2001: p. 375). This committee applied structural power to enforce their will on the couple. No mention was made of any form of genetic counselling which should have included various possible options available should they want to remain as a couple. Abigail’s father actually said he could not disobey God even after Aaron and his fiancée presented their plans to engage pre-implantation genetic methods PGD/IVF for conception. If the church refuses, so be it, he said. Aaron and his partner went through an enormous level of anxiety and pressure as they

navigated efforts to save the relationship in the face of disapproval from Abigail's father and the church marriage committee.

The ethical stance of such reproductive decision making is expected to be personal and voluntary but making it a directive in the church constitute an enforced decision. The paternalistic inflexible rules of the church institution imposed a restriction on the choice Aaron could make in the area of romantic partner selection. It constitutes a clear example of *Disablism*, a "social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their *psycho-emotional* well-being" (Thomas, 2007: p. 73). Moreover, Link and Phelan (2001) argued that instituting such structure in a group will separates the people with the 'right' gene socially and behaviourally from those "who are deviant" (Link & Phelan, 2001, p. 366). Though the church leaders may have felt they were *doing the right thing*, considering the genetic implication of the union, the emotional consequences for the person living with the illness, were not taken on board. Kitchin (1998) argued that disabled people are marginalised and excluded from mainstream society (Kitchin, 1998). The exclusion feeling experienced by Aaron is also described by Goodley (2012) as being relational and society constructed. Though mostly unintended, institutional marginalization of people with SCD stems from pre-existing paternalistic ways of handling issues, authoritarian practices, organizational structures and cultures of the church which unfortunately are designed for people with culturally accepted normal bodies. If the church leaders made efforts to understand the PGD/IVF approach Aaron and partner were presenting, they would not have felt excluded or marginalised. It would have meant the leaders were genuinely searching for a solution to the problem. But they stuck to the rules at the expense of the emotional trauma caused to the couple.

Postmodern disability perspectives criticise the rigid, binary categories of *SCD/non-SCD*, *normal/abnormal* or *fit/misfit* mindset existing in church (Wendell, 2010). The slogan "nothing about us without us," is central to the cause of disability movement emancipation (Charlton, 1998). The discourses about SCD and the marriage guidelines should have had inputs from the people who are affected by the condition being debated.

Michael, another participant, had a similar experience. The leader of his church encouraged the potential partner to terminate the relationship based on church genetic responsibility rules.

"I was in love with this lady and was convinced she loves me too and would just take it as one of the challenges of life... She came to me one day and said she cannot continue the relationship because of the harm we can cause our offspring. Wow! I pleaded with her, you know. I said that we can find solution

because life is always throwing challenges. I mean look after all we are Christians. But you know what? She refused, and she even said that she has told the pastor and he confirmed that... According to the policy of the church we cannot, you know like be married. So, you see, that is how it ended."

Michael expressed his frustration as he pleaded with his potential partner not to terminate the relationship, but the pastor had asked her to do otherwise. He continued,

"Okay fine, well... Don't I look okay? I mean I did not even know I had this condition until as an adult you know. I may not be of excellent health, but I am good. I am okay, I say fair enough. I am not a vegetable; I can function well. So, what is all the much ado about nothing for then? I am proof that one can have sickle cell and still live life well. There are worse diseases. It is not epilepsy TB or HIV... I honestly believe this thing has been over-flogged, the stigma is too much. The painful thing is that churches are adopting that rhetoric. I mean, it is not good to pass this thing on you know. Of course, it should be avoided but to my mind, the way they are campaigning about this thing is as if they do not care about us who live with the disease. Don't we too deserve to have families? Should we not also have children? I really do get pained when they talk and preach it as if we are not members who should also be cared for. What is Christianity all about then you know... Okay look; I better stop talking. I however do not agree with the campaigns that is all..."

Michael's concern was that the concept of genetic responsibility is factually right, but the social and emotional consequences on the people with embodiment is totally neglected. He reasoned that though the wellbeing of the unborn child is important, it cannot be more important than people who are already living and who are members of the organization. Kearney and Donovan (2013) suggested that risk is recognized as a critical area in contemporary society, one which "impinges on people both at the political and cultural level, and also at the level of how they live their own day-to-day lives" (p. 1). Michael lamented about the unfair oppressive attitudes of the society towards SCD when compared with some other diseases. The frustration of Michael during the interview depicts the pain and burden experienced by participants as he actually broke down in tears. I had to pause the interview for a while, so he regains his composure.

While Kitchin (1998) posits that disabled people are excluded and marginalised in many areas of life including schooling, housing and public transport, in the case of this study, such discrimination extends to the private space of relationships. Campbell Skovdal and Gibbs (2011) argued that "religion is a significant social force in Africa, where traditional and more mainstream religions have long had a stronghold... Religion shapes the beliefs and activities of many people... and their growing number of adherents either facilitate or undermine stigma" (Campbell Skovdal & Gibbs, 2011: p. 1205).

Ezekiel also showed his utter disgust of the institutionalization of the stigma and its impact on efforts by the target population to select partners and live as normal a life as possible. He vented about the unfair practices of selling out to the public the narrative of being irresponsible to select partners living with SCD. He alluded that such narrative is pushed by normative persons who are not affected by the condition (Kitchin, 1998; Link & Phelan, 2001; Thomas, 2007; Goffman, 1963). He also said like Michael,

"I'm not walking dead; I'm relatively healthy through the condition. And I think when people try and press that narrative about, oh well don't get with another sickle cell, I feel like its stigma. Its stigmatises people that have sickle cell and also it pushes awareness to the back bone because if we are always going to speak negative about sickle cell, those that have sickle cell, then it's not good for people that have the condition and it not good for the future generation moving on and I think that every life is precious, definitely, and I think we need to push the narrative that sickle cell is manageable... We need to improve the awareness, we need to stamp out the stigma... Their issue is it's not about awareness, it's not about education, it's not about support, it's about segregation. You have sickle cell; I'm going to stay away from him. You have sickle cell don't marry him, don't be in a relationship, don't spread it on... That can't be good. That can't be good at all because there is a social impact, there's a mental health impact of sickle cell and... I feel as if that narrative is normally pushed by people that don't have sickle cell disease and that's why I find it kind of offensive cause you don't know my daily struggle with sickle cell. They don't know what I go through, they don't know what I'm feeling so to push that narrative I think coming from mainly people that don't have sickle cell disease, I find it a bit offensive."

Ezekiel suggested people with SCD are so marginalised in society that they find it difficult to get partners for marriage. This is corroborated in literature, "Establishing close personal friendships, including romantic relationships, has been problematic because of the reactions of others to their disabilities" (Green *et al.*, 2005: p. 208). An individual who embodies SCD may have his reproductive decisions subject to some collective accountability, beyond personal preference. This means the popular culture expects such an individual make choice that demonstrate what society translate as rationality (Lippman, 1994). Thus, the individual's life is subject to surveillance and monitoring which can become oppressive and restrictive of the choices that can be made. Ezekiel lamented that such rhetoric is pushed by the ableist population, without regard for the socio-psychological wellbeing of the people suffering from SCD.

Deborah narrated how members of her community recoiled from her when she was growing up because of her disorder. The dominant belief in her community was that people with SCD do not live long. These cultural beliefs caused people with SCD to be devalued.

Unfortunately, most churches, such as that of Aaron, still support that way of thinking, which causes the people with SCD to feel isolated and marginalise. Since they may be unable to *perform* like the rest of society, and could be frequently sickly, they are deemed unsuitable to be partnered with. To buttress this point, Mary said,

“Because, you know, growing up, there was a lot of negativity around sickle cell. People thought you’d die, and people generally didn’t want to have a lot to do with you. And you were an object of pity”.

Many disability scholars argue that the contemporary society is hostile to people with disability, making them to be excluded from good social amenities of life. (Goodley *et al.*, 2017) As found in previous studies, lay understanding of genetic knowledge can be faulty. (Shaw & Hurst, 2008). During the interviews with participants in this study, some participants such as Zipporah and Hannah used sickle cell trait and sickle cell disease interchangeably. They clearly did not know the difference between them. Such misunderstandings among lay persons must have affected the genetic information in the public sphere about the transmission patterns of *HbS*. Their equally defective knowledge about PGD options could influence the outcome of their community discourses about genetic responsibility. Incomplete and inaccurate genetic information are sources of stigmatization. “Such developments remain set against the background of an inherent ableist culture which propagates compulsory ‘*ableness*’, therefore simultaneously devaluing disabled peoples’ existence” (Campbell, 2009 in Liddiard, 2011: p. 16). Finger, a disabled activist said, “Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain” (Finger, 1992: p. 9).

Drawing from the narratives of Mary and Michael, they felt devalued by society, as if they didn’t matter or exist. It is not so much their impairment or the rational decisions to be made to avoid transmission of *HbS* to future generations that is the problem, but the attitude of the wider society that covertly expect them to forfeit their rights altogether about having a romantic partner or making attempts to parent children. Cultural standards to genetic positive result are *prevention*, while neglecting the social and psychological dimensions in the lives of the people affected. So, it is not just the embodiment that is problematic to society, but from the perspective of society, it is that the body is a misfit; an *abnormal* body that is transgressing cultural boundaries of trying to engage in social activities of selecting romantic partner and even try to engage in reproductive activities meant for “*able-bodiness*”. Goodley and colleagues suggested that “disability is normatively understood in late capitalist societies as a deficient problem with(in) the person but... disability might be better

conceptualised as the place for reconfiguring our relationships with one another” (Goodley et al., 2017: p. 491-92).

In conclusion and as found in literature, Structured / institutional stigma were effective in oppressing some participants because the organisation exerted power or authority through policies, rules or regulations without an apparent person to blame for the stigma. The authorities who enact the policies seemed to believe it is *the right thing to do*, given the probable consequences of such relationships.

It is also possible the social implications of exclusion and shaming of the target population in an organization such as the church may not have been given enough thought by their leaders as they implement the marriage guidelines. The participants who experienced this felt excluded, isolated and stigmatized. They had a sense of *public stripping* and their self-concept tainted, as they were disqualified from being of marriageable quality to *normal* members of their society because of their genotype. Thomas (2002) summed this behaviour up as “the disablist practices that undermine psychological and emotional well-being of people with impairment” (Thomas, 2002: p. 53) set in the ableist culture.

7.3 Stigma from Family

Family is an important part of an individual’s social network. In the minority population where SCD is prevalent, there is a close sense of kinship among members of the family. Therefore, families, (and particularly parents) play a central role in decision-making about important life events such as marriage partner selection (Jennings *et al.*, 2012). Thus, the understandings of parents about the genetic risk, shaped by the meanings being constructed by the wider society, do influence the decision making of people.

This section highlights how stigma associated with SCD from the family (of partners) impacted the selection of partners and maintenance of the relationships.

Deborah experienced several traumatic and stigmatizing incidences from her partner’s parents. They were adamant that their son would not marry a ‘*Sickler*’ because they believed she will not live long and will not be able to bear a child. She narrated humiliating experiences she had after they were married (against partner’s parents’ wish), such as never being welcomed into the family home, and she had to stay in the car while her husband visited his parents.

“Yes, it was a big issue, a big one because his parents were against it and he wanting to marry a Sickler. They said I won’t live long, the mortality rate is bad, I wouldn’t be able to have kids, so um, it was so bad that I was banned from his

house, you know. When we go to Lagos I will pretty much just sit in the car while he goes to see his parents. It was, it was terrible. Well, you know, in hindsight I kind of think maybe because they knew he had the trait as well, um, and maybe that's why they were, I don't know, like I said, I was never accepted.....most of the problems came from his people because they were adamant that they didn't want a Sickler as a wife and then that there was no, you know, point of celebrating anything because I wasn't going to live long anyway, and I was not really going to have babies too. The advice they had to give that they thought in their mind what happened to me, that will keep the relationship very unsustainable"

The stigma of being made 'invisible', as if she does not exist was demeaning. Even though she was already married to their son, she was "marginalised and excluded from 'mainstream' society" (Kitchin, 1998: p. 343). This was to oppress her and to let her feel and know she is "out of place" (Kitchin, 1998). Kitchin had argued that this type of *disability* is spatially and socially constructed. Deborah mentioned in her narrative that in hindsight, she thinks the parents realised that their son's (her partner) genotype is *HbAS*, and they may have been so adamant he should not marry her as a form of protection for his future life. This seem to correlate with Kitchin's psychoanalysis that disabled people are oppressed by the ableists because of a deep-seated fear in human *differentness* and innate desire or instinct to protect *self* from harm (Kitchin, 1998: p. 344).

The next extract from Deborah's narrative depicts being "deeply discredited and reduced from a whole and usual person to a tainted and discounted one" (Goffman, 1963: p.3). The couple both sensed an obligation to ensure their baby is not affected so they terminated about three pregnancies that were affected. Her partner could not inform his parents that she was getting pregnant contrary to their held belief that she cannot get pregnant. For the period they lived together, they thought the parents will eventually accept her, but they never did. They had to start living separately eventually after which she had a baby that was not affected.

"When I actually got pregnant they told him that it wasn't his baby, that why is it that, you know, after all this while was when I left the relationship or the marriage that I got pregnant, you know, and denied any form of, you know, attention or anything, you know, he did ask them as is culture, you know, "Give us a name?" And they said, no, they are not naming the baby because it is not their child. So, it was that bad, it was that, there was that pressure, I mean in the end he gave into that pressure, you know, he just."

In Yoruba culture in Nigeria, giving a new-born baby a name is a significant milestone in the lives of both parents and grandparents of the baby. Therefore, refusal by the grandparents to give her baby a name was emblematic because it signified that they have rejected not only her, but her daughter as well. Her parents-in-law were adamant that people

with SCD could never live normal lives or bear children. Though the couple were doing post-conception genetic diagnosis method and terminated three pregnancies that were affected, they could not inform them because it would only add to their disdain of her. Her parents-in-law stigmatized her because of her seemingly inability to achieve social expectations such as parenting children. Ola *et al.* (2016) had argued that social stigma did not result from SCD but from cultural assumptions of parenthood and other life course activities. Bulgin *et al.* (2018) also suggested that this health-status-induced stigma is demeaning, judgmental and socially invalidate the individual who is affected. Her partner could not stand up against his parents and that exposed her to much abuse. Further narrative of Deborah describes how much this dented her self-esteem.

Though not as extreme as Deborah, Ruth had a similar experience of stigma from her then boyfriend's family. Her partner was not so concerned about her genotype but was concerned about how his parents will take it. He did not subject her to indignities while he tried to convince his family which took a while. He negotiated with his parents by trading-off her character to them.

