LIVING WITH SICKLE CELL AND DEPRESSION IN LAGOS, NIGERIA

by

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ABSTRACT

Sickle cell disease (SCD) and depression are each major public health issues globally. Nigeria currently has the largest proportion of people with SCD worldwide, with up to 150,000 annual births. This study highlights the limitations of previous studies, which only utilize the biomedical model in explaining SCD, and which pay insufficient attention to the lived experiences of people with SCD. Extant literature reports strong associations between SCD and depression, and locates the problem ‘only’ in terms of disease severity, levels of service utilization or alleged psychological maladjustment to SCD condition. Biomedical research tends to treat stigma as a predicament that automatically correlates with SCD.

Data collected was guided by a modified three-staged theoretical framework derived from Arthur Kleinman, with the use of questionnaires (incorporating Patient Health Questionnaire) to describe depression in persons with SCD; 15 in-depth interviews to explore the illness experience of SCD, and a series of six focus groups to examine depression and stigma in SCD as a form of ‘societal sickness’. In the first stage, questionnaires were administered to 103 outpatients at an SCD clinic in Lagos, Nigeria, and findings revealed an association of depression with age, and severity of SCD as indicated by symptoms such as leg ulcers. The first stage enabled those with moderate depression to be identified and invited into the subsequent stages (two and three) of the research.

In the second stage, fifteen in-depth interviews with adults living with SCD were conducted and analysed using interpretive phenomenological analysis (IPA), also drawing on the influences of Herbert Blumer and Erving Goffman. Testimonies suggested that people with SCD face overwhelmingly negative criticisms from a wide range of significant others, including close family members; that the discrimination they face arises not from their condition per se but from the societal norms and expectation that they are assumed to break; and that they themselves identify pathways from the negative experience they endure to their own depression and mental distress.

In the third stage, a series of three focus groups, each with five participants, found that people with SCD began to reject negative labels, identify challenges in their own terms,
gain a sense of confidence and identity from their participation in groups, and began to identify social barriers to their full participation in society that they wished to challenge.

The overall findings of the research suggest that by coming together in groups, people with SCD themselves suggest that rigorously researched social interventions may be considered an important adjunct to medical interventions in improving the lives of those living with SCD in Nigeria and throughout sub-Saharan Africa.
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Sickle cell disease (SCD) is a chronic set of blood conditions that impact the lives of many affected persons worldwide (Yusuf et al., 2011; Piel et al., 2013). In SCD, the primary abnormality is with haemoglobin causing distortion of the normal spherical shape of red blood cells into sickle shapes (Bunn, 1997; Lane, 1996). SCD is common among blacks in diaspora as well as those from areas where malaria has been prevalent such as Arabia, countries in the Mediterranean region, or South Asia.

Recent studies in the U.S. reported that nearly 90,000 persons live with SCD with a prevalence of 1 in 396 among African American births and 6% of neonates with SCD among Hispanic Americans (Piel et al., 2012, 2013; Yusuf et al., 2011; Hassel, 2010; Brousseau et al., 2010). In England, estimates of the number of affected persons range from 6500 to 12,500 with a birth prevalence of 1:1850 (Bennett 2005; Piel et al., 2010). SCD affects 275,000 conceptions each year according to the World Health Organization (WHO) estimates, and represents a considerable health challenge 71% of countries including those that account for 89% of worldwide births, and accounts for the mortality rate of 3.4% in children up to pre-school age (Modell and Darlison, 2008; Weatherall and Clegg, 2001).

Prior to 2013, the North American and European-centred nature of the literature has rather overshadowed the fact that SCD is an important public health issue in Sub-Saharan Africa.
(Dennis-Antwi et al, 2008; Grosse et al, 2011). Several authors (Grosse et al., 2011; Dyson and Atkin, 2012) have suggested that SCD will be of increasing public health importance in sub-Saharan Africa in the near future. Piel and colleagues (2013) in their article have drawn attention to the need for systematic focus on sub-Saharan Africa. According to them, an estimated 242,200 to 302,000 of new babies who have SCD happened in many African countries South of Sahara in 2010. This is more than the estimated number affected worldwide reported by Modell and Darlison in 2008. In contrast to this increase in proportion of newborns with SCD in sub-Saharan Africa, the proportion of affected newborns is reduced in other places where SCD has been prevalent such as the Americas, Eurasia and Arab-India. Two nations (Nigeria and Democratic Republic of Congo) in sub-Saharan Africa represented 57% of babies with SCD that are delivered yearly worldwide (Piel et al., 2013). While the relative contribution of Nigeria will rise from 30% to 35% according to projection, that of DRC will decrease from 13% to 11% (Piel et al., 2013). Piel and colleagues (2013) estimated a particularly high rise in the figures of newborns with SCD from 91,000 in 2010 to 140,800 in 2050 in Nigeria. On one hand, it is important that the findings of Piel and colleagues should not be framed as persons with SCD constituting a significant burden, and on the other hand, it is pertinent to note that persons with SCD may face challenges including the disabling attitudes of others including disabling language such as “burden”. In extending the stigma-power concept of Link and Phelan (2014), people living with SCD, particularly where they exist in large numbers, might live in situations where others (without SCD) have strong motivations to keep them subjugated through social processes that are indirect, broadly effective and hidden in taken-for-granted cultural circumstances. In other words, it is imperative to understand persons with SCD and their challenges within the context of the society and the existing social infrastructure, particularly in societies where they are large in numbers, such as in Nigeria.

In general, many large scale epidemiological studies, such as the Isle of Wight study (Rutter et al 1976), which has been consistently replicated since, show that people with chronic physical disorders like SCDs are at increased risk of psychosocial difficulties. One particular factor that has been associated with SCD in the literature is depression. The
prevalence of depression in SCD patients has been reported to be high both in the high income and low-and-middle income countries (Hasan et al., 2003; Udofoia and Oseikhuemen, 1996; Jenerette, Funk and Murdaugh, 2005; Levenson, 2008; Edwards, 2009; Asnani et al, 2010). SCD has also been associated with stigma (Ola et al., 2013; Ani et al., 2012; Burnes et al 2008; Helps et al. 2003; Alsaker, 1996).

Reflecting on Brown and Harris’s (1978) delineation of social origins of depression among women and Goffman’s (1963) stigma associated with chronic illnesses, depression and stigma as they relate to SCD might not be exclusively as a result of their biological attributes but may instead be a product of social attribution. In other words, there could be social origins of depression in those living with SCD. For example, lack of services, negative attitudes of peers and significant others in the society could be about social relations in their life experiences, as suggested in the social model of disability as proposed by Oliver (1992). Similarly, the experience of stigma in people living with SCD might not be attributes of the biological disease but about social relationships (Goffman, 1963; Mishler et al, 1981; Link and Phelan, 2014). The social model of disability (Oliver, 1992) argues against the biomedical model, which unwittingly victimizes affected persons by locating the difficulties associated with their condition entirely within them and posits instead that the real causes of disability are social barriers and negative attitudes rather than the actual physical impairments that may be associated with the disease conditions.

Generally, the biomedical framework describes SCD and depression “as is” rather than understanding SCD in a counterfactual way as a representation of “what could be”. Proponents of biomedical view do not accommodate other views and also tend to present the view that people who have conditions need to accept their conditions (i.e. SCD and depression) and cope with them. However, there are alternative views to biomedical view such as perspectives grounded in social realities and in addition, proponents of this view would inquire that if social situations are changed, would certain aspects change in persons who have conditions (i.e. SCD and depression). In other words, the impacts on the experience of sickle cell disease cannot be understood in biological terms alone as this
oversimplification has been found to overlook and neglect factors such as social relations, familial bonds, economic constraints, and survival strategies that influence the illness experience and the social expressions of the people living with SCD (Mishler et al, 1981; Helman, 2007; Kelleher and Hillier, 1996; Radley, 1993). Thus the exclusive use of biomedical model to SCD can only thus illuminate pathology and advance treatment but cannot make “complete” contributions to its causation, prevention and promotion (Mishler et al., 1981; Fullwiley, 2008). Additionally, the causation of depression and stigma in people with SCD could be elucidated by situating their lived experiences in their social and culturally nuanced contexts. Consequently, the social model of disability would thus argue that if social relations are changed, the issue of stigma and depression would probably be greatly reduced in the experiences of people with SCD.

The research aims of this study were to (1) capture the life-world experiences of people with sickle cell disease (SCD) who have depression, (2) explore how broader social relations may result in stigma and depression in people living with SCD, (3) explore what various strategies they use to legitimate their experience of the illness and re-negotiate their social identity and (4) establish what could be done to change social relations resulting in depression and stigma in their life-world experiences.

The specific objectives of this study were to (1) identify a sample of people living with SCD who score as mildly depressed on a validated psychiatric scale (2) ask people with sickle cell disease who have depression to describe their life world, (3) explore their perceptions of life and lived experiences with stigma and depression (4) explore what, if anything, they may consider is oppressive about their social conditions (5) explore what could change in their social relations, how change can be negotiated, and how to help others with similar social situations (6) assess the impact of research participation on people living with SCD.

Chapter 2 comprises a literature review. This literature review commences with a historical approach to SCD, then an introduction to the epidemiology, biology, and pathophysiology
of SCD, suggesting that SCD is an important public health issue in Africa. It next considers depression first as a public health issue worldwide and then jointly with SCD as worthy of in-depth study. Furthermore, depression in people living with SCD is discussed as well as its social origins. Apart from inattention to the possible social origins of depression in persons with SCD in the literature, there is a lack of consideration of how stigma develops in the social relationships of persons who live with SCD. Moreover, limitations in existing literature suggest the opportunity to address the social challenges of discredited and alienated groups via the social model of disability. This chapter further considered the use of Kleinman’s framework of disease, illness and sickness to frame our understanding of SCD, depression, and chronic illness.