"I don't know what my husband said to her. But he must have said a lot. From conversations that I can remember he would say how kind I am, and the goodness of my heart. I think he just wanted her to meet me. I met her not as his girlfriend- I just met her at his graduation. She knew I was the girl he was interested in. Maybe her just seeing me and meeting me was part of the process of bringing her around. Till this day I really don't know what brought her around. Maybe God just came down and spoke to her.

Ruth recounted her mother in-law initial disavowal of her while suggesting other ladies who are *normal* to her son. Being a non-carrier of HbS, he insisted his choice for partnership was Ruth so, his mother accepted their relationship. Ruth appreciated her husband for his tact. She narrated an incidence of her own mother who also vowed not to allow her son who has *HbAS* to get married to someone with *HbSS* even in her own presence.

"Being a Nigerian mom [laughs]. I even heard my mom say my brother can't marry someone whose got SC and I'm just like, I'm standing right here. It's just the Nigerian mentality. But to be fair, my brother is AS-it can't really work"

Ruth's mother who is a registered nurse also adhered to the stigmatising narrative about SCD despite her own daughter having the condition. She (Ruth's mother) disapproved of her son (Ruth's brother) with SC trait (*HbAS*), selecting a partner with SCD. So, having birthed and cared for a child with SCD, she sensed an ethical responsibility to prevent other offspring being born with SCD and could voice it out in the presence of Ruth, without knowing its effect on her psyche. According to Cresswell (1996), most non-disabled people

in society are not aware that their attitudes create marginalisation for the disabled because they are just playing out the accepted norms of the society. Ruth's mother was simply expressing what is accepted as norm medically and culturally in society. Her comments were stigmatizing for Ruth even though it may not have been intended.

Damaris, another female participant had a similar experience of stigmatization and termination of relationship just like Deborah and Ruth:

"Well, okay so I went, and the uncle was friendly it was good. It was really, good. After I told him about my SCD I had asked him to go do the test. Just to make sure and that we were a 100% sure of his own status. He hadn't done the test when we visited the uncle. So just a few weeks later he called me to say that there was a time when I was in hospital, he just mentioned that I was sick to the uncle and he wanted to quickly come and see me you know. The uncle had asked him what was wrong with me and he told him I had SCD. His uncle didn't take it well at all. He told me that he had tried to calm the uncle down by telling him he was AA. But at the time the uncle didn't hear of it at all. He insisted that my boyfriend should go for screening immediately. Okay so my boyfriend ended up going for a screening and uhmm, it came out that he had the trait. That he was AS not AA as he had thought. When his uncle found out, he told his mother. And that was that. It was so horrible because I had really liked him, and I thought the relationship could finally be going somewhere positive unlike my past ones. But it wasn't... She made him break up with me. She didn't like the fact that I had SCD. That was a done deal for her. He tried to reason with her for some time, but she had her mind made up... The relationship went downhill from then, you know. Until we finally broke up."

In Damaris case the first social interaction she had with her partner's family was his uncle. Her boyfriend had told her early in the relationship that he was *HbAA*. Though his uncle initially accepted Damaris, his attitude changed when the potential partner tested as *HbAS*. Link and Phelan (2001) argued that this type of stigma resonates with Goffman's relational components of stigma forming. First is the 'mark' of *HbSS* gene. Then, society labels the individual with a negative stereotyping, 'Sickler', who will not live long, unable to get pregnant or have a child. This categorization separates 'them' from 'us' within the normative culture. Through the stigmatizing process, the society, church, medical discourses present the rational reasons for not selecting the individual for partnership because it is just *the right thing to do* considering the 'dangerousness' of the body. Society-constructed stigma is the "legitimatization and perpetuation of a stigmatized status by society's institutions and ideological systems" (Bos, Pryor & Reeder, 2013: p.5). The society is, as it were, empowered by the genetic *fact* to exclude the person. The able-bodied partner goes through periods of being convinced to be rational in reproductive decision making as advised by the clinicians. The outcome in the life of the person with the label, is loss of status in society,

reduced power of negotiation in the space of intimate relationship and personal respect. Ola *et al.* (2016) argued that “stigma is a special discrepancy between actual identity and imputed identity, in relation to the breaking of social norms or expectations” (p. 29). In other words, the unaccepted characteristics or stereotype by Deborah’s parents in law that she cannot live long or have a child may not be true. That imputed identity was an assumed stereotyping by society. In line with the concept of social model of disability, her disablement is located in the social actors who assume she cannot bear a child or even get pregnant.

7.4 Stigma from *Others* in Society

A positive genetic test casts an individual as *risky* and *different* for possibility of transmitting the mutated HbS gene to future generations. Participants expressed feelings of anxiety and pressure from rejection due to the stigma they experienced from relational people as they got to meet a potential long-term partner. All participants acknowledged that they wanted to be in intimate relationships such as marriage and be parents just like everyone else. A common thread running through participants’ narratives was that SCD-associated stigma impacted on who they knew they are (*self*), who they were in the eyes of the ‘*other*’ (identity) and who they eventually became (*constructed self*) (Jenerette & Brewer, 2010; Ross, 2013). Some of the older participants who were diagnosed with SCD in the era when SCD was still relatively unknown by the public were known to be sicklier than their peers as they were emerging from adolescence, but the society being virtually ignorant about SCD, did not stigmatize them. *Social Model of Disability* locates the source of *disability* of the affected people in the society rather than in the SCD.

Jonathan, a participant in his mid-50’s who had married twice, had this to say about his first wife

“we never really got into the state of having to worry about it (SCD) because she, she, she had my very first daughter, she’s now 20, 21. And back then like I said sickle cell was still in its infancy. I’d say over here. Um, because not many people knew what the disease meant.”

“*Because not many people knew what the disease meant*” denotes that the problem of stigma started with the “*knowing what the disease meant*”. As society assigned meanings to the condition, the *problematization* of the bodies with the condition started. Jonathan had a moderately severe form of SCD, but SCD was relatively unknown by the members of the public, so he did not experience any stigma as it is today in the UK. For him, selecting partner was not impacted by his embodiment. His medical carers were well informed about

the transmissive nature of HbS and so advised him to be rational in choice of partner. The authorities had not started the implementation of the universal genetic screening program during that period so, the genetic nature of SCD was not *publicised* and the laypeople in the public were still uninformed. Thus, he did not experience the oppressions or performance of any emotional work in respect of stigma associated with SCD as he made choices around selection of partner. This demonstrates how the notion of “*dangerous bodies that are misfits for reproduction*” is enacted by society and shaped by complicated interaction of bodies, genetics, medical diagnosis, social policies and governance. The *publicization* of the genetic knowledge created the dominant binary understandings of *health/illness* and *normal/abnormal* which caused the stigmatizing oppressions for Jonathan (Michalko, 2002). The older participants who selected romantic partners when very little was known about SCD, and the transmission pattern did not experience social stigma. For example, when Eve was asked if she made a disclosure to her potential partner, she said.

“No, it was not an issue. I did not know all about those things then, about testing before marrying or anything like that. It was non-existent in those days. I am talking about over 30 years ago. No-one talked about genetic or screening and all those things.”

The younger participants who became adults in this era of genetic screening with state, medical and broader expectations of genetic responsibility, experienced stigmatizing events that generated enormous tension and anxiety as they tried to make a choice for intimate partners (Hallowell, 1999).

Theresa’s loneliness and ill-health on arrival in the UK made her proactively look for friendship. She instinctively formed a relationship with a classmate who seemed to care for her. She reported a healthy, and supportive relationship which she expected will lead to marriage. However, she noted as time went on that he was not forthcoming with a marriage proposal. She was not aware the partner was sticking to her because he wanted to use her British status to get a British permit if he married her. Immediately he realized it was not going to work out, he left her. In her words,

“I noted his unwillingness to push for marriage. When it became obvious, he will have to leave the UK, I noticed he became rude and just different from the person I knew. I was still trying to figure out what was happening when we had a misunderstanding. He bloated out at me ‘you should be grateful you have me as a boyfriend. Even my parents are totally against this relationship with your sickle cell. You better be careful.’ Something died in me that day. I could not believe what I heard. Although we were having a conflict when he said those things, I still was so taken aback. He left the country about three months later and literally disappeared into thin air. I never heard from him again. Later one of

his classmates confessed to me he said he was relating with me because of my British status. Even if he married me, he will seek a divorce once his status stabilizes. I was shocked. That was the end of that relationship. It really tore me apart. Trusting anyone has become difficult for me.”

That was a demonstration of loss of respect and value. She constructed her experience of internalized oppression and stigma as *something in her died that day* and could not trust any other person again. Her sense of worth was drowned in that experience. Her next relationship in which she had a baby was with a partner who did not really fit into her list of values for partner selection but partnered with him because she did not think she could get someone else. Having borne a child, she decided to remain single.

Caleb’s account clearly indicated like all other participants his disdain for being discriminated against and treated differently.

“All my girlfriends in university, I didn’t tell them that I had sickle cell. The reason being that I just didn’t want that stigma. I just didn’t want sickle cell to be a factor as to the girl wanting to date me... I just didn’t want anybody to look at me as different from anybody else. I didn’t want anybody to pity me or have some form of sympathy for me. Because that was very common in Nigeria. People tend to say ‘eya pele’ [‘oh no... sorry’]. When you say you have sickle cell, you know can I help you with this, can I help you with that. Oh, hope you are fine. Oh, don’t do this and don’t do that. You get that a lot in Nigeria. So, I wanted to avoid that... I think it was probably due to the way I was brought up. My parents were never comfortable about it... They probably weren’t that comfortable about telling people that I had the condition so that transferred to my thinking also.”

Caleb did not want to be defined by his embodiment. The hegemonic perspective of nonconformity of his body to the accepted norm was oppressive to him and he wanted to resist that pattern of thinking through concealment, a *‘passing behaviours’* (which is Goffman's concept of *normalizing*) by masking the stigmatized label (Spiegel *et al.*, 2016). Caleb’s narrative did not imply that he did not have negative experiences of his impairment., but he was resisting the biomedical model of individualizing experiences of chronic sickness while neglecting the social dimensions which devalue the SCD-embodied bodies.

Goffman (1990) suggested that stigma, or a tainted social label, affects the self-concept of an affected person. Caleb inherited a socially imposed label (SCD) that he was taught is discrediting and that he must keep as secret. This may have contributed to his decision to seek for a romantic partner among the White people. There is a culturally held norm that people with SCD cannot bear children and so unfit for romantic relationships. Therefore, many families tend to keep their children’s genotype secret if affected (Oni, 2006). In some cases, this secrecy rubs off on individuals like Caleb, creating in them a lowered self-

esteem. Such self-concept could impact on the confidence required to seek a romantic partner.

In the previous section, I made a quote from Ruth's narrative in which her mother insisted that her son (Ruth's brother) whose genotype is *HbAS*, must never select a partner with *HbSS*. This statement was made in Ruth's presence. Reeve's (2006) suggested that the majority of lay people do not deliberately stigmatise *others* but are only unconsciously involved in discriminatory attitudes of exclusion against the target population. Ruth also pointed out that in some instances, some people with *HbAA* feel reluctant or are discouraged to start a family with people with SCD. She made an important point about her feelings about that.

"I have always struggled with people-even Christians who say God forbid! You can't marry SS but your son is AA or your daughter is AA. You are discouraging them. I may be biased. But fair enough the person may have issues like quite severe or mild crises. I just don't prescribe to that mentality that you must not marry SS especially when you are AA. People look at us differently and I'm like there is no need you don't know me, what I've been through, accomplished and who I can be. You don't know that, but you are judging me based on one element of my life."

She did not agree with that mindset, and she felt being judged or blamed because of her genotype was not proper. This mindset of Ruth constitutes what Loja *et al.*, (2013) called resistance to social stigma. They argued that "In order to deconstruct the exclusionary and demeaning aspects of ableism and respect the value of disabled identity, an embodied politics of recognition is required" (Loja *et al.*, 2013: p. 190). Just like Caleb, Ruth said her identity is not just SCD, she cannot be defined by SCD only. She was resisting the stigmatising environment.

Goffman argued that stigma presents the stigmatized as 'not quite human' or 'inferior'. Selecting a romantic long-term partner is one of the most important decisions and closest human interactions any individual can cultivate in a lifetime (Hamon & Ingoldsby, 2003). Therefore, such discrimination constricts the choices people with SCD have, thus causing them emotional tension.

Zipporah also grew up in a culture that held the belief that people living with SCD do not live long. Unfortunately, she did not have a secure home environment, moving in and out of care homes.

"I didn't think that I was going to live so I didn't respect life. So, I was out there raving, talking it, drinking and you know. I just didn't think I would live long because when you hear that you think it's all over but then I continued to live, getting into relationships and sort of changed my life image especially when you have children, you start realising that this people do not know everything."

Zipporah's lifestyle was constructed around what she was made to believe, that she will not live long. This became her self-concept which affected every facet of her life. She did not care about any self-dignity because she thought her death was imminent. This social construct of SCD formed her identity and impacted on how she formed her relationships. Rebecca also argued philosophically about constrained choices of partners,

"People generally didn't think that you could live life and the moment you would say I have sickle cell; it will be sorry I am AS, I am not going forward with this."

David had a rude shock as an eighteen-year-old man working in a factory. He narrated,

"I met a girl in the factory who I felt liked me. I was only 18 then, she was probably about 20. I asked her for a date which she conceded to. But just an hour before we were to go for the movies, she called to cancel it. When I asked her why, she said my closest friend in the factory told her I have sickle cell and it is better she does not start any romance with me. That is how that first relationship ended."

He reported that his date was discouraged from having a relationship with him by his closest friend in the factory. David had SCD but his friend stigmatized him by persuading his potential partner to terminate the date. His marginalization by his friend because of his embodiment *oppressed* him. The popular standards suggest a body that is *normal* should avoid the dangerous *abnormal* body with SCD.

7.4.1 Stigma in privacy of Intimacy

Of all the people who participated in this study, only Deborah talked explicitly about stigma due to actual sex and intimacy with her partner.

"Um, you know, even when it came to sex, there was certain, I was only limited certain positions which again was a problem. So, everything then became a problem and it's one thing to look at it from the outside, I'm saying, yeah, I can live with that but when you're living it, it's a different story... I can have friends, I can have you know, men with benefits, um, but I don't think I can actually live with somebody else because I know that it's not an easy task, you know, I mean, it will take more than being a man to actually be with someone like me that has a sickle cell, that has my kind of sickle cell."

The extracted data from Deborah's narrative clearly reveal the physical impact of her SCD impairment effects in her sexual life with her romantic partner. While some of the other lived experiences were located in the society, the source of this oppression is clearly situated in the impairment. She mentioned two different sources of oppression with sex. First, she expressed her physical pain during sex which made her develop an internalised hurt of inadequacy as a sexual partner and the emotional labour of putting up with her physical and psychological disability. This is a clear example of the implicit involvement of impairment in disability which some medical sociology academics such as Shakespeare (1996), French

(1963) and Reeves (2002) argued about. This disability of Deborah was due to her embodiment which made her feel a lowered self-esteem. Secondly, Deborah also mentioned that her husband was becoming resentful of her because of the many things she could not do. This impacted their relationship immensely as she sensed she is devalued in the eyes of her partner. This aspect is induced stigma from a social actor, her husband. She said she could no longer pretend that she was 'normal'. She had become somatophobic, repulsive of her own body. She cast herself as of lesser or lower value than her partner who is abled-bodied. Goffman (1963) called this an "abomination of the body" when chronic illness gets embodied, and burden of the disease becomes visible, and identity gets tainted due to a failure to meet the expected identity. Goffman further argued that the gap created between this failure and a disabled person's actual identity creates stigma and they are discredited (p. 3). Freire (1970) also reported that disabled people are constrained to 'know their place', to believe the reasoning behind the oppression; that they are unworthy and deserve to be where they are on the social ladder, "fatalistically accepting their exploitation" (Freire, 1970: p. 46). Reeves (2006) also said about the long-term impact that internalized oppression can have on someone's *psycho-emotional well-being*, directly restricting the choices about who they can be, such as potential parent or lover. From the narratives of the participants, it is noted that this fear or anxiety of being disapproved ran throughout the interviews. The more severe the symptoms of SCD, the more the anxiety of being rejected and the more the emotional work performed to be stable psychologically. Ruth, one of the participants reported that she needed to take some time off to rest after a failed relationship.

"I met my husband when he (the partner who terminated relationship with her because of SCD) stopped talking to me. But we waited a year and a half before we started courting. I wanted to heal, after such a break-up I didn't want to enter into another relationship so soon."

This was a relationship terminated before she met another person who fortunately became her husband. She felt she needed healing from such rejection or failure before she can perform any emotional work to be able again to form another intimate relationship.

Aaron narrated how he felt stigmatized about his being labelled 'other' by virtue of his genetic status, his sexual capabilities being undermined when he said,

"It's not like a, it's not like I'm impotent. It's not like I can't produce healthy sperm. It's her egg, it's my sperm."

Galarneau (2010) suggested that the dominant culture judge the person with the embodiment as *different* and *unacceptable*, being marked out as 'Other' different from 'Us'. For Aaron, he declared that he acknowledged his own identity as human, capable of human sexual activities, but he felt the dominant culture undermined him as being inferior. The difference between the two identities created embodied tensions for the participant.

7.4.2 Attribution of Blame by Others

Hannah narrated about being blamed for her condition by her partners. Two other participants also reported being blamed for their crisis and pain by other family members.

She said:

"I would say that has probably been my most intense relationship. He used it to compare my actions to my condition for example if I had a drink, he would say this is why you are so sick and not getting better. I would say I have been living with this for twenty years, so you can't tell me therefore I am sick. I think what is hard in relationships is that people think that you are doing something to get your crisis, as if it is your fault when you have a crisis."

Deborah had the most difficult experiences at all levels, of stigma-induced blame impact on her relationship. Her SCD was severe, having affected her hips, knees, and some other body parts which impacted on her mobility. She walks with a limp. Her partner was initially understanding and supportive. However, after a prolonged period, the burden of SCD started to have its toll on him and he started blame her, which caused Deborah an immense hurt.

"And then after a while he started to resent me for it, because he will say things like... Because he's a, he's an outdoor person, so he will plan trips, you know, oh, let's go to Glasgow for the weekend let's go there and just maybe then we will plan to leave on Friday and about Thursday or Wednesday I will call him, I will have a crisis and he will have to cancel and that had happened on several occasions and he will want to do things like lets walk and hold hands in the park. Like I said, my legs are not very good, so it's was a no, no. When it's cold I can't go out, you know, all this oh let's go and do snow fight and all, no, I can't do that. What else affects me is things like swimming, if I keep myself in water when I come out, I'm in so much pain, you know, I can't even have a bath, that's how bad it is. Um, so it really affected him, I could, I could see him, and he started saying stuff that I knew that, you know, gosh, you know, it's not my fault, you know, that I fall ill on occasions when we've had plans and we had to cancel and all of that. It got to a stage where I started having to pretend that when I have crisis I will act like I didn't have one, I will try and be normal, I'm in so much pain but I'm still in the kitchen cooking and all of that and to an extent it became a farce to be honest."

Deborah tried initially to conceal her condition and appear as 'normal' as possible for purpose of managing her marriage. According to Karp (1996), "one of the strongest norms

surrounding illness experience is the expectation that the sick person 'work' diligently at living as normal a life as possible. Even people who are literally dying from chronic diseases are expected to minimize the extent to which they are a burden on others and do whatever they can to normalize their circumstance" (Karp, 1996: p. 106; In Snelgrove, 2012: p. 13). The participants' narratives of their experiences of impact of stigma on their efforts to form relationships portrays the feelings of injury and lowered self-esteem. Due to the burden of disease on their bodies and everyday living, there seems to be more emphasis on the emotional pain and shame and sometimes guilt accrued.

Another aspect of blame apportioning has to do with expression of disbelief from partners due to not fully understanding the nature of SCD. Referring back to the excerpt provided by Hannah in terms of her alcohol intake, having to explain the burdens of her condition to her able-bodied partner sapped her energy. This compares well with Church *et al.* (2007) reports about the "complex invisible work performed by disabled people" (p. 1) as they take on the roles of educator, negotiator, performer, "within a variety of spaces in their sexual and intimate lives."

Ruth said of her husband before they got married:

"When I told him, he was surprised. He was like are you sure? You don't look it. And the thing is- this is exactly what I was going to say before. He didn't think I look it and he thought I was quite strong- which I am. Because I don't think my SC is severe. I mean I can't remember the last time I had a crisis. So, he has never experienced me with a crisis. I have had pain in a long time and I think that is just being blessed to be honest. He had this mindset of it can't be, she really isn't sick."

But after they were married, she felt he still did not fully understand what SCD entails,

"I am trying to get my husband to understand a bit more- he hasn't gotten some things. He'll be like oh he's not sure. So maybe if I say I need to go to the GP he will be like are you sure? Is it that deep? He doesn't quite get it."

Ruth's husband had not yet realized how seriously ill she could get sometimes because of her mild form of SCD. Most of the time, she was quite healthy looking and strong.

7.4.3 Stigma Effect on Partner's Support System

Getting a life partner is positioned as the key that could enable participants to gain companionship and support while avoiding isolation and aloneness. (Christensen, 2011). From data, some of the participant's relationships that had complete acceptance, were soothing and supportive. There appeared to be companionship, intimacy and a sense of worth, confidence and esteem. This clearly challenges cultural views of disabled people

ascribed as embodiment of hopelessness and personal tragedy within broader social constructions of disabled people.

Aaron said of support and acceptance of his partner.

“I had a couple of crises even before we got married, you know... She came around to nurse me. And even after we got married, obviously we got married in 2009, I still had crisis up until 2011, you know. And, she used to come and see me at the hospital and there was even one terrible crisis that I had. I thought I was going to die. I remember saying to her that ‘My God will look after you’, you know. ‘You’ll be fine.’ I was already giving my parting words, you know. But for whatever reason, she just seemed to believe that nothing was going to happen, and she would stuck by me.”

Aaron’s partner supported him fully even in the spiritual sense. Deborah presented her anxieties and loneliness and her emotional labour to manage the situation she found herself in the UK when she went for further studies (before she married).

“That I realized then, pretty much then, that I can’t, you know, I can’t afford to be on my own. I realized that my parents weren’t... So, it wasn’t a case oh! going back home. I had passed that. I realized that my parents, so the support system was sort of, you know, out of it, so I had to form, you know, friendships, I had to, you know, contact cousins or anybody that I knew and you know, sort of like seek support that way by that time as well my boyfriend had come from Nigeria to be with me. So, I think I sort of latched on to him, you know, as my, as my support really”.

She said she latched on him, held on for dear life because there was no other person she could hold on to. She confessed that the relationship was her first romantic one because of her parent’s cocooning of her due to her ill-health as she was growing up. She never had the space, privacy or opportunity to develop any intimate relationship and so when this potential mate came along, she latched onto him. According to Kuczynski and Grusec (1997), parents are the primary and most influential in the socialization of children due to close parent-child relationships during the growing stage of the child. So, for a frequently ill child such as Deborah, attempts to protect the child from getting sick or from disruptive environment turned out to be disabling environments for engaging in or learning to form relationships. In the previous chapter, Deborah had narrated how members of the community refused to associate with her. In addition to this, she mentioned that she barely had any friend of her own. This could provide a reasonable explanation as to why she chose to marry her first ever boyfriend despite her knowing she may not be his favourite and her parents were not quite in support. It could be that when she travelled away from her parents, she realized that she needed support beyond companionship to help ease her impairment pain.

Theresa's then boyfriend latched on her for personal advantage of possibility of obtaining British citizen status through her and divorcing her after. She recounted another experience she had with another potential partner. She said,

"I met this guy who was a bit older than me, a divorcee. Since there was no other person in the horizon, I agreed to a relationship. My sister and even parents were not in support of him because of his cold attitude. But then where will I get someone else?"

The consequences of her experiences of stigma made her exhibit "a fundamental re-thinking of the person's biography and self-concept" (Bury, 1982: p.169). This lowering of her standards could have far-reaching effect, not only that she chose someone of less desirability, but the trajectory of her life-course got tragically affected in its entirety. She said she could not trust anyone again.

Mary learnt to be open and received support from her husband. Like many participants, because of the frequency of pain and desire not to be looked at as being different, she used to conceal her feelings. That is also an emotional labour or work done to hide her true feelings.

"If I'm with you and I'm having a crisis, I don't say it. I just pray and bear it and I say 'Oh, I need to buy paracetamol.' And you say, 'Ah Why? Do you have a headache?' And I'll say, 'Yes I have a headache.' So, you do tend to hide it a lot. But the thing is, being married, even before my marriage, being in a serious relationship, he helped me open up. I could say 'Oh I'm having a crisis', and, you know, sometimes I'd tell him 'It's nothing to worry about.' I'd tell him 'Oh it's a small one, It's a slightly, It's a big one'. Even if I felt it coming, I could say 'I feel a big one coming.' So, being able to communicate that to someone, and, and I think also it's a training period when you're with someone, and you're spending a long time with them because they start out by freaking out, every time you have a crisis, you mention a crisis. But after a while, they learn to ask 'Okay, what's the pain like on a level of one to ten?' Or 'Is it a big one? How are you feeling?' So little by little they tend to understand, and they know that they don't have to call 999 in this country every time you have a crisis, and all that."

As a personal control strategy, to avoid too much sympathy, she employed concealment until her partner learnt to understand SCD issues. They learnt to live lives as normal as possible.

Rebecca recounted that in one of her relationships, her partner was supportive.

"I remember when I first got ill, the first time he. it was a month in. He actually came down to where I was, and he was you know caring because I was ill. My sister walked in and she was like, he is taking care of you while you are ill! I think it was the first time I ever experienced. sometimes you can be like he is very understanding that man."

As explained in the previous chapter, when there is acceptance after disclosure and relationship is established, the impact of stigma diminishes as was Rebecca's case. Unfortunately, there are circumstances whereby disclosure leads to termination of the relationship.

7.4.4 Resignation/Termination of relationship

The impact of SCD-associated stigma on some participants led to termination of the relationships. The tensions and anxiety of "meeting up to standards" that the participants had to put up with required some invisible work at all levels of the relationship. These diverse works constitute a level of *psycho-emotional disablism* (Thomas, 1999).

Deborah for example, expressly indicated her struggles to purposefully avoid conflict by concealing her true feelings within the relationship to a point where she felt her SCD crisis was standing in the way of her non-affected partner living his ordinary life. Such struggles to refrain from upsetting the normal couple's 'living life' meant having to strategize dynamics within the relationship. She would perform various forms of emotional work like being nice, gracious, performances expected of a wife and pretending to appease her husband to ensure the relationship survives. This obviously became injurious to her positive sense of self. She had to eventually let go of the relationship. She decided she is better off being single.

For Zechariah, when his partner died, he felt he will rather be single than go through all the emotional upheaval of another mate selection. In his words, he said

"No, my experience in relationships hasn't been... In some sense it hasn't been the best. I've been fortunate in some ways. Like how I've had a few relationships but one of my most significant relationships was with a partner who passed away... Yeah so from that perspective it's been difficult, in the last five years I've just decided to stay on my own."

Aaron too, after many failed attempts, was frustrated and tired of all the emotional efforts that failed. He made some decisions as seen in the conversation below,

"You know, and I just, I remember I wanted to buy a one bedroom flat, you know, and buy a dog, you know. And just live my life in my one bedroom, no space for visitor. Just me, myself and I. One, only bedroom in the house. No girl, nothing. I was just, I was going to buy an Alsatian dog, and that would be my partner in the house. That was my decision, you know... I gave up on... Obviously from where I come from, the idea of having kids outside of wedlock, it's a taboo, you know. So, you can't have kids unless you're married. So, I had given up on marriage, let alone having kids. So, I was just going to buy a dog, you know, to be my partner in the house. And that was what I resorted to do."

Though he did not follow this decision or mindset through as he got a partner at a later stage, he gave up on any relationship's formation due to experiences of *psycho-emotional disablism*. Most of the participants experienced one or more termination of the relationships because of their embodiment of sickle cell disease. The source of the terminations was either directly by potential partners or their family or their community institutions such as places of worship. While some participants recovered from the trauma of terminations, a few decided to remain single.

7.5 Conclusion

This chapter highlighted the SCD-associated stigma experienced by adults with the condition living in the UK as they attempted to select romantic partners and make reproductive decisions. It described the variety of oppressive encounters with a variety of social actors during their social interactions. Some were subtle and unintended while others were planned and brutal.

This study utilized the SMD as a framework to uncover and understand the oppressive attitudes of the social environment of these individuals as they interacted with society. The patriarchy attitudes are drawn on pre-existing and potentially marginalizing beliefs based on the concept of medical model, which is designed solely to sustain *normal* bodies, preventing bodies labelled *abnormal* from participating *freely* in society. Within the context of SMD, *disability* is defined as a form of social oppression experienced by people with impairment, “*something*’ that is imposed by the society on top of impairments” resulting in social isolation and stigma (Oliver, 1983; Shakespeare & Watson, 2002). A clear distinction is made between the effects of the impairment and disability; impairment being the bodily illness while disability is the feeling of restrictions, attitudes and barriers created by the society (UPIAS, 1975; Oliver, 2013). Though their embodied biology informed their day-to-day social and medical decision making, the participants in this study recounted experiences of being labelled, marginalized, stigmatized and sometimes rejected by society. This clearly confirms accounts in existing literature that the medical discourse and dominant cultural beliefs of society limited these individuals and prevented them achieving their potential or becoming who they intended to be (Reeve, 2004). The main principle of SMD is that *disability* is a socially constructed phenomenon.