Chapter 3 describes the research method and strategy used in exploring the lived experiences of people living with depression and SCD in Nigeria in line with appropriate research ethics. This chapter examined the eligibility criteria and sampling strategies and considered the use of questionnaires, in-depth interviews and focus groups as the methods of data collection for the project. SCD was conceived within Kleinman’s threefold framework, SCD considered in turn, as a disease, an illness and a societal sickness, with the methods of data collection broadly reflecting this framework. The questionnaires were used to identifying people with SCD who have depression, the in-depth interviews were used to explore the lifeworld of people with SCD who had mild/moderate depression and the focus groups were conducted to examine the varied means used by people living with SCD and depression to confirm their experience of the illness and re-negotiate their social identity.

Chapter 4 reports on the first parts of the data collection, specifically the results of the standardized mental health questionnaire, administered at a clinic in Lagos, Nigeria in order to identify those with SCD who were moderately depressed. This chapter also provides an inclusive view where, on one hand, the biomedical view reveals some important aspects of SCD while on the other hand it is limited in what it can tell us. This limitation is arguably significant because a biomedical view does not necessarily reveal where the possible points of intervention in people’s lives are that might make a socially significant difference.
Chapter 5 presents the results of fifteen in-depth interviews of a diverse sample of people living with SCD who are moderately depressed (as indicated by their completion of the standardized mental health questionnaire). Using interpretative phenomenological analysis (IPA), seven themes emerged from the data, and the potential for making practical and policy suggestions to improve the lives of those living with SCD is noted. This chapter attempts to capture possible points of impacts on the lives of persons with SCD, without which it would be difficult for interventions to make a socially significant difference.

Chapter 6 considers the result of the data from the focus group discussions. There were two focus discussion groups and each group met on three occasions. The first group was comprised of five people living with SCD and the second group consisted of five persons with SCD. All of the participants were from the pool who had taken part the in-depth interviews. Using IPA, seven themes emerged from the data including practical suggestions to negotiate some of the social barriers of persons living with SCD and depression. The themes were experiencing disapproval, experience of disbelief about pains from significant others, experience of stigma, ‘I am a different person’, thinking and talking about death, ‘we wished we were dead’, and coping with SCD.

Chapter 7 has three sections namely i) disease context of SCD ii) illness experience of SCD and iii) societal sickness of SCD. This chapter, guided by relevant theories of Goffman on stigma and Oliver on theories of disablement, comprises of the discussion that contextualizes, within the background of extant literature, the findings in chapters 5, 6 and 7. While this chapter considered similar and dissimilar findings in the context of previous findings, it then framed depression and stigma in the life-worlds of people living with SCD as being socially created and that these experiences could be addressed using the frame of reference of those living with SCD.

Chapter 8 is the conclusion chapter. This chapter describes the significant contributions of this thesis within the context of Chapters 1- 6. It also describes the original contribution to
knowledge from the study as well as some areas for future research. This chapter reflects on
the usefulness of Kleinman’s framework to represent SCD as disease, illness and societal
sickness to amplify the different dimensions of SCD experiences, including the
respondents’ search for consistency and negotiation of their social identity. The conclusion
argues that the real cause of disability are social barriers and the negative attitudes of others
in the society, and that giving voice to people living with SCD could be useful way of
addressing these challenges.
CHAPTER 2: LITERATURE REVIEW

Introduction

This chapter outlines the various strands of literature pertinent to the thesis. It commences with a history of SCD, then an introduction to the epidemiology, biology, and pathophysiology of SCD, suggesting that SCD is an important public health issue in Africa. This chapter then discusses depression as a public health issue worldwide in its own right, and then considers the importance of studying a situation where two major global public health issues overlap: people with SCD who are experiencing depression. The chapter moves on to discuss depression in people living with SCD and explores their depression as having social origins. The chapter concludes with a section examining the links between the extant literature on SCD, depression, social science, and chronic illness and the framing of the research questions to be addressed in this thesis.

Sickle cell disease:

In the Western medical literature, SCD was first formally described about 100 years ago by Dr. James Herrick, a cardiologist, in a dental student from Grenada who presented with a
history of chest symptoms in Chicago (Serjeant, 2010). Subsequently SCD had been observed commonly among people of African descent, and was therefore inaccurately considered as “black disease” (Wailoo, 2001). According to Wailoo (2001), from a historical account, SCD has been presumed to extend from tropical Africa to most part of Europe, Americas and Caribbean. This spread was ascribed to slave trade across the Atlantic in the mid-fifteenth to around mid-nineteenth centuries and to commercial movements of Africans to these parts of the world (Ohene-Frempong and Nkrumah, 1994). However, according to Ohene-Frempong and Nkrumah (1994) the Benin haplotype of sickle cell gene could have been in Europe from about 400AD up to 1000 years, that is, before the slave trade.

Furthermore, SCD is not necessarily a “black disease” since it has been found among natives of UK, India, Arabic, Hispanic, Mediterranean, or South Asian backgrounds who are neither Africans nor blacks (Lehman and Huntsman, 1974; Anionwu and Atkin, 2001; Sickle Cell Disease Guideline Panel, 1993; Serjeant, 2010). Sociological inquiries have revealed that in the western scientific inquiries the processes by which sickle cell has acquired its connotation as a “Black” disorder are due to social processes (Tapper, 1999; Wailoo, 2001; Dyson and Atkin, 2011).

SCD has been explored within the biomedical perspectives in the western world. Consequently, the understanding is restricted mostly to this perspective. For instance, some persons with SCD have been treated with a drug called hydroxyurea which has been demonstrated in clinical trials to lower the severity of the clinical symptoms and signs SCD’s in adults (Chararche et al., 1995; Odievre et al., 2008). The means by which this drug act could be related to the increase in production of foetal haemoglobin. However, it has been pointed out that in children, the clinical response to hydroxyurea could not be attributed in all cases to foetal haemoglobin levels (Green et al., 2013) and this suggests the possibility that other processes such as psychosocial factors may be involved in the clinical response.
In the non-Western world, SCD has been acknowledged for centuries by Africans (Konotey-Ahulu, 1991). In these populations, SCD was interpreted at the level of the whole person, and was described in terms that reflect the continual knowing pains that the person tolerated. It was also an entity that was characterized in environmental context: “rainy season rheumatism”. This condition had also been depicted by Africans in genetic terms: it runs in families. Moreover SCD has also been portrayed with regards to the relief of its symptoms with the use of fagara (a plant used in traditional remedies in West Africa). Fullwiley's (2011) study of Senegalese people living with SCD sheds light on the importance of sociological factors such as social networks and social bonding, in contrast to the view of mainstream biomedicine that such people were coping well because they had the mild (Senegalese) haplotype of SCD. In essence, SCD cannot only be understood in terms of its biological attributes but also in terms of the prevailing socio-cultural and environmental factors.

The assumption in Western biomedical literature is that, because SCD is genetic, that it must involve high-cost technical solutions and expensive treatments (pre-implantation genetic diagnosis, stem cell transplants, bone marrow transplants). Furthermore, it should be noted that currently most aid agencies and WHO assume that health priorities for developing countries in Africa must be water, sewerage, and food supplements and not genetics which is assumed to be ‘high tech’ and expensive. However, beyond initial laboratory costs, SCD initiatives may not be as expensive in the African context and initiatives such as newborn screening (NBS) suggest that improved childhood survival is possible in Africa. Evidence to support this is emerging in Ghana (Dennis-Antwi, Dyson and Ohene-Frempong, 2008). It was therefore the aim of this study to understand SCD by situating it within its socio-cultural context.

**Sickle Cell Epidemiology**

SCD is a life-long group of disorders and affects many people globally (Yusuf et al., 2011). It is most prevalent monogenic disease in the world (Modell and Darlison 2008; Weatherall 2008). Several authors (Grosse et al., 2011; Dyson and Atkin, 2012) have highlighted that
SCD is now a major public health importance in sub-Saharan Africa more than in the western world. Piel and colleagues (2013) in their article consequently draw attention to the need for a focus on sub-Saharan Africa. According to them, an estimated 242,200 to 302,000 of newly delivered babies with sickle cell anemia (which constitutes about 83% of SCD) were in sub-Saharan Africa in 2010. From this finding it is estimated that the number for babies born with SCD is more than the estimated number affected worldwide reported by Modell and Darlison in 2008, suggesting that official statistics may previously have undercounted the numbers born globally with SCD. In contrast to this increase in proportion of newborns with SCD in sub-Saharan Africa, the proportion of affected newborns is decreased in other HbS regions including the Americas, Eurasia and Arab-India. Two developing nations (Nigeria and Democratic Republic of Congo - DRC) in sub-Saharan Africa constituted more than half of the yearly number of newborns living with sickle cell anemia (with the figures for SCD higher) around the world (Piel et al., 2013). While the comparative contribution of Nigeria will move from 30% to 35%, that of DRC will fall from 13% to 11% (Piel et al., 2013). By 2050 in Nigeria, using Piel and colleagues (2013) estimates, there would be more than 55% rise in the number of newborns with SCD. Furthermore in line with Piel and his colleagues (2013) arguments, in Nigeria, there might be difficulty in responding to the challenges of increased numbers born with SCD since a corresponding large increase in the economic capacity of the country is not anticipated. Moreover, addressing the challenge of SCD in Nigeria will have significant impact on the global burden of SCD.

Scientific data have demonstrated repeatedly and validly that the rates of diseases, (including non-communicable diseases such as SCD, are heavily influenced by the socioeconomic status of individuals (National Research Council, 2004; Patel et al., 2009a; Hosseinpoor et al., 2012), ethnic traditions or beliefs (National Research Council, 2004), and other socio-cultural factors (Ezzati and Lopez, 2004; National Research Council, 2004). Therefore health, or lack of health, cannot be merely ascribed to biological or natural conditions. Hence, while biomedical research might gather evidence to locate SCD within a biological framework, a sociological perspective on an illness would provide
insight on what social factors are more likely to influence the nature of SCD. The study by Fullwiley (2011) highlighted the importance of social factors on the health status of Senegalese people living with SCD. This study therefore examines the interaction between society and health status of people living with SCD in order to elucidate the underlying social factors.