Though SMD had critics (feminist academics, who themselves were people with *disability*) about the non-inclusion of impairment effects as part of the ‘*troubles*’ faced by these individuals, the stories told by the participants situated the impairments effects at a separate

location from the social oppressions they experienced. The narratives demonstrated a recognition of the impairments effects and how they can be managed. They also separately recounted the overarching oppressions (piled up 'on top of the impairments') based on the hegemonic medical model approach of prevention of SCD re-occurrence in society. By placing the participants at the centre of analysis of this study, they told their subjective stories unabashed in their own words and on their own terms. It is hoped that with their experiences prioritised rather than the predetermined ideas of *Others*, this study will serve as an empowerment tool for them to be heard by the policy makers for policy change.

SCD is a genetic condition embodied from birth. It is therefore a part and parcel of the identities and biographies of the individuals with the disorder since there is no reference to a pre-illness state of being. The participants in this study all understood and experienced SCD experientially, not so much from the medical discourse. They lived all their lives with embodied consciousness of SCD and its consequences. While they interacted most of their lives frequently with medical professionals for treatment and health management, there was no attraction of dominant cultural disdain or demand for accountability to community until the point of partner selection and the making of reproductive choices (most certainly because of the medical discourse about transmissive nature to offspring of SCD and financial burden to public health). Also, through these social processes, their narratives demonstrated deep awareness of ethical obligation to *Others* therefore, their impairment was not the issue. The fierce opposition, oppressions, fears, anxiety and shame experienced at their social intersection with society while attempting to select partners and make reproductive decisions corroborates with the concept of SMD that the oppression of *disability* is not in the embodied SCD but in the meanings and attitudes of the social actors who align with the medical model of judging SCD. It assumes that SCD is a dreadful disease which must be prevented, though the sociopsychological factors in the lives of the individuals that inform the sufferers' decisions notwithstanding. Locating disability in society rather than in the impairments makes it a social problem to be solved by society. The marginalization and stigma which these individuals face shifts from being a personal tragedy or medical problem to social policy issues.

Some participants narrated how they suffered structural or Institutional Stigma right from the level of authority in the community. They recounted that their places of worship (churches) adopted the concept of genetic responsibility and developed marriage guidelines to guide the worshipers on the type of *bodies* (or not) to marry. They forbade these participants from getting married to persons of their choice because of their embodiment of *HbS* gene. Even

when some of them presented the new hi-tech genetic options available (PGD/IVF) that will enable them avoid transmission of *HbS* to their offspring, the church leaders refused. They exercised their church *political* power to ensure the individuals do not have their choice by denying them wedding in church. The participants recounted enormous pressure and anxiety during the process of negotiation with them. They were *disabled* at those points as they endured “hostility or pitying stares, dismissive rejection, infantilization, patronising attitudes” (Goodley 2010: p. 96) from those community institutions. The SMD assertion that disability is from the social realm can be confirmed from these experiences of institutional stigma. The stories were marked by feelings of tainted self-concept and low morale, believing they have *abnormal bodies* that is in deviance from norm. Deborah said, “*it will take more than being a man to actually be with someone like me that has a sickle cell, that has my kind of sickle cell...So, I don't think it's something that I think any man will be able to*”. Such statements demonstrate *somatophobia*, a type of self-hatred. The hegemonic assumptions/judgement about SCD, presented by the dominant medical expertise which is culturally accepted as “*the truth, the whole truth and nothing but the truth*” slithered into communities like those places of worship and individuals with SCD got marginalised and even refused the right to get into partnership with the people of their choice. The stigma was a collectively approved societal phenomenon.

Drawing on the analysis, I argue that the strength of *disability* is directly proportional to the *largeness* of the social actors involved in the stereotyping. This “*largeness*” may mean the number of the social actors, strength of political power, level of authority or governance or level of education. This does imply that when the *largeness* of the social actors is reduced such as through increased public education or training, *disability* can reduce. For example, I will take the case of a participant, Aaron, to verify this hypothesis. For purpose of transparency, he decided to take his potential partner to his doctor so that she can be completely exposed to accurate and complete information about SCD, its genetic nature and the available advanced technology procedure options. He is *HbSS* while she is *HbAS*. The discussions and exposition to the knowledge made way to their getting married because they realised they can avoid transferring *HbSS* to their offspring. With the PGDIVF procedure, their child is merely a carrier, not the full blown SCD. In fact, he mentioned that they still have two fertilised non-affected eggs in the facility that can still be placed in Abigail’s uterus for more babies should they desire to have more. This, I think contributes further to the development of the Social Model and how disability can be tackled.

Of note are the older participants who formed relationships when little or nothing was known about the genetic nature of SCD. They never encountered any labelling or stigma. This goes on to confirm that the impairment was not the disabling factor as the concept of SMD stipulates. I argue that the *language* of health department in promoting genetic responsibility is laced with a covert motive insinuating that the only solution to SCD is prevention. This probably invoked the meanings and attitudes of the society to the people living with the disorder. Fox argued about the fluidity of language when he said, "Due to the undecidability of language, meanings are not based on underlying reality but on differences from other things." (Fox, 1995). Thus, with such non-firmness of meaning of spoken medical language, the manner in which some knowledge is infused especially into a society can construe a totally different meaning from what was intended. Also, some critics of medical language commented "that physicians sometimes employ an impersonal vocabulary when referring to their patients." and that "language uses us as much as we use language" (Lakoff, 1975: p. 3; and p. 65 In Anspach, 1988); Emerson, 1970:73-100), "while patients in turn are compelled to surrender their subjective experience of illness to the authority of the expert" (Anspach, 1988). My suggestion is that the society extracts from the medical language of genetic responsibility that people with SCD are better off not attempting reproductive agencies because of the *dangerousness* of bearing children with SCD. This assertion *disables* the affected individuals in the eyes of the public when they decide to challenge that collectively held notion.

Apart from the older participants, all the other participants experienced stigma from potential partners at some point in their lives. Some narrated how their potential partners walked out on them once they knew they had SCD. Two participants narrated how their partners insulted them orally because of their condition. Of note is the experience of Theresa whose partner said, "*you should be grateful you have me as a boyfriend. Even my parents are totally against this relationship with your sickle cell. You better be careful.*" That was an epic example of level of stigma that can be experienced in the life of a person with SCD. She was so worthless to him that he could tell her so. The *disability* she experienced is "*something*" that is imposed by the society on top of impairments" (UPIAS, 1975).

Some participants also narrated how *Others* in society such as friends and associates stigmatized them. An example is Michael who was trying to date a potential partner and an associate in the workplace advised her not to honor the date because Michael had SCD. Another case was David who had a loving relationship with a potential partner and made a disclosure of his genotype. The partner abruptly terminated the relationship because she

said she was advised by their pastor. It was not that the pastor called to counsel both of them, rather he called the *able-bodied* partner and 'gossiped' his counsel to her. This is another example of Goodley's "hostility or pitying stares, dismissive rejection, infantilization, patronising attitudes" (Goodley, 2010: p.96). Goffman (2009) described stigma as the impact of "negative attitudes and behaviours" from the public which usually results in "negative psychological and physical health for the stigmatised individual" (p. 948). Goffman (1963) also said that a stigma is an attribute of a person that is "reduced in our minds from a whole and usual person to a tainted, discounted one," an attribute that is considered "deeply discrediting" (p. 3).

The most dramatic of all the sources of stigma are those from the potential parents-in-law. This phenomenon is found to be common among participants who originated from Nigeria. (Nigeria incidentally have the largest population of people living with SCD globally.) Participants of Caribbean origin did not report such reaction as it appears they were more independent from their parents in such decision-making when compared with West Africans. (This is not within the scope of this study).

These parents were very adamant that their children would not marry *Sicklers*, as they call people living with SCD, and so fought the relationships until they got terminated. A few narrated that their potential in-law initially refused the relationships but later became agreeable when they met in person. My argument about Social Model of SCD is that just as the power of *disability* can become intense with aggressive medical discourse, in the same way, some other social factors can be introduced to eliminate or reduce *disability*. This forms the basis of my proposal that policy makers can intentionally design policies that will target reducing social understandings and meanings ascribed to the condition in society. "It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live. I was being dis-abled - my capabilities and opportunities were being restricted - by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all the problems had been created by society, then surely society could un-create them. Revolutionary!" (Crow, 2010: p. 55).

Some of the participants like Aaron had to decide to remain single at a point because of the frequent termination of relationships, not by the partners but by their parents. Fortunately, he eventually got a yielding spouse. Even when these parents were informed about the new genetic possibilities, some remain unpersuaded. I must mention here that the case of Ruth's mother who unintentionally stigmatized her own daughter confirm some thoughts that many

people in society may not always be aware that their attitudes and beliefs stigmatize some vulnerable members of their society (Goffman, 1963; Link & Phelan, 2001).

An overarching observation is that the lay understanding of genetic information seemed often inaccurate. Some research reports in literature have demonstrated that laypeople's understanding is frequently at variance with medical facts (Shaw & Hurst, 2008; Richard & Ponder, 1996; Bates, 2011; Walter *et al.*, 2004). The inheritance statistic which is probability are often translated as concrete realities by many lay people. Even among the participants in this study, the concept of sickle cell trait as a carrier and SCD as disease still seem confusing. Many parents believed that the individual with SCD cannot bear children and cannot live long hence the basis for their disapproval against the potential children in-law. In this vein also, the clinical facts presented to the lay people seemed to have created a cultural understanding and meaning which does not change easily even with the advanced technology that offers options. Also, most public genetic guidelines adopted in the public institutions are not easily updated to accommodate the new knowledge brought by these emerging technologies. My proposal for this anomaly remains aggressive public enlightenment through various media avenues.

Some participants reported that the support (or lack thereof) they received from their partners is sometimes laced with stigma. This could be that the partners apportioned blame internally as to why the participants who embodied SCD cannot conform to normative culture of prevention if they cannot perform. Deborah narrated her difficulties during sex which her partner started to resent. Social model of relational *disability* (Thomas, 2007), which is an extension of Oliver's SMD provided a structure for better understanding of the lived experience of *disablism* as experienced by Deborah. Some of the participants' relationships succeeded in spite of the stigma they experienced, while others terminated.

SMD is an emancipatory approach for identifying physical, social and even emotional 'barriers' that prevented or limited the participants in this study from participating fully in society without social judgement and accountability. Thus the 'removal of barriers' is expected to influence the inclusion of these individuals into society. In this study, some of the stories of the participants confirmed barriers such as, notions of them being misfits for reproduction, or that they cannot live long and so not useful for partnership. This study recommendation is that policy makers can implement policies that will aggressively change social perceptions about people with SCD. This may include enacting legislation to back up the policies. This research was conducted not only as an academic exercise but also as a

strategy to understand the phenomenon being studied and hopefully expose the weaknesses in social practices for purpose of instituting change.

Considering the overwhelming political power of medical rhetoric, adults embodying SCD lack social capital to negotiate inclusiveness in their quest for relationship and making reproductive choices. The marginalization and stigma from being *othered* in society at those locations are connected with their refusal to comply with the cultural medical expectation of complete prevention of SCD in society. A paradigm shift in cultural beliefs will require intentional change in health and social policies. I will submit my full recommendations on how this can be done in the next chapter. However, I suggest the multilevel societal change will be based on a grandiose re-education/re-training of both the public sector, the medical fraternity as well as the adults who embody SCD.

CHAPTER 8

CONCLUSION AND RECOMMENDATIONS

8.1 Introduction

This thesis sought to explore and improve understanding of how Sickle Cell Disease (SCD), a debilitating, genetic disease, impacts on the partner selection, reproductive decision-making, genetic status disclosure and moral responsibility of adults living with the condition in the United Kingdom. I explored the following broad areas to capture the lived experiences of the participants at the intersection of social consequences, selecting romantic partners forming and making reproductive decisions:

- In what way is SCD status a consideration in selecting romantic partners and negotiating the relationships?
- To what extent does this health status feature in people's account of reproductive decision making?
- How do people living with SCD view the cultural understanding of their condition particularly as it relates to romantic relationships and reproductive decision making? Is their perspective in congruence with the perspectives of the society?

My main aim in exploring these three areas is to unearth, using the experiential evidence and narratives of the individuals with the disorder, the biosocial meanings of SCD as a health risk in the UK, and the implications of this illness in the lives of those affected as they select romantic partners and make reproductive decisions.

Existing literature suggests that predictive genetic screening apportioned the category 'risk' to genetic illnesses such as SCD in relation to health policy (Morden *et al.*, 2012). Such categorisation forms the basis for societal allocation of identity to the affected persons (Armstrong & Fitzgerald, 1996, p. 274). The themes evolving from the experiences of the participants, helped to contextualize the social meanings and perspectives of SCD and the partnerships the affected people try to select as well as making reproductive choices relative to their socially assigned identity.

By means of a qualitative phenomenological research approach, the in-depth experiences of 23 adults living in the UK revealed their understanding of how embodying SCD impacted their lives as they interact with dominant socio-cultural beliefs in selection of partners and making reproductive decisions. I looked at the domains of

- Genetic responsibility and how the participants made decisions.

- Status-disclosure: how this was navigated, the responses of their significant *others* and how the relationships survived or not
- Stigma: The reactions of various segments of society to the SCD embodiment and how these affected the participants.

Inductive thematic analysis enabled the unearthing of the participants' experiences with regards to the private internal difficulties they encountered, the *psycho-emotional disablism* from *Others* and the shame they endured from society. With qualitative method, interviewing of affected persons allowed me to gaze, as it were, into the heart or soul of the participants and acquire a "deep level of knowledge and understanding" of the complex phenomena, (Johnson, 2002, p. 106), in domains of partner selection and reproductive decision-making. The study framework was grounded in the theories of *Social Model of Disability* (SMD) and *Embodied Risk*. From literature in Disability Studies, stories of disabled people are littered with evidence that their disablement is caused by their social environment (their able-bodied peers as well as the institutions in society) rather than the burdens of their impairments. They also confirm that the disablement is oppressive to their psyche and personhood. The SMD, as a theoretical framework for this study, helps to illuminate the implication of the restrictions the society imposed on affected people so that their freedom and full participation in society is hindered (Oliver, 1990). So, the SMD relocates the disability from the biology of the body to the social structures and actors in society.