**Sickle cell disease pathophysiology and clinical symptoms:**

SCD is characterized by chronic anaemia, intermittent sickling crises and infections. In the spleen, sickle cell haemolysis results in anaemia, and when there is repeated sickling crisis, autosplenectomy can be a complication of having sickle cell childhood.

Three types of crisis can occur in SCD: vaso-occlusive, aplastic and visceral sequestration crisis. Vaso-occlusive crisis, also referred to as the painful crisis, is the commonest. This event occurs when sickled cells block blood capillaries. The aplastic crisis can occur after dehydration, conditions that result in hypoxia, infection by B19 parvovirus, exercise, cold exposure, climbing high altitude, intake of alcohol, stress events and pregnancy. As a result of red blood cells pooling in the liver, spleen or the lungs, splenic sequestration crisis occurs. Thus, from a biomedical perspective, the potential physical symptoms and complications of SCD are both numerous and potentially severe. However, apart from these physical symptoms and complications, SCD has also been associated within the biomedical literature with mental health difficulties, in particular depression (Alao and Cooley, 2001; Alao et al., 2003; Levenson et al., 2008).

**Depression**

Depression is at present the foremost mental health condition responsible for high burden of disease both globally as well as in poor third world countries, and is projected to be, overall, the second outstanding cause of burden of disease by 2020 (WHO, 2004; Mathers and Loncar, 2006; Lopez et al., 2006). The diagnosis of depression is derived from the International Classification of Diseases tenth revision (ICD-10) diagnostic criteria for
research for depressive episodes and is based on a scientific method that recognizes the phenomenological report of symptoms by the respondents (WHO, 1993).

The World Mental Health Surveys have profiled the prevalence of depression among children and adults in many countries (Wang et al., 2007; Demyttenaere et al., 2004). Major observations about the pattern and distribution of depression from these studies are succinctly described thus: (1) the array of symptoms that represent depressive episodes/disorder can be revealed in all cultures; (2) there is a considerable disparities in the prevalence rates of depression all over the world, with rates of nearly 6% in China to over 20% in the US, with lifetime prevalence in Nigeria at around 4.3% (Gureje et al., 2010); (3) the onset of depression is most likely in adolescence; (4) as a disorder, it often runs a recurrent or persistent course; (5) depression is twice or thrice as common in women than men, although some studies, mainly African and comparatively few, have not reported this preponderance in women; and (6) social factors, including socio-economic disadvantages, are considerable risk factors in the onset or progression of depression (Patel et al., 2009).

Apart from its serious consequences on function, depression has been connected with higher deaths (particularly through suicide) and it regularly co-occurs with other chronic diseases such as diabetes and asthma (Chapman, Perry and Strine, 2005). In developed countries, several authors (Prince et al., 2007; Lopez et al., 2006) noted that depression could also be linked to a significant proportion of the disability that follows these co-morbid conditions and also associated with a variety of poor health outcomes. While these impacts are well documented in developed countries there are fewer scientific reports from the developing countries. And even in the Western world, where the impacts are known, the degree to which these co-morbidities operate at the global level or cross-culturally has not been studied enough (Prince et al., 2007; Lopez et al., 2006; Moussavi et al., 2007).

A wide range of literature has investigated the validity of measures that have been used in case recognition of depression in high income countries (Mulrow et al., 1995). A systematic review by these authors explored the correctness and certainty of several commonly used
questionnaires including the Beck Depression Inventory (BDI), the Centre for Epidemiologic Studies Depression Scale (CES-D), The Patient Health Questionnaire (PHQ), the Zung Self-Rated Depression Scale (SDS), and the Hopkins Symptom Checklist (HSCL) and found that all these commonly used scales were precise and accurate in identifying depression among persons who used primary care facilities with no instrument having better recommendation than other ones. Among these instruments, the PHQ was developed with the specific purpose of identifying persons with depression and monitor the severity of depression severity in these persons. A lot of research in the Western world, and sub-Saharan Africa particularly in Nigeria supports its validity (Kroenke, Spitzer and Williams, 2001, 2003; Adewuya, Ola and Afolabi, 2006; Wittkampf et al., 2007). Screening scales that have been validated locally, such as PHQ-9 in Nigeria, can be used without problems by community health workers and other health care staff aside physicians (Kroenke, Spitzer and Williams, 2003; Wittkampf et al., 2007). These authors revealed that, when such instruments have been locally adapted in a systematic manner, they show good criterion validity when compared to biomedical Western diagnostic criteria as well as etic descriptions of depression.

It is important to note that the biomedical view of what comprises depression is not unproblematic (Jadhav, 1996). There is a general agreement among psychiatrists that “true” clinical depression can be distinguished from pseudo-clinical depression (Canino and Alegria, 2008). However, this view, though dominant, is but an assumption based on a Western orientation and biomedical view that has not taken into account the social meanings of depression found in different cultural contexts. Lay and social meanings of depression as illness have rarely been widely explored in sub-Saharan Africa (Canino and Alegria, 2008).

From the biological perspective, a disease, after being classified, would be labelled (Canino and Alegria, 2008; Jadhav, 1996). This Western method of recognizing and classifying diseases has increasingly been based on the underlying pathological lesion or process since this aligns with the professional consensus about specific illnesses (Canino and Alegria, 2008; Jadhav, 1996). However, in psychiatry, there is no such external biological lesion or
pathophysiological process to act as a pivot for illness identification (Canino and Alegria, 2008). The example of depression will be used to explain this, given the thrust of this thesis. As there is lack of reference to underlying pathology, depression is more likely to be a product of social processes that include the construction of depression through the variety of publications on it and the revisions of diagnostic manuals, for instance the ICD-10 and the DSM-IV.

It must be noted that the development of standardised psychiatric instruments such as PHQ-9 and clinical interviews has only allowed the achievement of a stable professional consensus for those biologically oriented researchers who investigate such mental illness conditions as depression. This perspective has not explored, or has treated as unimportant or inconceivable, the lay or cultural meanings of depression.

"Depression" was first used as a professional term in 1905 in the journal called Psychological Review and it has been cited accordingly in Oxford English Dictionary (2nd Edition, 1989). However, another author, Snaith (1987), reported that “depression” had been in use before 1905. He reported that Bevan Lewis used depression as a medical word in 1899. Aside debates as to when the usage of the term depression began, the concept "depression" is a medical term in use to depict pervasive emotional state and mental health and is recognized as a Western twentieth-century phenomenon (Armstrong, 1980). Therefore, depression, as a medical label, originated within the culture of the Western World. Furthermore, the sub-types of depression are products of contemporary Western social events and processes.

There is an emerging awareness that the usual practice of forcing the use of depression as a diagnostic concept onto non-Western contexts is likely to be problematic (Canino and Alegria, 2008). In agreement with these authors, this practice has many methodological pitfalls. For instance, it is possible that the word "depression" may not be translatable to Nigerian languages in terms recognized by Nigerians, or that the subjective experience of depression, its manifestations and social responses to it differ across cultures. In other words, people who are distressed in Nigeria may be given the inappropriate label of
depression and/or people in Nigeria may exhibit symptoms in different ways than westerners and so do not come under consideration as being depressed in the first place.

Some authors (Karno and Jenkins, 1993; Ribeiro, 1994) have argued with evidence that the culture of the person is certainly patho-plastic in that a person’s cultural background could create variation in dimensions of experience of an illness aside from other specific areas such as emotional undertone and the linguistic structure as noted by other authors (Kleinman, 1988; Lewis-Fernandez, 1996). However, there are still disagreements among authors on the extent to which culture in non-Western countries modifies the symptom profiles or patterns of mental illnesses (Canino and Alegria, 2008). While the issue of disagreement remains to be solved, some authors (Pine et al., 2002; Munir and Beardslee, 2001) have summarized that evidence is mounting to show that social and developmental contexts have a significant contributory role in what behavior is normal or abnormal. In other words social judgement determines what is a disease/disorder such as depression and what is not and thus the definition of a disease/disorder might arguably differ across cultures.

Given these differing cultural perspectives, some authors have aligned with a relativistic perspective (Lewis-Fernandez and Kleinman, 1995; Rogler, 1996; Wakefield, Pottick, and Kirk, 2002; Weisz et al., 2006), some lend support to a universalistic paradigm (Roberts & Roberts, 2007; Bird, 2002), while still others argued that a combined universalistic/relativistic model is more robust (Rutter and Nikapota, 2002).

Within the field of psychiatry, Canino and colleagues (1997) reported that many investigators subscribed to the universalistic view of disorders and they argue that disorders, such as depression, have core symptoms that map onto patterns that are universal. In the view of these universalists, what could vary across cultures could be the level at which a behavior is considered normal, deviant, or abnormal (Canino, Lewis-Fernandez and Bravo, 1997). Weisz and colleagues (1997) have denominated this concept ‘ethnotypic’ consistency. The underlying assumption here is that a similar collection of
symptom profiles is recognized across different cultures even if expression of the symptoms changes across cultures.

The relativistic paradigm on the other hand posits that culture molds and ascertains what pattern of symptoms is associated with mental disorders such as depression (Lewis-Fernandez and Kleinman, 1995). Hence relativists (i.e. Weisz et al., 2006) have argued against the attainableness of developing a disease classificatory scheme that would be universal for all cultures, such as the ICD-10 (WHO, 1992). The relativists conceivably contended that such system of classification is faulty because it is wrongly premised on the assumption that disorders are more or less the same in all cultures. However, they surmised that what may vary is how the symptoms manifest across cultures. Canino and Alegria (2008) depicted that within the relativists’ framework, culture can affect not only the content of symptoms as well as how they are expressed but also whether or not such a concept of any type of disorder (i.e. depression) is acknowledged in the first place in a particular society. This is essentially at variance with universalist argument which restricts cultural role and describes culture as influencing how symptoms, including social risk and protective factors, are expressed. Thus, there have been calls by some relativistic researchers that the criteria for the definition of what constitutes an illness need to change by paying due attention to relevant information in a culture in order to avoid and prevent misclassifications (Fabrega, 1990; Hughes, Simons, and Wintrob, 1997). The proponents of the combined universalistic/relativistic view suggest that there are similarities across cultures but the variation lies in both the psychosocial risk and protective factors.

From this discussion above, cross-cultural similarity for depression cannot be assumed as the universalist would suggest, and neither would the relativistic view be unproblematic. The perspective in this study is that of combined universalistic/relativistic. The prevalence of this disorder varies and these variations could be due to cultural differences in (biologically and socially determined) risk and protective factors that are related to the onset of the disorder, following the argument of Rutter and Nikapota (2002). However, it could be argued that even if an abnormality such as depression could be described as a western concept, its core symptoms could map onto symptoms of distress in other cultures.
such as in Nigeria. This is the experience of the investigator in this thesis and it is within this perspective that depression is used and explored in this study.

Another issue is that the even when a diagnostic instrument/interview in a particular cultural context is adequate this cannot hold reliably or validly true in another culture, despite a faithful rigorous translation (Canino and Bravo, 1994). Matias-Carrelo and colleagues (2003) posited that any diagnostic or screening scale should be developed with due consideration to the culture where it will be used, and if its use is intended for another culture, then it requires a comprehensive adaptation process. This process of adaptation (Matias-Carrelo et al., 2003) provides the means for such a scale or instrument to identify validly and reliably similar phenomena in a different culture to those identified by the original version. In this process, the adapted scale would be equivalent to the original instrument across useful dimensions such as: content, semantic, technical, criterion and conceptual. If the scale does not achieve this multi-dimensional equivalence, then the use of its thresholds or diagnostic formulae may result in systematic error of misclassification. For instance, when an adapted scale is not equivalent with the original instrument conceptually (i.e. when the construct’s meaning varies in different cultures) then misclassification might occur because the items in the scale will have different meanings as well as interpretations across these different cultures. In this study, the mental health scale used to screen for depression among persons with SCD does not seem to have problems of technical, criterion and conceptual equivalence as reported by virtue of its validation among Nigerian students by Adewuya and colleagues (2006).

The seminal work of Brown and Harris (1978) delineated the social origins of depression among women, pointing out that depression may be linked to other kinds of problem. While it is linked to a whole range of serious physical disorders, these authors explored the possibility that it could also be linked with psychosocial factors. Using a sociological perspective, they demonstrated a link between clinical depression and a woman’s daily experiences within wider social structures over and above social relations, familial bonds, and economic constraints. In other words, Brown and Harris (1978) argued, after showing that certain life events and long-term difficulties are significant in the onset of depression,
that depression is a link between many kinds of problem and that it holds a pivotal position in understanding what is wrong with a society. They further argued that mood states such as sadness, unhappiness and grief are inevitable but that evidence has accumulated to show that this is not true of depression but that the origins of depression could be closely linked to the quality of core social roles. It should also be noted that these authors accepted that depression is equally biological (Brown, 2002).

To develop the point made by Brown and Harris (1978) on depression and apply it to the topic of SCD and depression, the experience of depression in people living with SCD cannot be fully explained by inconclusive correlations of depression, pain and SCD because these variables, when viewed as causal variables indicative of social processes, might be essentially meaningless and thus cannot represent the kind of social phenomena that may influence SCD.

In essence, the social meanings of living with depression and SCD fall outside the province of biological sciences, which can provide neither a full understanding of the illness nor adequate principles and criteria for treatment. A fuller and more adequate approach requires an alternative perspective in which the primary focus of inquiry is not only the relation of “personal troubles” to public issues of social structure (Mills, 1959) but also on the impact of social systems as a whole on individuals with SCD caught up in them (Brown and Harris, 1978). This study therefore attempted to locate the personal troubles of people living with depression and SCD to public issues of society and attended to any possible origins of depression in the social environment of the person living with SCD.

**Depression and SCD**

Depression is indeed as common in SCD in the developed and developing worlds, according to review of literature (Alao and Cooley, 2001; Alao et al., 2003). Rates of depression in those with SCD are similar to the rates found in other chronic medical disorders, and the rates range from 18% to 44% (Wilson et al., 1999; Hasan et al., 2003; Laurence, George and Woods, 2006; Grant et al., 2000). These rates are higher than those reported in the general population even when physical symptoms that are related to illness
are controlled for (Molock and Belgrave, 1994). For instance, Levenson et al (2008) in the PiSCES project reported a higher (27.6%) rate of clinical depression in adults that live with SCD than the rate among general adult population of African-Americans (Dunlop et al., 2003; Riolo et al., 2005).

Among the various factors that could potentially cause symptoms of depression in those with SCD are the long duration and course of the disease, the crises that are unpredictable, the pains that are chronic, and the distress of accompanying medical complications such as anemia, fatigue, retarded growth, leg ulcerations, acute and chronic renal failure, and cerebrovascular accidents (Molock and Belgrave, 1994). SCD begins in childhood and may be associated with social factors such as social derision, disability, and financial stress (Scott and Scott, 1999), as well as stigmatization for false addiction to opioid analgesics, especially in North America and Europe (Elander et al., 2004). In the PiSCES study, Levenson et al (2008) found that depressed people living with SCD did not differ from non-depressed SCD participants in terms of the number of crises or medical emergency visits, but they differed significantly in terms of number of days of reported pain. In addition, on days when they had no crisis, reported rates of depression among those with SCD correlates with higher pain episodes, more distress as well as impairment in functioning when compared to persons who have other painful illnesses such as headache, rheumatoid and osteoarthritis, chronic back pain and diabetic neuropathy (Bair et al., 2003; Katon, Lin and Kroenke, 2007).

The authors in the PiSCES study also noted a complex association between depression and pain. While the symptoms of depression as well as pain co-occur, they are risk factors for each other (Bair et al, 2003). Bearing in mind the findings from Brown and Harris (1978), depression and pain in people living with SCD could have social origins and reasonable adjustments in the society could reduce the impact of depression and pain on people living with SCD. This study sought to explore the social origins of depression and possibly pain from the subjective viewpoint of the persons living with depression.
It is helpful to contextualize depression as related to SCD. In particular, an understanding of the difficulties in diagnosing depression in people with SCD is essential. The first difficulty in assessing depression in SCD is the overlap between some of the physical symptoms of depression and SCDs for instance, lethargy (Alao and Cooley 2001). Yang et al (1994) illustrated this in their study where they administered the Child Depression Inventory (CDI) to children with SCDs and controls and compared the risk of depression from CDI scores with the outcome of a diagnostic clinical interview for both groups of children. With the inventory, they found high rates of depressive symptoms on the CDI among children with SCDs (29%) compared with controls (12%). However, with clinical interview there was no difference in rates of depressive disorder between the two groups. Further investigation of this apparently conflicting finding revealed that questions that related to fatigue (anaemia) and physical complaints (pain) in the CDI accounted for the high rate of those wrongly identified as having depression (i.e. false positives) among children with SCDs.

Consequently, there is a general need for caution in interpreting studies where depression among people with SCD is measured with self-report questionnaires, which are designed to screen for, but are not diagnostic of, depression. There is also the issue about what is an appropriate cut-off point for self-report questionnaires in delineating depression. Schaeffer and colleagues (1999) illustrated this using the Centre for Epidemiologic Studies-Depression Scale (CES-D) to screen for depression in adults with SCD and noted that the percentage of patients categorised as depressed reduced drastically from 43% to 18% following a slight change in the threshold used.

Nevertheless, despite their limitations, what makes the use of questionnaires attractive are their simplicity and ease of their application to a large number of subjects. In order to address the issue of false positives that undermine the use of questionnaires, Grant et al (2000) explained that when properly applied and validated, (i.e. when the instrument is adapted to the culture in which it will be used and the scientific principles, which establish that the instrument reliably detects what it is supposed to within the culture, are followed, and when appropriate cut-off is chosen (i.e. the cut-off needs to be appropriate for the
culture in which the instrument is being used), questionnaires can have good agreement with diagnoses made with clinical interview in SCDs. In other words, the overlap between some of the physical symptoms of depression and SCDs could be teased out when validated questionnaires measuring depression are properly applied. This is the approach that this study used.

The second difficulty with diagnosing depression in SCDs is the transitory association between depressive symptoms and acute episodic complications of SCDs such as painful ischaemic crises. While these symptoms may be very distressing and impairing, these symptoms may not meet the duration criteria for a depressive disorder because of their transient nature. In a qualitative study of adolescents with SCDs and thalassaemia, Atkin and Ahmad (2001) found that even though most young persons have times when they experience feeling low and crestfallen, such periods were in general transitory and they were often caused by life circumstances. They did not find evidence of prolonged withdrawal from family and peer relationships that is characteristic of an established depressive disorder. Once the stressor, such as a hospital admission, ends or is removed, these persons could successfully rebuild their positive coping strategies and renegotiate periods of normalcy.

This transitory nature of depressive symptoms in SCDs raises another concern that genuine depressive disorder may not be accorded the appropriate significance it deserves in SCDs. There is a high risk that both clinicians and patients could see on and off symptoms of depression as part of the “normal course” of having serious life-threatening disorders like SCDs. As a result, patients may not seek help even when their depressive symptoms are sustained as in genuine depressive disorder. Similarly, clinicians may be reluctant to ask or to pursue a more detailed assessment when patients volunteer a history suggestive of a depressive disorder. Thus for people with SCDs, unrecognised and consequently untreated depressive disorder could be a major factor impairing their quality of life over and above the direct physical complications of SCDs.
In summary, depression in SCD could result from biological, psychological and social processes. Within the level of the biological or disease process for instance, the severity of SCD, its specific complications or the unpredictable nature of some complications could be implicated in leading to depression. On the psychological platform, factors such as lack of acceptance, negative attitude to SCDs or the need to make frequent adjustments in life-style to accommodate the illness could be associated with depression. With regards to social factors, depression could be a product of lack of social support, the lack of strong policies to support persons with SCD in socially valued activities such as accessing education or employment, and the negative and discriminatory attitude of others.