The theory of *Embodied Risk* on the other hand, moved the searchlight to the *problematized* body. Kavanagh & Broom (1998) suggested "a third category that might be called corporeal or *embodied risk*... so called because they are located in the body of the person said to be 'at risk'. Environmental risks are due to something that happens to a person; lifestyle risks occur because of something a person does or does not do, while embodied risks say something about who the person is" (Kavanagh & Broom, 1998: p. 437). Embodied risk is the identity of the possessor, an attribute that does differentiate the affected individual from the normative environment. This attribute cannot be ignored by society or the affected person, particularly as it has an overarching influence on future generations. There are abundant research reports which demonstrate that most impaired bodies, particularly those that can be transferred to offspring, are assigned meanings by society. For example, people with SCD are called *Sicklers* in all of West Africa as well as some people in the UK (Serjeant, 2001). Savitt *et al.*, (2014) argued that "the words used to name and describe disease phenomena are a reflection of society's beliefs and attitudes. This social construction of

illness includes the voices of patients, physicians, advocacy groups, government, media, insurance companies, scientists, and the pharmaceutical industry to name a few. It also includes an invisible context: transmissibility, moral judgment, and stigma. All of these ingredients make for a complex frame in which to hang what may seem like a simple diagnosis. Disease in this way goes far beyond pathology and genetics, and into the realm of medical sociology where people make Janus-like assignments: normal/abnormal, victim/villain, guilty/innocent, heroic/pitiable, good/bad. These assignments dictate how individuals, family members, and society perceive and respond to medical conditions” (Savitt *et al.*, 2014: p. 23).

Thus, the two concepts, *SMD* and the *Embodied Risk*, provided adequate framework to explore how embodying SCD elucidated meanings and understandings for the bearer as well as the wider society. The constructions of those meanings are based on the characteristics that is obvious or told to them such as symptoms, how transmittable, vulnerability of affected persons etc. These understandings translate to the biased lay assumptions about the affected individual. Such socially constructed meanings within the context of selecting a romantic partner as well as making reproductive decisions to bear a child can be problematic for the affected person.

The research approach of inductive phenomenology provided a rich description of experiences of the participants as is in their own words, ‘thick, rich descriptions’ of how SCD impacted them without pre-conceived ideas from history or culture (Moustakas, 1994; Creswell, 2009; Creswell, 2003, Omery, 1983). The collection of data from 23 adult participants (n=23), who embodied SCD, and resident in the United Kingdom were selected by purposive sampling method. I began the interview with discussions with each one about the fact that they are the *experts* when it comes to the phenomenon being studied.

This study investigated three specific research questions.

(1) In what way is SCD status a consideration in selecting romantic partners and negotiating the relationships? I investigated this segment of the study by trying to gain an understanding of the meaning the individual assigned to SCD as an embodiment within the context of the popular societal construction of the condition. I also focused on gaining an understanding of the activity behaviour of the affected person in relation to the medical construction of SCD and prescript intervention for the selection of romantic partner and reproduction decision making. All the participants acknowledged the fact of being as entitled to having romantic partner as everyone else. They also recognised their embodied risk which can have

consequences for future generations. So, most of them submitted their bodies to be *medicalized* even at the intersection of selecting and forming a romantic relationship. They also all sensed the necessity to be morally responsible when it comes to bearing children to ensure future children are not endowed with *HbSS*. However, the strategies employed by the participants varied from person to person. These varied responses have all been extensively discussed in the earlier chapters of data analysis.

(2) To what extent does SCD health status feature in people's account of reproductive decision making? The participants gave narratives that helped to gain understanding into the difficulties they experienced because of embodied risk. The narratives reveal complex factors and social agencies that contributed to the process of reproductive decision-making which differed considerably from the experiences of non-affected people. Varied strategies were employed by the participants in different situations in the attempt to ensure future offspring were not endowed with the abnormal gene.

(3) How do people living with SCD view the cultural understanding of their condition particularly as it relates to romance and parenting? Is their perspective in congruence with the perspective of the society? This section of the study reveals social stigma, discrimination and exclusion from various segments of society experienced by the participants. The UK healthcare policies underpinning the decisions made at intersections of romantic relationship and reproductive decision making also influenced by the impact of SCD (Morden *et al.*, 2012). The suitability of the concept of SMD for the study is highlighted as the oppressions felt by the participants is demonstrated to be socially constructed and not because of the bodily attribute of the sickle cell gene. The view of the participants is clearly stated that their decisions, particularly in reproductive agency, should be autonomous as per their citizen's right, but they seem to have been disempowered by the authorities as well as wider society.

8.2 Study Findings

This study has addressed a range of questions concerning how SCD has impacted the selection of partners of individuals who have SCD and also how it has impacted on their reproductive decision-making. The findings are reported extensively in the analysis section of the thesis, that is, Chapters 5, 6 and 7.

The stories of the participants described social interactions at intersections of selection of partner and reproductive decision-making as very oppressive and stressful. The participants' perception of self and identity is constructed from interactions with their social environment which includes the clinicians, family members, other social actors such as places of worship and community they belong to. Thus, the understandings of SCD in the eyes of the wider society shaped the cultural worth of the affected and this in turn impacted the affected person's sense of worth.

The findings from the study showed that the predictive genetic screening and diagnostic programme is offered by the United Kingdom NHS as a governance tool to incorporate the policy of self-management into NHS clinical practice (Morden *et al.*, 2012). The self-management programme was enacted to enable health risk to be identified in the population, "managing risks and lifestyle to avoid longer-term health problems" (p. 82). This is expected to help reduce the economic health burden associated with long-term chronic illnesses. Therefore, genetic screenings enabled the affected individual to know their own genetic risk, and with the support of clinicians who provide the "*right* information and advice" (p. 81-82), manage the risk that ensure future offspring are not genetically affected (Morden *et al.*, 2012). Thus, the *creation* of genetic risk split society into *affected/non-affected*, *abnormal/normal* or *acceptable/non-acceptable* individuals. The problem of the affected individual becomes their *embodied risk*. Conrad (1992) suggested that when social domains of life are assessed and attempted to be solved by medicine, lives are medicalized. Illich (1975) also argued in "the medicalization of life", that "Medicine is a moral enterprise and therefore inevitably gives content to good and evil. In every society, medicine, like law and religion, defines what is normal, proper, or desirable. Medicine has the authority to label one man's complaint a legitimate illness, to declare a second man sick though he himself does not complain," (Illich, 1976: p. 2). He further explained that "medicalization occurs whenever some aspect of ordinary, everyday life comes to be so defined that it requires input from an institutionalized medical system" (Illich, 1982: p. 466). The participants in the study are categorized as unacceptable for romance and parenting by their embodied *HbSS*. It is not only a serious health problem but also injurious to future generations unless it is subjected to social control to prevent further damage to society. Thus, the social environment which include members of society, families, clinical professionals and even the government construct this embodiment as deficient to serve as a partner for long-term romance and parenting. This cultural and social understandings of SCD within the context of the UK policy of self-management underpin the lived experiences of the affected people

at the interception of selection of romantic partner and making reproductive decisions (Morden *et al.*, 2012).

While the embodied risk concept helped explain some of the difficulties experienced by the participants as a result of their impairment, the Social Model of Disability (SMD) further helped understand the phenomenon under study as a result of the societal construction of SCD. So, as disabled people, they “have restrictions placed on them by a society that devalues people with impairments” (Oliver, 1996: p. 33). Thus, disability is not really the medical problem in the body but a problem residing within society who demean and devalue affected persons due to the popular understanding of implication of the risk; an information originating from medicine.

The summary of the three themes that emerged from the data will now be individually presented below.

8.2.1 Genetic Responsibility

With the concept of Genetic Responsibility (GR), the department of health assumes that any good citizen in society has the “responsibility to know and manage one’s own genome for oneself and the sake of others, focusing particularly on responsibilities to family and kin” (Weiner, 2010: p. 1760). This is an assumption that the information about one’s health and its outcome should demonstrate a moral obligation to society. So, in the case of SCD, the owner of the body should feel a responsibility to ensure the gene variant is managed and does not ‘spread’ to *others* in the future for the sake of the state. The participants expressed as a burden, this concept practicality in the area of selecting partners for intimacy and romance, and even bearing children as constricting their choices. They all agreed it is needful to exercise some agency to ensure the gene is not transmitted for the sake of self and sake of *others*, considering their lived experiences of their embodiment as well as the oppression they have had to put up with from society. Rose (2001) argued that “choices about marriage, procreation, financial planning, inheritance, career and much more are made in a web of entanglements involving actual and potential kin, employers, partners and children” (Rose, 2001: p. 19).

The point of departure, however, may be at the point of practically making genetically responsible decisions. The different accounts of the participants exhibit the fact that these decisions are not always simple linear and logical ones. Multi-factorial social, physical and emotional issues can influence these decisions and they disabled the affected. For example, the fact that their choices are constricted puts some of the participants in a state of anxiety,

such as Theresa who decided to stick with her partner even when she did not quite approve of his cold behaviour. She said, “*My sister and even parents in Nigeria were not in support of him because of his cold attitude. But then where will I get someone else?*” or in Aaron’s situation when at a specific point in his life’s journey, abandoned seeking for a partner altogether, determined to live single.

Selecting romantic partners and making parenting decisions are not medical issues but social. However, when affected persons seek partners for romance and parenting, clinicians are involved to conduct genetic screening so that the result can be used to inform appropriateness of the potential partner. Thus, I suggest that involvement of medical solutions to these erstwhile social issues is medicalization of participants’ lives (Illich, 1975; Conrad, 1992). This is very emblematic and problematic in the lives of the participants. One of the participants Ezekiel narrated how the clinicians tried to get him to terminate two pregnancies because of the possibility of pregnancies being risky. Fortunately, he said, one of the babies was only a carrier of the gene.

The UK self-management program is a forum where the individuals with SCD and the medical professionals share responsibility in managing patient’s health and wellness. Autonomy is the distinct *mark* of GR, that is, decisions must be made solely by the person affected with support from clinicians in area of appropriate and adequate information to enable patient to take responsible decisions. Doctors urging Ezekiel to terminate the pregnancies felt to him like coercion, so, autonomy of GR seems to be compromised.

The participants displayed concern for their future offspring and significant *other*. Their experiential knowledge of SCD impacted on the level of sacrifice they were willing to make for sake of their obligation to their offspring. They all said they will do all they can to ensure that they did not pass the disease on to their future offspring. Some like participant Damaris said she would not have borne any biological child if she had to partner with an at-risk individual. Others like participant David said he is only trying to select partner among Caucasians, avoiding the race where SCD is prevalent. The decision to ensure one is being rational about choices stems from the participants lived experiences of facing the effects of SCD from childhood, the current struggles they deal with due to SCD and the information they have acquired through their lived experiences. Disclosure of one’s genome is an aspect of genetic responsibility which will be discussed in the following section.

8.2.2 Status Disclosure

Several factors were found to inform the decisions of how to manage the process of disclosure. The embodied risk is a private information and so part of own identity (Charmaz, 1995). Status disclosure at point of selecting a potential partner is critical and problematic for many of the participants. Many of them knew disclosure could impact on efforts to get a willing romantic partner to reproduce with. They also recounted that this knowledge impacted on their self-concept. This agrees with other literature, such as Bury (1982) who said that chronic illness is a *disruption* of life (Bury, 1982).

One very dominant cue from the data is that most of the participants agreed that being in long-term relationship and parenting is part and parcel of the life course that they desired to be engaged in. They also agreed that as much as possible, *HbS* gene should not be endowed to the future generation and so efforts must be made to find compatible partners. Most participants felt they have a moral obligation to disclose status to potential partners in serious relationships only and not casual relationships due to the nature of the information. They were also aware that disclosure can result in termination of relationship. However, most of them narrated the ethical dilemma they encountered as they tried to make a disclosure. For example, Mary said of disclosure “*then comes the dilemma of when to tell them. Cause it’s kind of like coming out of the closet.*” She calls it “*coming out*” because of the privacy she felt her status and inner self is. Broekema & Weber (2017) referred to rare genetic illnesses such as SCD as having a *public–private* nature. This means, though the embodiment is private, yet it is a public matter because the implication extends to others such as future offspring who will be a member of society and also the impact on health economic concerns of the state.

The ‘whether to disclose’, ‘when’ and ‘how’ to disclose status was riddled with *psycho-emotional* burden. They discussed the difficulty of balancing their moral obligation to disclose with the hurt in case the relationships terminated. They all agreed that though this is privately owned information, the potential partner has the right to know, particularly because of the possible implication on their coupledness. Apart from the older participants who did not have knowledge about SCD or who were limited in knowledge of the genetic nature of SCD, they mostly disclosed their status to their potential partners. A participant, Hosea, did not feel an obligation to disclose to his partner because he considered his relationship casual even if a pregnancy occurred within the relationship. Apart from Hosea, all others considered any possibility of bearing an affected child a very serious matter. They all agreed though that disclosure should only be made when a relationship is serious and

long-term. Two of the participants narrated how they concealed their status in serious relationships simply out of fear of losing their partners. And in both cases, they lost the relationships because their partners could not trust them any longer. This is in congruent with the report of Newheiser & Barreto (2014). Also, Pennebaker (1985) argued that "the act of not discussing or confiding the event with another may be more damaging than having experienced the event per se" (p. 82).

Now concerning the '*when*' and '*how*' to do the disclosure, varied responses were made by the participants. Many of them believed disclosures must be strategic. Some said they would disclose immediately they start dating just like Participant Ruth said, "*I tell them early on. You know if you're not happy- just keep it moving*". Others advised that disclosure should not be done haphazardly. It needed to be intentional and at a time when the partner has become well acquainted with the individual but must not be too long after the start of dating. A reaction to an earlier disclosure may be based only on the fear of the consequences of SCD and may likely terminate. According to Charmaz (1995), "chronic illness assaults the body and threatens the integrity of self" (p.657).

In terms of the reactions to disclosure by various actors in the society, participants narrated enormous *disablism*. Shakespeare (2000) had argued that the major contribution of the British disability studies to the disability debate is the demonstration of the fact that *disablism* experienced by the chronically ill is more of a social construct rather than due to the bodily impairment of the affected individual. From the data, it is obvious many of the participants struggled to find people willing to partner with them for intimate romantic relationships. "*Coming out*" at disclosure point obviously reduced society's perspective of them. Charmaz (1983) argued that chronic illnesses caused the sufferers to have a "*loss of self*". Bury argued that disability affects social relationships not only because the individual may be physically impaired in some way, but such disability causes embarrassment which disrupts normal social relationships (Exeley & Letherby, 2001). Goffman's definition of stigma as "an attribute that is deeply discrediting" and reduces the bearer from "a whole and usual person to a tainted and discounted one" (Goffman, 1963: p. 3). This fully reveals the experiences of many of the participants at junction of disclosure. From a theoretical perspective, Goffman (1963) proposed a theory of stigma in which individuals try to manage 'tainted' aspects of themselves and 'to pass' as 'untainted'. Here, individuals try not "to pass, but to avoid rejection, and establish an ongoing relationship" (Klitzman & Sweeney, 2011: p. 5). Many of the participants were of Nigerian origin and I noted that family, particularly parents played a huge influence in the reaction of the partner and subsequent outcome of the disclosures.