**Pain and depression in SCD**

Painful crisis is the hallmark physical complication in SCDs (Wethers 2000) and pain has been linked to depression in those living with SCD (Schaeffer et al., 1999; Hasan et al., 2003; Levenson et al., 2008; Wolfe and Michaud 2009). In a study of 440 adults with SCDs it was found that those who reported occurrence of higher numbers of painful episodes had higher likelihood to report symptoms of depression (Schaeffer et al., 1999). Hasan and colleagues found in their study of 50 adults with SCDs, that at least four out of ten were depressed, and they were more likely to have poor pain control and frequent ischaemic crises (Hasan et al., 2003). In a six-month prospective study of 308 adults with SCDs, Levenson and colleagues (2008) found that three out of ten subjects were depressed. When compared with the non-depressed subjects, the depressed respondents had a significantly higher frequency of mean pain rating as well as more distress and interference from pain. While these studies have demonstrated the association of pain and depression in persons with SCD, another study highlighted the mediational role of emotion with regards to pain and sleep difficulty. This study investigated 20 children with SCD and found that mood mediates the relationship between pain and poor sleep (Valrie et al., 2008).

These studies assume a causal link between depression and pain, using the background assumption that there is a relationship between psychological factors (such as depression and pain), and to understand this relationship, these factors measured in objective ways can
be manipulated, using statistics just like natural objects, in such a way that laws governing their relationship could be exposed. However, such psychological factors cannot be adequately explained outside their socio-cultural context. It could be argued that pain could be biological and psychological and both in combination would not explain 100% variance in depression. In other words, there could be other aspects of pain not located in persons with SCD. It is therefore appropriate to consider the extent to which pain as well as depression in SCD has social origins in addition to their biological origins.

**Depression and other physical markers of severity**

Ample evidence generally stipulates that people with more severe forms of SCDs are at more risk of depression (Hasan et al., 2003). Segbena and Sangare (1994) used the Hamilton Depression Rating Scale to assess 30 adult patients with SCDs and 31 heterozygous carriers of the sickle gene. Although no subject in either group scored above the threshold for moderate depression, the level of anemia and the number of sickle-cell crises per year was associated with depressive symptoms in the SCDs group. The study by Hasan and others cited earlier also showed that patients who make more frequent use of accident and emergency department and had more frequent blood transfusions (both good markers of disease severity) were more likely to be depressed (Hasan et al., 2003).

However, other than severity, social factors such as poverty, degree of exposure to discrimination, and lack of social support networks could also influence depression. In other words, disease severity alone is not a sole determinant of mood or function in SCD (Grant et al., 2000). Grant et al (2000) investigated depression in 44 patients with SCDs using the Structured Clinical Interview and found that disease severity alone did not explain the level of patient’s mood or level of impairment. The unexplained variance in mood might be located in social factors such as poverty, and the attitude of the society (negative reactions in families, peers, and institutions) to people living with SCD. Thus this study aimed to explore the lived experiences of people living with SCD and depression with a view to explaining, within a social framework, the variance of mood problems in persons with SCD.
Depression and psychosocial factors

Carpentier et al (2009) have shown that personal psychological characteristics such as behavioural inhibition (behavioral inhibition is a temperament that relates to the inclination of a person to experience distress and to withdraw from situations, people, or environments that are unfamiliar) are associated with depression in SCD. They examined the relationship between behavioural inhibition and depression among 30 adolescents with SCD and found that the adolescents who scored high on self-report of behavioural inhibition had significantly higher levels of depression than those with low behavioural inhibition. The study by Hasan and others cited earlier also found that adult patients with SCD had more tendency to be depressed if they had poor family income (<$ 10,000), below high school education, were female, or had inadequate social support (Hasan et al, 2003). Similarly, Schaeffer and colleagues (1999) found in their study of adults with SCDs that female gender and low family income were positively and significantly associated with depressive symptoms. Eaton and colleagues (2001) reported the involvement of depression in the process of status attainment. These authors maintained that the evidence for depression as causally related to status attainment (i.e. low-income, low education women) is small and not statistically significant. They also said evidence for the corollary, depression as a consequence of status attainment, is similar. However, Eaton et al (2001) reported findings, similar to those of Brown and Harris (1978) as well as Hill (1994), which lend credibility to the idea that depression may be a socially created variable in the context of poverty and an adverse work environment. This suggests that the resolution of conflicting findings such as enumerated could be achieved through a paradigm shift. In other words, sociological perspectives, in paying attention to social and cultural meanings associated with complaints of psychological distress such as depression, have often highlighted the influence of social factors in the family and wider community, and could equally well do so in the case of people living with SCD and depression.

Among women, low levels of education and economic dependence have led to poverty, domestic isolation, and powerlessness, and these consequently have been associated with higher prevalence of psychiatric morbidity in women (David and Low, 1989; Desjarlais et
al., 1995). Social changes or reorganizations that include among others employment may bring self-esteem and independence. It is notable that the resilience of individuals and the ability of society (including families, governments and community organizations) to make policies, strategies and programs that essentially and effectively consider and attend to both the needs of the ill and the social origins of psychological and psychosocial distress offer not only hope but examples as well (Jacobson, 1993; Desjarlais et al., 1995). Such long term goals are what this study aimed to initiate by exploring lived experiences of persons with SCD, what could be challenges or oppression in their social life and what could change in the social structure.

**Depression and neurological complications**

There is ample evidence that reduced blood supply due to pathological lesion(s) to certain parts of the brain (i.e. cerebral ischaemia) increases the risk of depression (Hackett et al. 2008). The risk of cerebral ischemia is now well recognised in SCDs and Pegelow et al. (2002) have estimated that about one in every ten persons with SCD might suffer overt strokes (which cause reduced or blocked blood supply to the brain). Their study also revealed that up to one out of five persons with SCD had evidence of ischaemic brain damage on MRI by the age of 20 years (Pegelow et al, 2002). Such brain injury has been implicated in the intellectual decline seen in children with SCDs (Schatz et al, 2002). Given the high prevalence of ischaemic brain pathology in SCD and the robust association between brain ischaemia and depression, it is reasonable to hypothesize increased rates of depression in people with SCD, particularly those with evidence of brain ischemia. Interventions to prevent depression, and/or intellectual decline in persons with SCD would thus focus on prevention or early diagnosis and treatment of brain ischemia. However, as discussed in other sections above, such focus would not be comprehensive in that depression cannot just be understood within one dimension. In the next section, the representations of SCD including depression are presented as emerging from social interactions.
Sociology of Sickle Cell Disease as a Chronic Disease

SCD representations could be argued to emerge from social interactions. One could compare these representations with Kleinman’s (1988) model of how a disease could give rise to three different kinds of representations. This author referred to these kinds of representations as one, the biomedical event which is the disease; two, the personal experience which is the illness; and three, the sociocultural experience which is the sickness.

Each of these conceptual dimensions represents a source of critical experiences for people living with chronic illnesses. They therefore follow a kind of trajectory with the rise of the biomedical event (disease) and its subsequent influence at subjective level (illness) and also at the social level (sickness). Kleinman also suggested that people with chronic illnesses search for consistency among these representations in an attempt to stabilize the biographical disruptions, and in an attempt to normalise the discrepancies between their experience of the disease and the way it is accepted by others in the society. This study of people living with SCD and depression was set to explore how they searched for consistency among the three representations and negotiated their acceptable self-identities among other members of their society.

It should be noted that although the course of SCDs are variable and many affected persons live relatively healthy undisrupted lives, a proportion require frequent hospitalisation as a result of different acute illness episodes particularly pain (Wethers, 2000). In addition, some experience even more frequent but less severe episodes that do not require hospital admission but nonetheless necessitate some rest at home. Without counteracting supportive policies, these limitations imposed by these illness episodes could be disruptive to schooling, employment, and social encounters (Atkin and Ahmad 2001; Dyson et al., 2010). Furthermore, these disruptions make concealment more difficult and increase the potential for stigma. The resulting threat of unwanted disclosure could be a source of emotional distress for affected persons.
Thus far, it is important to note that biomedical involvements through technology and medications in re-organising the disruptive experiences of people with chronic illnesses, and in re-ordering the arbitrary and threatening characteristics of chronic illnesses are incomplete and limited, and that this has to be complemented by a body of knowledge and meaning drawn from the biography of individuals living with chronic illnesses.

In conclusion, this study focused beyond people with SCD's experiences of physical sufferings (a narrow medicalized view) and rather explored their often taken-for-granted views and their daily contextual social interactions in order to draw attention to the interwoven ways in which various dimensions of the illness experience may strengthen and build on one another. For example, the study aimed to describe ways in which experience of stigma associated with SCD might prompt people with SCD to experience feelings of depression and to disengage from social activities. This study, in following Link and Phelan (2014), might highlight the stigma-power concept where possibly people living with SCD might live in situations where others (without SCD) have strong motivations to keep them down, in or away through social processes that are indirect, broadly effective and hidden in taken-for-granted cultural circumstances. Second, this research followed studies (Williams, 1984; Pinder, 1995; Paterson et al., 1999; Kralik et al., 2004) which have drawn out certain strategies people with chronic illnesses use to have and maintain a sense of coherence, stability and order following the biographically disruptive events of their illnesses. These studies showed how people with chronic illnesses through their narratives rebalanced the discrepancies between body, self and their world. They fixed the gaps in their life trajectory via a framework that links the different building blocks of their biography and that explains their connection in such a way to make a coherent past and present as well as a coherent sense of self and society. Likewise, this study extended these works by exploring the strategies of how people with SCD having depression attempt to find a legitimate and meaningful place for these personal troubles in their lives and how they reconstitute and repair their self-identity in their life-worlds. As such this study aimed to locate and understand experiences of illness in SCD within a range of macro and micro contextual factors.
Stigma

Stafford and Scott (1986: 80) defined stigma as "a characteristic of persons that is contrary to a norm of a social unit". This definition follows the concept of stigma as expressed by Goffman (1963) in focusing on social norms, but does not do justice to Goffman’s emphasis that stigma is a matter of social relationships rather than individual characteristics. Several decades after Goffman, Link and Phelan (2001, 2015) noted that the conceptualization of stigma is as varied as the circumstances to which stigma has been applied. They remarked that there is a considerable overlap despite differences in emphasis. In combining these perspectives, Link and Phelan (2001, 2014) defined stigma as the simultaneous happenings or co-existence of the following components: labelling, stereotyping, separation, status loss and discrimination. These components also represent the various concerns of people who have applied the stigma concept to their fields. In addition, this paradigm of stigma also incorporates the perspectives of those who are stigmatized. Stigma represents a plight that is persistent in the lifeworld of the persons who are victims of it and impacts on different aspects of life including status and health (Link and Phelan, 2001, 2014).

It is essential to highlight the two main challenges to the stigma concept identified and addressed by Link and Phelan (2001). The reason is that the thrust of this thesis aligns with line of arguments of these authors, as will be noted in later chapters. First, many researchers who have applied the stigma concept using quantitative methods have done so without being informed by the lived experience of people who are being stigmatized that they studied (Kleinman et al., 1995; Kleinman and Hall-Clifford, 2015). In this way, priority has not been given to the point of view and actual descriptions of the (stigmatized) people that they studied. Hence according to Link and Phelan (2001), the outcomes of the works of stigma researchers in general represent misunderstanding of the experience of stigmatized persons and continuation of faulty assumptions such that stigma is linked to disease processes and associated with the persons who ‘suffer’ from the diseases. This study was designed to explore the views of persons with SCD and present their accounts in a transparent manner. The second challenge is that stigma research has been focused on
individuals at micro-level interactions rather than societal level (Oliver, 1990). This work also took this into consideration by exploring the power structures that discredit, isolate and exclude persons with SCD beyond micro-level interactions.

It is also necessary to recall Goffman (1963: 3) who advised on the need for "a language of relationships and not attributes". Hence, stigma is not "in the person" but it is rather a label that others put on the person. In applying the definition of Phelan and Link (2001, 2014), stigma exists when its interrelated components converge within the power structure. The first component is labelling where human differences are distinguished and labelled. The human difference that is picked upon is the one that is the society deems important socially. Hence there is social selection of the human difference that is significant for labelling. It is important to note that the attributes that are seen as salient vary according to time and place (Phelan and Link, 2001). Of importance is determining how culturally created categories that are labelled arise, and how they are perpetuated.

Linked to the first component is the second where dominant cultural beliefs associate those labelled with socially defined undesirable characteristics, referred to as negative stereotypes. Once this link is established, these disadvantaged persons are placed in distinct categories in order to separate them. Social labelling here indicates a separation of 'us' from 'them' (Devine et al., 1999; Morone, 1997). For example, people with SCD are referred to as "sicklers" instead of having sickle cell disease. This represents the third component.

In the fourth component, the victim experiences loss of status and discrimination. The consequence of these experiences is dissimilar paybacks. When a person is labelled, segregated and linked to unacceptable attribute, a rationale is born for discrediting, discarding and excluding the person. This component makes persons that are victims of stigma to be disadvantaged in life profiles such as income, education, well-being including mental well-being, and housing status, to mention a few (Druss et al., 2000; Link, 1987). It is important to highlight the loss of status. The connection to unwanted characteristics leads to a reduction in status in the eyes of those who stigmatize. This illustrates how having a status that is underrated can lead into various forms of inequality.
The attitudes and beliefs of others underlie whether or not their labelling and stereotyping the victim of stigma will lead to acts of discrimination against that person, such as the refusal to appoint to jobs. Stigma also affects social structures around the person being stigmatized, such that that person experiences structural discrimination, for example lack of funding for beneficial interventions for them. Moreover, low status itself is another basis of discrimination. This low status can lead to make a person less attractive to being accepted in social networks. This can have a cascade of unpleasant impacts on social opportunities.

Of relevance to stigma theory is the social psychological processes that characterize the stigmatized person. People develop conceptions of certain illnesses early in life as part of socialization into their culture (i.e. Angermeyer and Matschinger, 1996). Once these conceptions are formed, they crystallize into a lay theory about the meanings of a particular illness (i.e. Angermeyer and Matschinger, 1994). People therefore have presumptions as to whether most persons will reject an individual with such illness as a friend, employee, neighbour or intimate partner. Such ideas become part of the person's world view. These understandings have unpleasant relevance for a person who later develops such illness because then the possibility of rejection becomes salient. The expectation and fear of rejection may lead to strained social interactions with potential persons who stigmatize (Farina et al., 1968), restricted social networks (Link et al., 1989), depressive symptoms (Link et al., 1997), and unemployment (Link, 1982, 1987).

According to Link and Phelan (2001, 2014), power (which could be social, economic and political) is the thread that weaves together the components and leads to stigmatization. In other words, power situation allows these components to link together in producing stigma. Power is needed to stigmatize. However in many instances the power differential is taken for granted in that it seems power has no role in stigma production.

At this point, the view of Foucault (1995) concerning stigma is relevant. Foucault (1995) argued that the society focuses on people that are stigmatized, and puts them under preventive surveillance from others in the society. In other words, the society polices them. Foucault (1995) referred to this social mechanism of control as the “disciplinary gaze”. It is
important to note that these acts of control (also called enacted stigma) can be internalized by the stigmatized group and afterwards lead to self-doubt, loss of self-esteem, shame, guilt and feeling of depression (Schulze and Angermeyer, 2003). Such forms of discrimination and marginalization by the society can be termed external stigma and as mentioned above, it is often internalized with negative connotations for lived experience of the stigmatized. The aftermath of internalized stigma is sometimes known as felt or internal stigma (Scambler and Hopkins, 1986).

Factors that can counteract the negative influence of stigma at the societal level have been highlighted in various researches. Such factors are anti-discrimination legislation as well as targeted campaigns against stigma. These have been found to reduce the levels of enacted stigma with positive implications for internal stigma (Stuart, 2006; Pinfold et al., 2005).

Literature has revealed that quantitative research cannot explore the impact of stigma (Whitley and Campbell, 2014). These authors reported that qualitative research is best suited to understand the subjective influence of stigma through delving into the lived day-to-day experience of social actors. They also noted that a few qualitative studies have explored the impact of stigma. This study set to explore the impact of stigma among persons with SCD. Whitley and Campbell (2014) also pointed out that even as the few studies have portrayed the nature and extent of stigma from a phenomenological view, there are important questions left unanswered. One important question that begs for answer is how do stigmatized persons challenge stigma? This study intended to address this important question by exploring what possible strategies and orientations persons who live with SCD and depression can use to challenge external and internal stigma; how can they prevent themselves from being cast, in their own frame of reference, among Goffman’s (1963) ‘tainted and discounted’?
**Stigma and SCD**

This section underpins the sociological perspective of this study to illuminate the social origins of stigma in people living with SCD. In societies, persons are put into categories based on a complement of attributes that are felt to be ‘natural’ and ‘ordinary’ for such members of these categories. In social settings, people rely on the societal assumptions of the social identity of the persons they encounter. These normative expectations become righteously presented demands in social relations. Goffman (1963) referred to these demands as demands made "in effect" and the character people impute to those they encounter becomes a virtual social identity. This identity most times is different from the actual social identity of the persons encountered. When certain people fall short of these normative expectations, that is, the virtual social identity demanded from them, they become prone to being stigmatized. It should be noted here that it is not their actual attributes that lead them to being stigmatized, but the falling short of the expectations of the society (virtual social identity). In essence, stigma has social origins. The perspective of this study was to explore the social origins of stigma in SCD.

When people with certain illnesses present before other members of the society, tell-tale signs can be seen in this group of people that make them different from others in the normative categories available for them. These less tolerable attributes bring them down in people's mind from a whole and usual person to a tainted and discounted one.

For instance, where optimal biomedical treatment is not available from birth (as is the case for all but the very rich in Nigeria), people with SCD have easily recognizable bodily manifestations/attributes such as bossing of the skull, yellowness of the eyes, leg ulcers, delayed physical development and thin body frame (Wessberg et al., 1980; Acquaye et al., 1985; Dick 2008), and these make them different from normative categories of people who have a “normal” body. Thus there is a discrepancy between virtual and actual social identity in terms of body which likely constitutes stigma for people with SCD who have these bodily attributes. In general, stigma theory predicts that the more visible and disfiguring an attribute the more stigmatizing it is likely to be. More visible and disfiguring
attributes are likely to be greater in developing countries where effective treatments are not widely available, in contrast to Western countries where widespread access to disease-modifying treatments and access to good food and nutrition have made these gross physical attributes uncommon (Ohene-Frempong and Kwaku, 1994; Atweh and Schechter, 2001).

This contrast reveals the importance of understanding the different social contexts in the production of certain attributes. It is against this background that this study explored the relationship between the actual and imputed identity version of the body in people with SCD in Nigeria. The intention was to illuminate the social origins of stigma along this dimension.

Apart from the relationship between idealized version of body (virtual body) and actual body, one can posit that there are other special relationships between actual and virtual identities in the lifeworld of people with SCD that could lead to various aspects of stigma. First, in many societies, there are idealized versions of people who can undertake certain roles such as education and being fit for employment. The resulting stigma fits into the dimension of “disruptiveness” of Katz (1981) and Jones et al (1984) which describes the extent to which possessing the attribute interferes with interpersonal relationships. This disruptiveness is also related to the aspect of chronicity, as more severe and long-standing disorders are more liable to be also more disruptive.