The participants of Caribbean origin did not exhibit family interference in the disclosure interactions. Many participants experienced intense negative reactions from their potential in-laws when they disclosed their genetic status.

This is discussed more in the next section on stigma.

Lastly, I presented some of the excerpts of narratives of participants whose partners accepted their status disclosure and supported them and those whose partners rejected them after status disclosure. A very interesting phenomenon that emerged is that for the ones that received support from their partners, I confirm the argument of Christensen (2011) and Wood (2007) that self-disclosure, when well received, can add quality to intimacy in a romantic relationship and generate robust intimate romantic relationship. All participants' narratives exhibited varying levels of psycho-emotional pressure as they disclosed their status to the potential partners, and they all agreed that SCD has cost them an enormous '*loss of life*' (Charmaz, 1983).

8.2.3 SCD Associated Stigma

My analysis reveals oppression, discrimination and stigma experienced by participants at all levels of their lifecycle; from selection of partners, managing relationships, exercising agency to reproduce, and even at conception, interacting with medical professions towards bearing a child. I argue that, though the impairments effects of SCD do impact these various life events, it is the stigma experienced from society that is most problematic for the people living with SCD. The tendency to marginalize SCD-affected people is deep-seated in UK policy of self-management, in families, other society institutions and generally in culture. With the current mind-set of NHS cost-cutting policies as well as overmedicalized lay people's perspectives of SCD, it seems people with SCD may continue to experience stigma in the private area of decision making for selection of partner and reproduction. Unless efforts are made towards "deconstructing and reforming the very cultural norms" that legitimize violence against disabled people in the first place" (Goodley & Runswick-Cole, 2011: p. 614). I suggest that this study may have exposed the level of suffering affected people are subjected to as they are disavowed within their families, rejected within the communities they belong to and not fully socially supported by the medical profession that originated the stereotyping in the first place, The process of "deconstruction and reforming" of society will require education, health and social welfare and professional practice, which collectively work together to reduce social aggression towards people living with SCD (Goodley & Runswick-Cole, 2011: p. 614).

In the concluding segment of this final data analysis, chapter on stigma, I note that Goffman (1963) had defined stigma as an “attribute that is deeply discrediting” and this reduces the bearer “from a whole and usual person to a tainted, discounted” (Goffman, 1963: p.3). SCD associated stigma is as a result of stereotypes developed due to the predictive genetic screening and its implications. From the data, the participants described the various dimensions of stigma they experienced and the impact on partner selection and reproductive decision making.

For example, Theresa narrated her experience with a trusted partner who showed how repulsive she was to him. Her identity spoiled in his eyes. Another participant, David had his four- year relationship terminated.

Another type of *disablism* that featured is the institutional or structured stigma. This has to do with structures in society like places of worship. These organizations, as explained in the analysis, developed guidelines that excluded the affected persons from full participation and socialization in the community. The reasons they felt excluded is because the restriction placed on them about who they may marry without providing possible options available for discordant couple who are in love enough for marriage. They just order that once they are discordant, they will not be allowed to wed in their places of worship. Invariably, the individual affected would feel left out of the commonwealth of the church blessings. They felt uncared for, as if they are, according to Goffman, “not quite human” (Jacoby *et al.*, 2005: p. 171). The so-called ‘*normals*’, (like the church and their leaders), construct “a stigma theory, an ideology to explain the person’s inferiority and account for the danger the person represents” and might also “impute a wide range of imperfections based on the original one” (Jacoby *et al.*, 2005: p. 171). These ‘imperfections’ are untrue assumptions that participants will not live long, or that they cannot bear children and even if they do, their children will have SCD. Some participants like Deborah narrated how her parents in-law refused to recognize her marriage because of their assumption that she cannot bear children, (and she did bear a child who did not have full blown SCD), and she cannot live long (and she is still alive in the UK after twenty years). The lives of the participants such as Deborah and Aaron were filled with oppression and stigma from potential partners, societal institutions such as church, family of non-affected partners and even ordinary members of the society.

As mentioned earlier, family has a huge impact in moulding an individual in most African communities and so does places of worship. The stigma that religious bodies place on their followers trickles down to the family setting. This provides a reasonable explanation as to why some of the participants’ parents (despite some being in the medical profession) could

not come to terms with their son or daughter choosing a life partner with SCD. From the examples, it is evident that genetic compatibility of the couple was put aside even when the potential partner embodied *HbAA* and so marrying an individual with SCD should not be a problem. The parents just insisted they will not support the marriage. Their only viable explanation was that they did not want their loved ones to purposefully choose a mate with SCD. In situations where the couple tell the parents of the unaffected that they can engage in Preimplantation Genetic Diagnosis (PGD) procedures and have a non-affected child, some families still refuse. They insist babies are better conceived and born naturally.

Lastly, the stigma that could exist between the couple was discoursed. Deborah was the only participant to openly discuss her sex life with her former husband. She noted that due to the condition, she was unable to have a normal, healthy and active sex life sometimes because she would develop pains. Participants noted that the support (or lack thereof) they received from their partners was laced with stigma. This is because the partners apportioned blame as to why the participants could not conform to normative culture. Some of the participants' relationships succeeded through the stigma they were dealt with; and others had to terminate theirs.

Thomas (2007) suggested that "disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being" (Thomas, 2007: p. 73). The participants in my study have narrated how stigma, discriminations, abuse and so many negative stereotyping has been their lived experience from the various society structures, from friends, partner, family and even medical professionals as they navigate this important life domain of selecting partners and making reproductive decisions. Thomas had postulated disablism to describe these strangulating experiences of the affected which 'undermining of their psycho-emotional well-being' preventing them to be and aspire to be who they can become, and even who they desire to share lives journey with. This study has explored and reveal these disabling processes of intimidation oppressing the participants in their social and medical relationships.

I propose that the tensions experienced by adults embodying SCD in the UK at the interchange of selecting partners and making decisions for reproduction is shaped by cultural norms of the society in which they live. I argue that society's perceptions that something is wrong, rather than different, about the body of the affected person is engrained in dominant culture. There is a need to relook at the operational documents of implementing

the self-management policy of the Department of Health which continue to present the bodies of these citizens as being unsuitable for romance or parenting.

To round up this chapter with the other two findings chapters, I have discussed how stigma at three different levels can be a liability in a relationship for an individual living with SCD. If stigma is not resolved while a relationship is in its infancy, it may have an impact on the individual's choice to start a family. Therefore, I can answer the question that SCD does impact heavily on the selection of partner, forming and maintenance of the relationships, and the reproductive decision-making agency when the individuals decide to have children.

8.3 Study Limitations

Contrary to my expectations when I started the study, I discovered very quickly that participant recruitment can be difficult. I attended many sickle cell group meetings and was surprised to find that my appeal for participants met with very few responses. Even after scheduling meetings with some of those willing, I could travel all the way from Sheffield to London to meet with them only to be told they are not feeling well enough, or they can only be available if the interview will be by telephone. So, some of the interviews were conducted by telephone. Although this is quite acceptable, I believe some benefits of face-to-face talk which could have revealed more *deep rich* information was truncated. Adhabi & Anozie (2017) argued that "interviews form the backbone of primary data collection in qualitative research designs" (p. 2), because it is an attempt "to understand the world from the subject's point of view, to unfold the meaning of peoples' experiences, to uncover their lived world before scientific explanations" (p. 3). I engaged with participants using semi-structured methods since it gave me the flexibility to manoeuvre the interview process so as to develop a good connection with the participant. However, using the telephone instead of face-to-face interview did not permit me to observe the participants' behaviours and emotional expressions which may have conveyed important information relevant to the study (Adhabi & Anozie, 2017). I also observed the telephonic answers were snappy, not as free-flowing as the in-person interviews.

A second limitation to this study was that many people living with SCD were "interview-fatigued". Many potential participants complained about having been involved in so many research projects with no personal benefit. The difficulty I had with recruitment made me tread carefully so they did not turn it down altogether. So, the relaxation and flexibility of the

interviews may have been compromised. Such interviews were short. In such cases, I think valuable information may not have been adequately conveyed and so lost.

Another possible limitation to the study may be in the area of diversity of participants, in terms of ethnicity. It was difficult recruiting participants as I mentioned earlier. I employed snowballing strategy to recruit participants, which meant they were referred to me by organizers of the sickle cell group or by other participants. So, most of them were of Nigerian origin, people who came to the UK for post-graduate studies. Perhaps if I was able to recruit some persons of Asian origin or Mediterranean, study findings would have generated a result that will be more representative of all affected persons residing in the UK.

Most of the interviews were conducted during winter. I got to know later that the people with severe form of the disease are not readily available for interviews in the winter months because that is when they are most likely to develop crisis. This may have meant that most of the participants were those whose condition were not too severe. From the analysis of the data I collected, I realised that severity of symptoms does affect the phenomenon under study. This means an individual whose impairment is severe may respond differently due to their embodiment from the ones who are doing fairly well. Maybe if the interviews were conducted during summer, some erstwhile hidden potential participants may have been available to further enrich the data.

8.4 The Implications of My Findings

The focus of this thesis is the impact of SCD on the selection of romantic partners, reproductive decision-making, genetic disclosure and moral responsibility of adults with SCD living in the UK. The findings of this study have important implications for adults with SCD, their health provider who are normally haematologists, NHS, community leaders such as leaders of faith org, NGOs such as sickle cell societies, policy makers, social workers.

From the study data, it is apparent that the oppressions experienced by the participants can be linked to two broad main irregularities which are

1. Misinformation of the public: This has to do with inaccurate genetic information in the public arena about SCD, its contagion, its transmissive statistics, what people embodying it can and cannot do or achieve
2. The covert motive of Health authorities to genetic screening program and the language in which the genetic information is put across both to the public and also to people with SCD.

Implications for Misinformation/inaccurate of the public

The findings revealed the gross misinformation that exist in the public domain. In spite of the successes made in the UK with the universal new-born genetic screening and the vast advances in pre- and post-conception genetic diagnosis, there is still a significant misunderstanding and misinformation about the nature of SCD, its inheritance and reproductive implications. I found at least two of five participants with no university degrees who do attend support meetings did not quite seem to differentiate sickle cell trait from the full-blown disease. Also, one of them described possibility of transmitting HbS to her offspring in a particular relationship in definite percentage just as some studies in literature confirmed (Parson & Atkinson, 1992; Wöhlke *et al.*, 2019). The variance in the genetic facts and lay understanding can influence the meanings ascribed to the condition in the community and may challenge the individual's reaction management of the risk.

Based on the fact that the inaccurate information is so widespread as exposed from the participants experiences, I suggest there may be a mixture of folk beliefs handed down through generations and the biomedical facts from the hospitals about the meaning of the illness, and reproductive implications circulating the community. Many participants expressed and narrated the fact that the dominant belief in society is that people with SCD cannot live long, get pregnant or have children. Such meanings of SCD perpetuated in society will cause extreme revulsion of the bodies embodying SCD.

There is an urgent need for health-care providers and policymakers to know this and seek alternative educational modalities that promote genetic literacy among individuals living with SCD and the public. There is a need for clear communication about SCD with their patients, ensuring understanding.

Implication for the covert motive of the health authorities and the language in which the genetic information is put across both to the public and also to the individuals living with the condition

The UK self-management policy about SCD situates people living with the condition as rational subjects who calculate their health risk probabilities and manage them. The biomedical model's perspective is that SCD should be eliminated because it is a major health threat to the people embodying it and also a burden to the NHS resources (human and finance) because of the frequent need for the sufferers to use health facilities (Meyappan 2001). Thus, the dominant medical approach is employing the genetic

transmission statistical probability as basis of deterring people with the HbS from passing the disease their Offspring (Kenen and Schmidt 1978, Markel 1992). The health authorities completely neglected the socio-psychological consequences on the lives of these individuals.

The participants all narrated the oppressive marginalization, dehumanizing attitudes of many social actors in their environment towards them because of their embodiment at the point of selecting romantic partners and making reproductive decisions. They narrated the scrutiny by society of their autonomous decisions as they are judged and censured as if they have no right to have partners or parent children (Ross, 2013).

Ezekiel, one of the participants, said of their medical officer, “*So, when we were pregnant with my first born, the doctors they were basically trying to get us not to have the baby. Saying that, due to risks they could potentially have sickle cell, tried to get us to have an abortion with her*”. Another participant, Samantha said “*Especially with my last child when they told me that I should have an abortion. They didn’t say have an abortion, they said we strongly recommend that you terminate*” It does sound as if the goal of reducing SCD burden on the NHS system (human resource and finance) for sake of the health budget may be the concern of the health provider. The structures and social support to mitigate the challenges posed by social structural factors and social environments were not put in place. I suggest that a more holistic view of at-risk person in context of his social environment and social obligations ought to be considered by the Department of Health as the self-management programme is implemented for the purpose of mitigating the aftermath challenges (Morden *et al.*, 2012).

A patient-centred approach to medical management and genetic screening program will need to be instigated. Such an approach will involve incorporating the understandings and meaning patients attach to their condition to the policies being developed. The verbal and non-verbal communication from the provider should eliminate the paternalistic attitude of being the *expert* knowing what is good for the individuals.

From the narratives of the participants, it is clear that their embodied risk is entrenched in their consciousness, part and parcel of their day-to-day living with SCD. All their decision-making processes are laden with the consciousness of their embodiment. They all firmly agree to moral responsibility towards their offspring. Most of them in their narratives displayed strong parental instinct to protect their offspring from harm. Their experiential experiences, both from the impairment and their social interactions inform their resolve not to allow their offspring to suffer as they have. Quite unlike decades ago as shown in literature

as in Hill (1994), the participants do understand the consequences of their disorder. However, they also reserve the rights to be able to select partners, engage in intimate relationships and parent children if they so wish. The biomedical model within the genetic screening program tend to shift concern from the individuals to the not-yet-born offspring as a future member of the society. They view dominant discourses attempt to compel them to conform to medical expertise and expected outcome. The concern for the babies seems to out-weigh the concern for them who are already citizens, and who are entitled to equitable care as everyone else. One of the participants, Michael lamented, *“Of course, it should be avoided but to my mind, the way they are campaigning about this thing is as if they do not care about us who live with the disease. Don’t we too deserve to have families? Should we not also have children. I get really pained when they talk and preach it as if we are not members who should also be cared for.”* The participants feel, unimportant and devalued. *“Disability,”* according to UPIAS, *“is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS, 1975).*

8.5 Recommendations

In the past three decades, there has been gradually improving knowledge in the public domain since the implementation of the genetic tests program. The knowledge about SCD management has improved which are strides in the right direction. However, my research has demonstrated that there is a need for better management particularly in the social domain. I propose therefore,

1. There should be a proper booklet written about SCD in an unbiased way, giving all genetic information which can be handed out to people with SCD and their families when they attend the clinic. I propose that the booklet should be explicit but non-threatening. For example, in explaining the genetic nature of SCD, let it be said that anybody can form family with anybody. However, if *HbSS* form partnership with *HbSS*, then it is advised children to be adopted because all children will have *HbSS*. With *HbSS* together with *HbAS*, there is a 75% probability with EACH pregnancy, that baby will have *HbSS*. Further explanation must be given to explain this probability. That sort of booklet given to an individual will clarify issues without any threat. It is vital that the haematologists handling the healthcare of the individuals with SCD provide the patients with the accurate genetic information of SCD as well as the risks. The medical carer must ensure that they fully grasp the transmissive

nature of the disorder, rather than assume they understand. I will also suggest that someone with SCD should be part of the people compiling this booklet in compliance with “nothing about us without us” slogan.

2. The Sickle Cell society has been very strategic in public awareness and education about SCD over the past forty years of its existence. The support group has, through its programs mitigated illness-related stigma, fear of contagion in community and have advocated for improved health management from the authorities. I propose that the health authorities work closer and support these groups in achieving this objective
3. There is a need for re-training of health workers and social workers in SCD management, particularly the social dimensions of life. I propose that with holistic understanding about inheritance nature of SCD, and the advanced tech procedures available, counsellors, social workers, haematologists and other health workers should be readily availed for patient enlightenment programs and conversations about SCD. There should be stationed trained social workers to provide individual counselling support for people who are affected when needed. For example, this study participants, Aaron and Abigail both went to discuss with Aaron’s haematologist. He is *HbSS* while Abigail is *HbAS*. The haematologist counselled them, and they got married. With Pre-Implantation IVF methods, they have a healthy baby.
4. I propose that genetic information (Hematopathology, BRCA 1 & 2, etc) should be incorporated in the health science curriculum in high schools. Also, in the curriculum should be embedded the necessity to shun stigma and discrimination. According to Dyson, SCD may be considered as a resource for education across a range of national curriculum subjects, could bring an anti-racist dimension to subjects such as maths, biology, history and geography, and could challenge a number of prevailing disabling and racist discourses in wider society. (Dyson et al., 2007)
5. The study has exposed high levels of socially constructed disablism such as stigma, discrimination etc. There is a need to develop social services to work closely with community organizations such as places of worship and to ensure that those institutions align their guidelines to those of the authorities as well as provide them with all options of genetic possibilities, updating of guidelines should be made with each advancement of relevant technology.
6. Lay understandings of SCD are problematic. Even though sickle cell groups are doing a lot to educate the public. I think this study unearthed the sufferings people

with SCD are subjected to. The NHS should make aggressive efforts combat the stigma and marginalization by building awareness through public education using media such as BBC or Sky news to do presentations occasionally about the genetic diseases prevalent in the UK. The authorities might need to invest into this area of awareness by committing some funding into research.

8.6 Directions for Future Research

This study addressed how SCD impacted on the selection of romantic partner of adults living with SCD in the UK and also how it impacted on their reproductive decision making. I think it will be interesting to also study this phenomenon on those who have the SCT but not the disease. There is evidence in literature that many people, particularly young adults who are of age range for negotiating intimate romantic partnership are not aware of their genetic status. They therefore enter into relationship without any genetic screening. Such couples have a possibility of bearing affected children; Hence, it will be of benefit to society to study how the behaviour of adults with SCT is altered at the point of selecting partners for these long-term relationships and also how they plan to approach their reproductive choices.

Another suggestion I have is that a study can be conducted to explore and compare the genetic information knowledge between adults with university education and those without. During the study, I noticed a great disparity in the genetic knowledge in these two sets of persons. Even though most of the participants with less education attend the sickle cell group meetings more than the university educated ones, they still had less genetic information knowledge. Unwholesome partial knowledge may eventually affect their behaviour in terms of forming a romantic relationship as well as when making reproductive decisions. Although it was not the focus of this study, I noticed that the reproductive behaviour of participants with more robust knowledge of Preimplantation Genetic Diagnostic (PGD\IVF) procedures, was different. I suggest this can also be researched upon.

A study can also be conducted to compare the differences in reproductive behaviour of the different ethnic groups such as the affected people of Caribbean, Asians and Africans origins. This will help raise awareness and support that can be tailored to help all the sections of the society appropriately.

8.7. My Reflections and Conclusion

Conducting qualitative research in a topic close to my subjectivity and listening to stories of the participants as they '*lay bare*' their inner selves and the meanings they made of their

experiences impacted me in ways I never thought possible. As Dickinson-Smith and colleagues said, “undertaking qualitative research is an embodied experience and that researchers may be emotionally affected by the work they do” (Dickson-Smith *et al.*, 2009: p. 61). Since I share a *commonality* with the participants about personal experiences of the lived disability realities as told in the narratives, each of the interview required intense emotional labour to conduct as I heard my own encounters reverberated in the narratives. I had to constantly remind myself that I am the researcher, not the researched.

The study afforded me the privilege of having in-depth interviews and getting to ‘see’ what an otherwise hidden oppression of a target population have been, whose voices were silenced by the medical discourses of ethics. For me, it was an eye opener that it is not an individualised phenomenon, but a collective and yet socially constructed ideology underpinned by economic concerns (like in the case of UK, the Department of Health’s concerns about reducing cost of SCD burden on NHS resources). I came to realise that ‘margins’ (‘in marginalised’) are boundaries created by the dominant system designed for culturally *normal* bodies who determine which group of *persons* should be subjected under the socio-psychological, political and economic control of *Others* (Meleis & Im, 1999). Meleis and Im (2002) further argued that *this* mark of marginalization is “the extent to which they (people) are stereotyped rendered voiceless, silenced, not taken seriously, peripheralized, homogenized, ignored, dehumanized and ordered around” (Meleis & Im, 2002: p. 96). Feelings of being marginalized, stigmatized and devalued are internalised feelings that, culturally, is never voiced out as a way of accepted behaviour, so, ‘*pretend*’ or ‘*pass*’ for normal, as if it does not hurt (Brune & Wilson, 2013). Goffman (1963) argued that the concept of ‘*passing*’ reduces feelings of stigma for the disabled person. With the medical model of living with a chronic illness like SCD, each individual had assumed their embodiment is a personal tragedy and so, bottled up the internalised pains from violence by different segments of the society. The narratives of the participants served as a *demythifier* of the hidden feelings, breaking “down the ‘culture of silence’ which still allows the oppression of groups such as disabled people to continue” (Cole, 2009: p. 569). Narratives can empower people who are disabled by society because “personal narrative responds to the disintegration of master narratives as people make sense of experience, claim identities, and ‘get a life’ by telling and writing their stories” (Langellier, 2001: p. 699-700). My newly acquired embodied knowledge interlinked with my subjectivity, placed me in a privileged positionality to be a *co-constructor* of the alternative narratives and lived experiences of these adults living with SCD. I hope this will thrust them from silencing

obscurity into liberating prominence as the expressed collective truths about their experiences ('Nothing without *Us* about *Us*'), challenge the narratives of *Others* who claim to be 'experts' about their lives.

Drawing on feminist approach that places the voices, experiences of participants at the centre of analysis, this phenomenological study explored how SCD impacts on the partner selection, reproductive decision making, disclosure and moral responsibility of SCD-embodied adults in the UK. The interviews revealed the meanings they assigned to their lived experiences, bringing to light what is known but hidden of *shades* of oppression. My hope is that the findings will elicit public awareness of the oppressive stigma experienced by this population as relevant policies are being implemented, through social practices entrenched in discourses, politics, and medical/social relationships. In other words, the study findings will produce significant practical outcome for people living with SCD. I suggest that stories do "repair the damage that illness has done to the person's sense of where she is in life" (Frank, 1995: p. 54-56), and can be a powerful tool to impact positive change in the attitude of society as well as influence change in social policy (Lyons 2007: p. 600).

As an academic, I gained a lot of insight into the '*how*' and '*why*' of qualitative approach to research. The difficulties as well as the importance of such a method were clearly elucidated. Having gone through the rigors of this study, I believe I will be able to conduct other studies with more confidence. I found data analysis very tedious and that pushed my boundaries, but I learnt to be objective, being open-minded as a researcher and not impose my pre-conceived ideas. I realised I needed to be true and as accurate as possible to the stories of the participants.

I must say I did not find this research easy as I thought of quitting many times partly because of the difficulty of recruiting participants and being a self-funding researcher. On this note, I must say, should there be an opportunity for such a study in future, I must first ensure that there is some funding in place before launching into it. Midstream through the research, I had to shop for jobs as my sponsor could no longer fund my study.

On the issue of recruitment of participants, several points come to mind. The ethnic minority population mostly live in low-income area of London. There is evidence that many of them who I met at the sickle cell support meetings have participated in more than one study and so I experienced research-fatigue among them. I think a small token of money (maybe 5 to 10 pounds) should be given to willing potential participants as an incentive to participate. To get the *thick rich stories* that is needed in this study, there was a need to get diverse people from all the different identities, cultures and backgrounds for purpose of richer and possibly

deeper data. Most of the participants I could recruit were university-trained individuals. Perhaps some unemployed persons or people hidden in the dense ethnic minority areas may have some other type of stories to tell. For instance, I observed a difference in the oppression experienced by participants of African origin from participants of Caribbean origin. I also assume there might also be some differences in the behaviour of people of Asian origin. This therefore highlights the need for further wider study that will incorporate this missing diversity of participants.

Another issue with recruitment is that with SCD, winter period is not a period for collecting data. Many of the individuals normally stay away from the cold to avoid any crisis trigger. In spite of probability of holidaying, summertime remains, I believe, the best time for recruitment of these participants. I encountered an enormous difficulty in recruiting because of the cold season.

Apart from academics, undertaking this research has affected my perspective of romantic relationships. Many of my participants' narratives resonate deeply with me as I reflect on my own journey of selecting a lifelong romantic partner. From my teenage years, my parents constantly reminded me about the hazard of genetic incompatibility so I could only select partners that are not at-risk. This placed enormous strain on me as my choices were very much restricted. I remember my feelings of rejection and stigma when potential partners refused to commit to a relationship at points of status disclosure. During this research, my perception changed because of the availability of technologies to prevent passing on of SCD to offspring, which I consider vital. This newly acquired knowledge was emancipatory for me because choices became more permissive rather than being limited to a specific genetic group

Finally, I am so grateful to my two supervisors who saw me through this study. I could not have finished it without their support and encouragement. Getting to the end of the research is like a dream and I am so glad I was able to complete it. Above all, I have tried to stay true to participants lived and embodied stories and hope the socially constructive impact of SCD on the partner selection, reproductive decision making, disclosure and moral responsibility of SCD-embodied adults in the UK has been well illuminated.

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APPENDICES

APPENDIX ONE: Letter to Organisations

Ore-Ofe Oladiran
Postgraduate Researcher
Department of Sociological Studies
University of Sheffield
Elmfield Building
Northumberland Road
Sheffield, S10 2TU

Address of Organisation XXXX

XXXXX

RE: Exploring How Sickle Cell Disease Impacts Forming Relationships and Reproductive Decisions in People with the Sickle Cell Disease

Dear Sir/Madam

I am writing to introduce myself. My name is Ore-Ofe Oladiran, a PhD student at the University of Sheffield.

I am conducting a research study which seeks to explore how adults living with sickle cell disease view the disease and choices surrounding forming relationships and having children.

As part of my study, I would like to interview members of your organisation. I would like to give a short presentation of my research project to your members at a time that will suit

them. I would also be very appreciative if a staff member could forward my invitation and information letters to other members who have sickle cell disease.

I have included an information sheet about the study that describes what the project is about in detail. If you have any questions, please do not hesitate to contact me.

This research study is voluntary and identities of members from your organisation that choose to partake will be kept confidential at all times.

My mobile number is xxxxxxxx and email address is ooladiran1@sheffield.ac.uk.

My supervisors are details are provided below:

Prof. Paul Martin. paul.martin@sheffield.ac.uk

Dr. Kate Weiner, k.weiner@sheffield.ac.uk

I look forward to hearing from you.

Yours faithfully,

Ore-Ofe Oladiran

APPENDIX TWO: Participant Information Sheet

Research Project Title: Exploring How Sickle Cell Disease Impacts Forming Relationships and Reproductive Decisions in People with the Sickle Cell Disease

Hello. My name is Ore-Ofe Oladiran. I am a PhD student of the University of Sheffield. As a requirement for my degree, I need to complete a research project. It is important for you to understand what I aim to accomplish before you decide whether to participate. Please take a moment to read the information carefully and ask if you have any questions.

What is the purpose of the project?

The aim of this project is to explore the place of Sickle Cell Disease in people's experiences of forming relationships and ideas about having children.

Why have I been chosen?

I have invited you to participate because you reside in the United Kingdom and have sickle cell disease (genotype SS).

Do I have to take part?

Taking part in this project is voluntary. If you decide not to participate or withdraw from the project once it has begun, this will not affect you in any way.

What will happen to me if I take part?

If you do decide to participate, I will give you this information sheet and I will ask you to sign a consent form. Please note that you can still withdraw without providing a reason without it affecting you.

What do I have to do?

If you wish to be part of the project, I will invite you to take part in an interview. During the course of the interview, I will ask you general questions about your views on sickle cell disease and how living with it affects relationships and ideas about having children. I will arrange the interview at a time and place convenient for you. You can choose.

Will I be recorded, and how will the recorded media be used?

I would like to use a voice recorder during our conversation to get an accurate record of what we talk about. I will ask for your permission for this. I will transcribe these recordings. I might use sections of the transcript in my project, articles and presentations.

Will my taking part in this project be kept confidential?

If you decide to take part in this project, your identity will be kept confidential and you will not be able to be identified in any reports or publications. In all reports and publications, your name will be changed. I will be the only one to have access to your information. In addition to this, my supervisors will have access to your anonymised responses.

What will happen to the information I provide?

The information you tell me will be used for a research degree project which will be completed in March 2021. If you wish to view a copy of the published results they will become available at the end of the project through the Western Bank Library University of Sheffield and White Rose Depository. I can make these (or a summarised copy) available to you if you are interested in the results. Furthermore, the data collected may be used in subsequent publications after completing this initial project.

What are the possible risks of taking part?