Although the life trajectory of SCDs could be variable, and many affected persons live relatively healthy undisrupted lives, a proportion require frequent hospitalisation as a result of multiple and frequent acute illness episodes including pain (Wethers, 2000). Moreover, some experience even more frequent disruptions that do not require hospital admission but nonetheless would require rest at home. These authors, through a limited biomedical view, suggested that the limitations imposed by these illness episodes could be disruptive to schooling, employment, and social encounters (Adedoyin, 1992). However, it could be that it is the organization of the society with the negative attitudes of the constituent members that limits the social encounters, career progression and employment opportunities of persons living with sickle cell. These disruptions orchestrated by social structures and
attitudes could potentially worsen the quality of life and increase the burden of stigma of persons living with sickle cell.

In fact it has been suggested that school personnel and peers may exclude adolescents from activities in which they are able to participate due to erroneous assumptions about the disease and its physical restrictions (Schuman and La Greca, 1999). Moreover, despite well-intentioned legislative frameworks aimed at protecting people with disabilities from discrimination, many examples of discriminatory practices against people with SCD are still noted in access to jobs and health insurance in the United States (Kass et al., 2004) and the UK (Atkin and Ahmad, 2001). These may be indicative of persisting high levels of stigma against people with SCD. In exploring the life-worlds of people with SCD in Nigerian context, this study attempted to show how social relations might be related to this kind of stigma.

People with SCD also potentially fall short of the normative demands of motherhood and thereby are prone to stigma in terms of marriage and its associated roles. One again, this falls under the concept of disruptiveness of Katz (1981) and Jones et al (1984) which increases the potential for stigma as discussed above. In exploring their life-worlds in this study, the social mechanisms by which these dimensions of stigma are instantiated was understood and formed the basis for initiating social change for people living with SCD and depression.

In the Nigerian context there is an idealized version of the relationship between parents and children in which children are automatically expected to care for their parents in older age. Since parents were responsible for their children's care, there is a moral obligation for those children to take care of their parents when they become elderly. By virtue of the short life expectancy of people with SCD in Africa, and particularly in Nigeria where access to good nutrition, safe water and medical care among other things are poor, children with SCD are likely to fall short of this normative demand. This concept invokes the stigma aspect of “threat or peril” according to Katz (1981) and Jones et al (1984) which has to do with the perceived danger posed to others (i.e. parents) by virtue of a person possessing the attribute.
In Nigeria, a high proportion of relatives attributed SCD to malevolent spirits of reincarnation (Ohaeri and Shokunbi 2001; Nzewi 2001). Hinshaw (2005) suggests that the kind of demonological attributions to SCDs is likely to be associated with increased stigma. This study attempted to illuminate the social origins of stigma along this dimension.

According to the search five major electronic databases (Medline, Embase, PsycINFO, CINAHL, and Social Science Citation Index), there are limited articles on stigma in relation to SCD. Using different combinations of search terms (e.g. sickle, sickle cell disease, sickle cell anaemia, stigma, discrimination, psychosocial, disadvantage), four main studies were identified between 1992 and 2015. Two studies involved young people with SCDs (Adedoyin 1992; Atkin and Ahmad, 2001); one involved mothers of children with SCDs (Burnes et al., 2008), the fourth involved adults with SCDs (Sanker et al., 2006).

Adedoyin (1992) explored the attitudes of Nigerian adolescent with SCDs towards having the disorder using a semi-structured questionnaire. The aim of the study was not to examine stigma primarily. However, he found that the dysphoric adolescents attributed their unhappiness to a range of conditions including “a sense of shame in public”. This study explored the experiences of people with SCD who have depression. Following the work of Brown and Harris where the social origins of depression was demonstrated, this thesis would attempt to illuminate the social origins of depression and stigma in people with SCD through exploration of their social relations.

In a qualitative study of young people with SCDs and thalassemia major, Atkin and Ahmad (2001) reported that young people with these conditions felt that, due to ignorance, “disablist” and racism, people in their broader social network were not sensitive to their concerns. Burnes and colleagues found that all but one of the mothers (African and Caribbean origin whose children had SCDs) had experienced SCDs-related stigma. These mothers were keen to keep their child’s sickle cell disorder secret for fear the children would be stigmatized. They reported negative public perceptions including beliefs that SCDs are infectious, or represent an ancestral curse on the family. Some of the mothers reported being blamed for knowingly conceiving an ill child. In the life trajectory of people
with SCD, social relations or mechanisms have created a reality of perceived stigma (Jacoby, 1994) wherein having sickle cell is not the norm and therefore they are “justifiably” discriminated against. This study therefore sought to highlight the role of social relations in the origin of this aspect of stigma and how these social relations could be changed using the frame of reference of persons with SCD.

It is relevant to note that perceived stigma can have serious disabling consequences due to the tendency by affected individuals to take, sometimes, extra-ordinary measures to conceal their attributes (Scambler, 2004; Scambler and Hopkins, 1986). Typical consequences of these efforts to avoid disclosure include isolation, which could lead to depression, and loss of social and economic opportunities, which could also lead to depression (Leary et al, 1998). Within the purview of this study, the social relations that lead to stigma and depression were explored and highlighted among people living with SCD.

In a study to explore the relationship between genetic aetiology and potential for stigma, Sankar and colleagues interviewed eighty American subjects made up of people with SCDs, cystic fibrosis, cancer and deafness (Sankar et al., 2006). The study found that contrary to common belief, genetic aetiology did not automatically or universally confer stigma on affected individuals. Instead, stigma appeared more related to the varied experiences of particular individuals. The framework of biomedicine is to reduce disease to biological attributes which, if manipulated, can lead to the control of the disease. As discussed in this study, a biomedical framework is limited in its assumptions regarding social factors and cannot be used to understand the impact of social factors in people with chronic illnesses. This study therefore built on this premise to illuminate the social origins of stigma in people with SCD using sociological perspectives.

Further evidence of stigma in SCD comes from everyday language. People with SCD are sometimes referred to as “sicklers” both in general language and in published literature (Akuse, 1996). This description, which identifies the individual with their disorder, increases stigma (Slovenko, 2001). Although intended to describe a person with SCD, the term “sickler” also unwittingly conveys the impression of someone who is frequently ill.
The personal meanings of such expressions were explored in this study with a view to bringing about positive social change for people with SCD.

Stigma may be related to some of the physical and psychosocial disadvantages associated with SCD. Access to pain control may be a good example. In the UK Anionwu (1996) has suggested that some hospital staff view patients with SCD as “difficult” and that staff’s stereotypical beliefs can unwittingly result in inadequate management of SCD patients’ painful crises. While acknowledging the legitimate risk of iatrogenic opiate dependence, concerns about less optimal or denied opiate prescribing for pain management in SCD have been noted (Bevan, 1998). This study also explored whether these observations were parts of the life-worlds of people with SCD in Nigeria.

**Social model of disability and SCD**

“Disability refers to restrictions in the types of activities and social participation that an individual can perform as a result of physical or mental impairments or conditions of longstanding duration within an environment that does not provide sufficient accommodation to facilitate participation” (Swanson, Grosse and Kulkarni, 2011: S390).

The International Classification of Function, Disability, and Health (ICF), has differentiated constraints in terms of person-to-person social engagements from physical or functional impairments (WHO: ICF, 2011). The limitations, according to ICF, do not occur specifically because of the impairments in these persons but they happen within the social circumstances. Furthermore, the restrictions in the activities of a person as well as the restraints in social interactions may be related to the social structures and processes that prevail in that particular society where such ‘disabled’ person lives. In essence, disability is said to be the whole life story of how impairments combine with situational factors to result in differential social engagements or involvements (Swanson, Grosse and Kulkarni, 2011). Moreover, it changes over time and in accordance with changing contextual factors in the society.
According to Krahn and colleagues (2006), the above definition of disability harmonizes three disparate paradigms in disability field of study. First is the medical model of disability that examines the persons who go through the consequence of diseases (Krahn et al., 2006). For instance, within such a medical model, in persons with SCD, their experiences such as depression and stigma are held to be the consequences of biological attributes of SCD. This model recognizes impairment as disability. Second is the functional model of disability (Krahn et al., 2006). Similar to the first traditional model, the second one focuses on the individual and portrays functioning and activity regardless of aetiology. In the case of people living with SCD, the model assumes that their functioning and activities are explainable within the confines of their lives and does not take account of the social factors in the community wherein they live. The third tradition is the social model of disability that explores the social circumstances the produces disablement and thereby recognizes disability as the outcome of social interactions that involve loss of status and social exclusion.

The social model of disability argues that for disabling conditions like SCDs, the real causes of disability are social barriers and negative attitudes rather than the actual physical impairments that may be associated with the condition. Thus the social model of disability argues against medical and functional models. The proponents of the social model of disability argue that the other models victimize affected persons by locating the difficulties associated with their condition entirely within the affected person. For example, in relation to stigma and negative attitudes, the social model of disability would argue that instead of people with SCDs adjusting to cope with negative attitudes, it should be the other people in the society who should be adjusting their negative attitudes towards people with SCDs (Atkin and Ahmad 2001). These authors argue that discourses of SCDs such as experience of stigma and depression should not stop at the level of the individual but should as well encompass changes in the relevant social and political aspects.

Persons living with SCD are nonetheless at risk of impairments. They suffer from functional impairments in sensation (pain, vision, and hearing) (Fuggle et al., 1996; Brandow et al., 2010), mobility (Almeida and Roberts, 2005; Barden et al., 2002; Brinker
et al., 1998), cognition and language (Schatz et al., 2009). These impairments could result in undesirable troubles and challenges in school and workplace. In fact, people with SCD, just like those with other chronic illnesses, could be vulnerable to psychosocial or mental health problems such as self-esteem issues, peer relationship difficulties and depression as a consequence of these limitations (Schatz and McClellan, 2006). These authors emphasized that behavioural or mental health problems occur because of social relationship (i.e. person-social environment interaction) and not as a consequence of the illness per se.