It is unlikely that this study will bring you any harm. However, due to the nature of the study some sad memories may surface. In this event, I will suggest that you seek help from a counsellor at the organisation you belong to.

What are the possible benefits of taking part?

Though there are no immediate benefits for people participating in this project, I hope that it will lead to better understanding of experiences faced by men and women with sickle cell disease.

What if something goes wrong?

In the event that you are dissatisfied with the proceedings of the interviews or with how you have been treated, you can contact my supervisors: Prof Paul Martin and Dr. Kate Weiner. Their contact details are provided at the end of the information sheet.

If you feel that your complaint has not been handled satisfactory, you can contact the University's Registrar and Secretary.

Who has ethically reviewed the project?

This project has been ethically reviewed via the Department of Sociological Studies' Ethics Review Panel.

Who is organising and funding the research?

This is a self-funded project.

If you wish to obtain further information about this project, please feel free to contact me or my supervisors.

You will be given a copy of this information sheet.

Please read and sign the consent form signalling your willingness to participate in this project.

Thank you so much for your time and participation!

Ore-Ofe Oladiran

ooladiran1@sheffield.ac.uk

Supervisors: Prof. Paul Martin, paul.martin@sheffield.ac.uk

Dr. Kate Weiner: k.weiner@sheffield.ac.uk

APPENDIX THREE: Participant Consent Form

Title of Research Project: Exploring How Sickle Cell Disease Impacts Forming Relationships and Reproductive Decisions in People with the Sickle Cell Disease

Name of Researcher: **Ore-Ofe Oladiran**

Participant Identification Number for this project: **Please initial box**

1. I confirm that I have read and understood the information letter dated _____ explaining the above research project and I have had the opportunity to ask questions about the project.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences.
3. I understand that should I not wish to answer any particular question or questions, I am free to decline.
4. I give permission for the researcher's supervisors to have access to my anonymised responses. I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
5. I agree for the data collected from me to be used in publications after completion of the research project.
6. I agree for the researcher to use a voice recorder during the interview, accessible only by the researcher.
7. I agree to take part in the above research project.

Name of Participant Date Signature

Student Researcher Date Signature

To be signed and dated in presence of the participant

Researcher details:
Ore-Ofe Oladiran ooladiran1@sheffield.ac.uk

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g., a site file), which must be kept in a secure location.

APPENDIX FOUR: Participant Bio Data Form

NAME:

GENDER:

AGE:

MARITAL STATUS:

NUMBER OF CHILDREN:

HIGHEST QUALIFICATION OBTAINED:

PROFESSION:

APPENDIX FIVE: Interview Tool

1. How did you come to know about your SCD?
2. In what way has SCD affected you overall health? In what ways has SCD affected you – what's it like to live with SCD?
3. Do you have support from friends or family? When you have crises? With your children?
4. How has the support you received assisted in aiding you back to health?
5. How does SCD affect the way in which you form/ maintain relationships (that is friendships)? Explain further? Has SCD affected the way you form friendships, and you are friends with?
6. Are you in a relationship at the moment?
7. Does your partner/girlfriend/boyfriend have SCD?
8. When did you first talk about SCD with your partner and at what point in the relationship did they become aware of your condition?
9. When did you become aware of their status?
10. Has SCD been an issue in your relationship? In what ways?
11. How did/does SCD affect the way in which you develop and/or maintain romantic relationships? (a life partner/ significant other). Explain further? **Do you consider your partner's (future partner) genotype before entering or during the course of a relationship with them? Explain further?**
12. Do you want to have children?
13. Are there any particular reasons why you are thinking about having children not having children?
14. What issues might you face and how do you plan to manage them?
15. Before you have/had your child, did you know there could be a possibility they could be born with SCD? How did that make you feel (What did you think about that)?

Interview Schedule

Section 1: Warm up & Introduction

Section 2: Give a rundown of discussion

Section 3: Main discussions

Section 4: Summary

Section 5: Thanks & Appreciation

APPENDIX SIX: Ethics Application



Application 012681

Section A: Applicant details

Created:

Mon 30 January 2017 at 13:14

First name:

Ore-Ofe

Last name:

Oladiran

Email:

ooladiran1@sheffield.ac.uk

Programme name:

PhD in Sociological Studies

Module name:

PhD/Sociology FT (SCSR31)

Last updated:

01/06/2017

Department:

Sociological Studies

Date application started:

Mon 30 January 2017 at 13:14

Applying as:

Postgraduate research

Research project title:

Exploring the Views of People with Sickle Cell Disease in Forming Relationships and Having Children

Section B: Basic information

1. Supervisor(s)

Name

Email

Afua Twum-Danso Imoh

a.twum-danso@sheffield.ac.uk

2: Proposed project duration

Proposed start date:

Thu 15 June 2017

Proposed end date:

Fri 1 December 2017

3: URMS number (where applicable)

URMS number

- not entered -

4: Suitability

Takes place outside UK?

No

Involves NHS?

No

Healthcare research?

No

ESRC funded?

No

Involves adults who lack the capacity to consent?

No

Led by another UK institution?

No

Involves human tissue?

No

Clinical trial?

No

Social care research?

No

5: Vulnerabilities

Involves potentially vulnerable participants?

Yes

Involves potentially highly sensitive topics?

Yes

Section C: Summary of research

1. Aims & Objectives

Sickle cell disease (SCD) is an inherited blood disorder known to affect mainly people of African and Caribbean ethnicity. WHO recorded that about 5% of the world population is carrying the SCD genes. Furthermore, as at August 2015, the Action Medical Research for Children reported that in the U.K. one baby was born with SCD in every 1900 live births. SCD occurs when the red blood cells change from their usual disk-like shape into a crescent shape, blocking blood veins and preventing the free flow of oxygenated blood into different body parts thus causing pain and rendering the person quite weak at these points in time. The times when the person is experiencing pain is known as crises. #

My research aims to explore young people with SCD views on relationship formation and having children.

Research Aim

To explore the extent to which Sickle Cell Disease status affects intimate relationships and reproductive decision making in young adults aged 25-34 years.

Research Questions

To address this aim, the three sub-questions are:

1. In what way is SCD status a consideration in forming and negotiating relationships?
2. To what extent does this health status feature in people's accounts of reproductive decision making?
3. What characteristics and experiences of participants emerge as underpinning their views?

2. Methodology

Method of Choice & Methodology

A qualitative research strategy study will be the most appropriate for this type of study as it aims to understand the experiences of young people living with sickle cell disease (SCD). Since a qualitative study is text driven, data can be retrieved through narrative approaches, ethnographic approaches, case studies, phenomenological and the grounded theory (Bryman, 2008; Creswell, 2003; Kvale, 1996; Mason, 2002). Creswell (2012) noted that qualitative research involves collecting data in text (words) format from the participants. In this kind of study, I will rely heavily on the participants'™ views. Mason (2002) described qualitative research as "exploratory fluid and flexible, data-driven and context sensitive" (p. 24). This could be that this type of study aims to explore the reasons behind a certain phenomenon. Whereas, a quantitative study is mainly interested in numerical data (Grix, 2004), qualitative researchers analyse fewer cases in hopes of developing theories (Holloway, 1997). By adopting this approach to my study, I will develop a rapport with each research participant to gain additional information from them. Unlike quantitative based studies which takes place on a large scale, qualitative studies are small-scale based.

This study does not call for statistical data but rather narrative data. As it is an explorative study that fully relies on the participants'™ views, it will be a qualitative study. The technique of in-depth interviews will be utilised for this study as it is the most suitable method for collecting data bearing in mind the research questions. According to Mason (2002), the most important characteristics of interviewing is that it "operates from the perspective that knowledge is situated and contextual, the job of the interviewer is to ensure that the relevant contexts brought into focus so that situated knowledge can be produced" (p. 63). That is to say, that an interview is used to draw out information from the participant by posing questions related to the topic. Unlike questionnaires, interviews draw out participants'™ response instead of providing a

possible response. Interviews can transpire in a group setting (group interview) or with each individual participant (Bryman, 2008). However, due to certain ethical limitations pertaining to confidentiality within a group setting; I will only utilise one-on-one interviews.

This method has been selected as it is the most effective for my purposes. It will enable me to ask a series of questions to the participants. I can ask for clarification on a matter or for the participant to explore further into a point made. Interviews will be the most suited as it gives insight to the participants' non-verbal cues; questionnaires are not afforded this option of non-verbal communication. As the research questions ask for the participants to narrate their experiences in various contexts (relationship formation and (future) reproductive plans) this method of data collection is the most befitting in that it gives room for in-depth and detailed discussions unlike questionnaires.

3. Personal Safety

Raises personal safety issues? Yes

Personal safety management

Data collection could occur in either a café, the organisation (ASYABI, OSCAR Sandwell, Sickle Cell Society or Croydon Sickle Cell and Thalassaemia Support Group) or the participants' home and quite possibly after working hours. I will try and ensure my safety by not meeting participants too late into the night and in secluded areas. Furthermore, I give my mobile number to my supervisors so they can contact me. I will also inform my supervisors and a family member of my scheduling so they are aware of my movements and the time I completed my interview.

Section D: About the participants

1. Potential Participants

The participants will be identified from sickle cell organisations in London, West Bromwich and Leeds as these are the cities that provide non-NHS services to people living with sickle cell disease. According to the Office for National Statistics as of 2014 in England and Wales, the highest percentage of the mother's age as at the birth of the first child among UK nationals was 30-34 years at 30% followed closely by 25-29 years at 28%. A similar trend can be seen among non-UK nationals with 30-34 years at 35% and 25-29 years at 29%. It was established that also in 2014 by the same office, 62% of Africans have children within the confines of marriage or civil partnership to the 65% of Caribbeans. As ages 25-29 and 30-34 years were the highest percentages of when a woman had her first child I would propose adopting these two age groups. Therefore, the sample size should be men and women between ages of 25 and 34 who have either had children or are interested in having children in the future.

2. Recruiting Potential Participants

The participants will be approached through the non-NHS organisations of Oscar Sandwell, ASYABI, Croydon Sickle Cell and Thalassaemia Support Group and the Sickle Cell Society all located in West Bromwich, Leeds and London respectively. I hope to have an audience with the members of the organisation at the end of a meeting where I will present the project and offer information sheets. Members can signal their interest immediately or have time to think about

joining the project and contact me if they are interested. Furthermore, the organisation can forward a letter to members who may not have been present during the brief meeting and again, have them contact me if they are interested in participating in my project (Appendix One & Two). This letter will contain my contact details and information sheet. The information sheet discusses in detail the what I hope to achieve, how I will collect the data, who has access to the data, what the data will be used for during the course of the project (and after the project), implications (if any) of participating in the project.

Participants will be recruited from non-NHS sickle cell organisations. I have contacted the named organisations above in which participants can be recruited. The participants should have sickle cell disease, have children or be interested in having children in the future. These men and women should be between the ages of 25-34 years. I aim to recruit 30 participants. I intend on passing out a bio data form in which potential participants will be asked to provide their age, ethnicity/race, gender, employment and marital status. This will allow me to ensure diversity amongst my participants. Despite the fact that I plan on using this short screening form to recruit participants; I am aware that this could be limiting to a certain extent. Therefore, this tool will be used to assist in recruiting participants but it is not set in stone. I intend to be flexible when selecting participants.

2.1 Advertising methods

Will the study be advertised using the volunteer lists for staff or students maintained by CiCS? No

- not entered -

3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) Yes

The researcher will obtain informed consent by providing an information sheet detailing the purpose of the research and the freedom of choice they have in participating in the study. In addition, the researcher will highlight the fact that they have the option to withdraw from the study at any given point without supplying a reason for the withdrawal. Once they agree to be part of the study, I will provide an informed consent form which shows that they understand what the study entails, they give permission for me to collect data from them and give me access to record our discussion. At the end of the letter they sign and date it showing their interest to participate in the study. Before I begin with the process of collecting data, I will allow time for the potential participants to ask questions if they require clarification in certain aspects of the study. A copy of the informed consent form is attached in Appendix Two & Three.

4. Payment

Will financial/in kind payments be offered to participants? No

- not entered -

5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

This study may not cause any harm to potential participants. However, due to the nature of the study and the fact that I am exploring participants' experiences, some negative memories may surface and may cause them

to become emotional.

How will this be managed to ensure appropriate protection and well-being of the participants?

I am not trained to provide counselling and support if this occurs, I will provide a leaflet with the contact details of support organisations, should they require these services. In addition, if it is possible, I will request for counsellors from the organisations to be on standby.

Section E: About the data

1. Data Confidentiality Measures

To ensure the participants'™ personal data is kept private, I will keep all physical data in a locked cabinet in the University of Sheffield in which I will be the only one to have access to it. In addition to this, all digital copies will be stored in an encrypted folder on my computer which will be password protected. In instances whereby I will need to identify the participant, a pseudonym will be used.

2. Data Storage

I will seek permission from the participant to use a voice recorder during the interview. To make sure there is a clear understanding, I will explain the use of the recording, how it will be stored and destroyed. I will assure them that their identities will be concealed at all times by the use of pseudonyms. If the participants decline my request to record them, I will take notes. The physical data will be stored in a locked cabinet at the University of Sheffield; and digital data will be stored in an encrypted folder on my computer which will be password protected. The digitised data will be archived for post study usage (with permission from participants).

Section F: Supporting documentation

Information & Consent

Participant information sheets relevant to project?

Yes

Participant Information Sheets

- [PARTICIPANT_INFORMATION_SHEET.docx](#)
(Document 033420)

Consent forms relevant to project?

Yes

Consent Forms

- [PARTICIPANT_CONSENT_FORM.docx](#)
(Document 033423)

Additional Documentation

- [LETTER_TO_ORGANISATIONS.docx](#) (Document 033425)
LETTER TO NAMED ORGANISATIONS

External Documentation

- not entered -

Official notes

- not entered -

Section G: Declaration

Signed by:
Ore-Ofe
Date signed:
Sat 4 February 2017 at 14:41

APPENDIX SEVEN: Ethics Approval



Downloaded: 07/03/2022

Approved: 13/07/2017

Ore-Ofe Oladiran

Registration number: 150139175

Sociological Studies

Programme: PhD in Sociological Studies

Dear Ore-Ofe

PROJECT TITLE: Exploring the Views of People with Sickle Cell Disease in Forming Relationships and Having Children **APPLICATION:** Reference Number 012681

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 13/07/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 012681 (form submission date: 06/06/2017); (expected project end date: 01/12/2017).
- Participant information sheet 1026913 version 5 (06/06/2017). Participant consent form 1026914 version 3 (06/06/2017).

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Sally Midgley

Ethics Administrator
Sociological Studies

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:

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-

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<https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure>

The project must abide by the University's Good Research & Innovation Practices Policy:

https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf

The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.

The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.

The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.