For example, family conflicts have been responsible for the behaviour problems in some children with SCD rather than an association between the mental health condition and SCD or its complications (Wang et al., 2001). These authors also noted social factors like poverty and negative behaviors of others in the society worsen the stress that parents go through when they worry about the unpredictability of the complications of SCD in their children. Interventions focused on the family and the society are therefore of importance in addressing these issues rather than seeking adjustment from these children. This again is in line with the social model of disability.

In addition to above, people with SCD live with pain and episodes of pain that interfere with such people’s participation in activities at home, in the school and in the society (Fuggle et al., 1996; Brandow et al., 2010). Pain also often predicts vaso-occlusive events. School aged persons with SCD often are out of school on many days because of frequent painful crises and hospitalizations (Dyson et al., 2010; Day and Chismark, 2006; Nettles, 1994). However, pain can be understood as an outcome of a biological process but impacted on by social circumstances (Gil et al., 2004). In the same vein, Dyson and colleagues (2010) pointed out that social factors play a significant role in the period of time that the school pupils with SCD missed in school and are not just due to the biological pain. These authors suggested that the number of days missed on school calendar could be reduced by employing social strategies such as school policy that introduces supportive and collaborative health care plans involving school staff and primary caregivers. Koontz et al. (2004) were able to achieve a reduction in the number of days missed in school through the use of a school-based social intervention that involved teachers and peers of children with
SCD (i.e. changing the attitude - and thereby the level of social engagement - of the members of the society in which people with SCD live). Other studies have also shown that changes in the social context could reduce the negative effects of pain on quality of life and functioning in those with SCD (Anie et al., 2002; Ballas et al., 2010).

Thus far, in a world dominated by biologically oriented view, impairments are addressed in a clinical/community setting using a medical model of disability, which identifies with only the aggregate physical damage to organs in the body from the sickled red blood cells, chronic anemia and debilitating painful episodes. This approach ignores the social context and has thus been faulted as incomplete by social scientists that employ social model of disability, a perspective that integrates functional outcomes as well as interactions between the social and physical environments (Dyson et al., 2010; Abuateya et al., 2008; Dyson et al., 2007).

However, in reality, all the models (the medical model, the sociology of illness model as well as the social disability model) offer useful and practical understanding of the difficulties experienced by people living with chronically impairing and disabling conditions like SCDs. Hence in addition to management of disease complications, social intervention would be effective in alleviating certain socially created aspects of an illness. For example, these interventions can include promotion of healthy social behaviours and social policies that lead to inclusive education, improved quality of life in terms of employment and economic independence, active participation in community life, and supportive relationships among network of friends, families, and others in the neighbourhood. At micro-level of individual interactions as well as macro-level of societal involvement, there should be operating mechanisms that facilitate flexible policies and practices that empower the individuals with SCD.

**Conclusion:**

In this chapter, the author has considered SCD as a condition of major public health importance in Sub-Saharan Africa, particularly in Nigeria where majority of persons with SCD live. While the understanding of SCD in extant literature was reviewed this chapter
raised issues about how the understanding of SCD was restricted by the biomedical perspectives including the assumptions about its historical origin, spread, clinical parameters and particularly its associations with depression. The author considered the relevance of depression as a western concept in a non-western culture and argued that a more robust understanding of SCD and depression is possible when SCD is situated in its sociocultural context. Contributions of the works of Brown and Harris (1978), Goffman (1963) as well as Kleinman (1988) were considered in arguing that SCD representations in terms of depression could emerge and/or be closely linked to the quality of core social roles, wherein having sickle cell is not the norm and therefore they are “justifiably” discriminated against. Finally, in the consideration of the social disability model of Oliver (1990), the author argued for the need to empower persons with SCD and for the need of other social actors to make necessary adjustments in their social roles to reverse the impact of ongoing disablement and to prevent further disablement. This chapter creates the foundation for a view of research methods, in chapter 3, that identifies persons with SCD and depression, explores the firsthand account of their lived experiences to identify social contributions to distress, and takes an approach to research that is open to researching possibilities for change. Chapter 4 reports on the identification of persons with SCD and depression using a mental health scale. The evidence of distress and the possibilities for change are presented in the subsequent chapters 5 and 6.
CHAPTER 3: METHODS

The preceding chapter tried to situate SCD not only as an important public health issue in sub-Saharan Africa but also noted that persons with SCDs are at increased risk of depression, itself the second most important cause of disability in the world. The literature review considered studies that addressed both SCD and depression but highlighted that, to date, the potential social origins of depression have been given insufficient attention. This chapter outlines the approach that was taken in researching the experiences of people living with depression and SCD in Lagos, Nigeria. The chapter begins with an outline of the research philosophy as well as strategy before considering the use of questionnaires, in-depth interviews and focus groups as the methods of data collection for the project. The chapter continues by examining the eligibility criteria and sampling strategies, before considering the ethical issues raised by the research and how these were addressed.

Research Philosophy
This study was anchored on Kleinman’s (1988) theoretical framework. Kleinman’s (1988) model of disease leads to three different kinds of representations: first is the biomedical event which is the disease; second is the personal experience which is the illness; and third is the sociocultural context of experience which is the sickness. Kleinman’s (1988) framework on one hand illustrates three perspectives: biomedical, subjective and societal ones, and on the other hand weaves the strengths of each of the perspective to round off the respective limitations of each. The biomedical perspective falls within positivism with its
attendant limitations/criticisms; the subjective experience of person with an illness or the person’s lived experience might most appropriately be associated the philosophical school of thought known as phenomenology and this has its strengths and limitations as well; while at the third level, social interactions/factors, beyond biomedical conceptions of SCD as a “condition” that lead to dys-ablement of persons with an illness, suggest the need for a perspective beyond either positivism or phenomenology. To develop Kleinman’s (1988) perspective, living with SCD and depression could be argued to encompass not only the biomedical event (disease i.e. SCD and depression) and its subsequent influence at subjective level (illness i.e. the lived experience of SCD and depression) but also be considered at the social level (sickness i.e. the social forces behind SCD and depression). The study attempts to capture several perspectives to situate the “reality” of depression and SCD. Living with SCD and depression is therefore potentially seen on three levels: a biological disease, an individual illness experience and a societal sickness.

Within the biological perspective, certain factors might stand out as independent causes of depression. This perspective only underlies a third person account of a phenomenon and does not capture the phenomenon from the perspective of the person living with the phenomenon i.e. a first person account. Within this perspective, the psychiatric depression scale is used. The scale reveals a certain type of knowledge but not the whole truth. The use of such a scale implicitly locates depression as a biological agent that lies within the person with SCD and that needs to be addressed as such. In this research the use of standardized psychiatric scales is not used in the sense of the pursuit of one scientific truth, but rather is used to (1) guide respondent selection and (2) allow the audience of this research to situate the Nigerian research participants in terms of other populations on whom the scale has been used.

The second perspective, that is the illness experience, explores inductively how depression and SCD is understood by the people who live with it and how these people make sense of their experiences. This exploration could also highlight possible social factors lying behind the experience of depression, social factors uncovered by the biomedical perspective. It is in the lived first-hand experience of living where people to know their world on a first-
person (and not third-person i.e. scale determined) account. This can be illustrated with the perspective of Merleau-Ponty (1962) and Blumer (1986). In a way consistent with Merleau-Ponty’s (1962) phenomenological philosophy, people experience their own world through their bodies, essentially via dynamic changes that involve space, time, language, sexuality, emotions, and perception (Wilde, 1999). Within this concept of embodiment, where individuals gain knowledge through personal interactions, the state of being assumes that the mind and the body are inseparable and life experience is grounded in the intercalating contexts of the person, culture and history.

Persons in their life-world construct their meaning of beingness through social interactions such as running, breathing and having relationships. Merleau-Ponty (1962) posited that the accounts of our speech and perceptions are keys to understand our lifeworld, and overall embodied existence is perceived in the relation of our speech and perceptual engagement with those of others. Each individual comprehends his/her interactions with others through an intentional arc. Each individual’s arc is unique and produces unique sets of meanings. When an illness occurs, a disrupted intentional arc of meanings is produced which can only be captured by sociological enquiry and not by the biomedical perspective.

Using the perspective of Blumer (1986), persons with SCD and depression would derive reality from social interactions with others. Meanings exist in their human experience. These meanings are imbibed and modified as they go through encounters with others. In this thesis, the world of reality of SCD and depression as it exists as meanings within the lived experience of persons with SCD and depression was explored. These meanings may be located in what experiences they feel, how possible that they feel the experiences that they do, how they note, interpret and assess situations including arrangements of social positions, norms and role relationships in their interactions with others in their society.

With regards to stigma, Goffman (1963, 1986) noted that individuals are stigmatized when they are perceived by others to have certain socially unacceptable attributes which mark their identities. These socially undesirable attributes, marks, or signs can also manifest in
behaviors, characters or both and Goffman delineated three classes of stigma. Physical stigma that is enacted against persons with physically visible attributes, such as yellow eyes, and leg ulcers in SCD persons; character stigma that is enacted against persons who display behaviors that suggest his or her character problems, such as frequent and unpredictable sickness, and avoidance of certain duties; and tribal stigma that is enacted against persons with particular familial or group traits, such as ethnicity, nationality, and religion. With regards to tribal stigma, other people in the society not only impute negative identities to individuals with SCD whom they encounter, they extrapolate these negative virtual identities to the whole class of persons with SCD otherwise referred to in this context as a “community” of people living with SCD. Others in the society see the virtual identities of whole class of persons with SCD over a long period of time as deviations from the prevailing normative class of others. This “knowledge” is shared within the community of others who do not have SCD such that these negative virtual identities are imputed to those who have not even been met because such characteristics are held to be shared by all of them.

Goffman (1963, 1986) and later authors (Crocker, Major and Steele, 1998) noted that the set of conditions that facilitate stigmatization is not permanent or universal. This set could vary from culture to culture. Therefore the occurrence of stigmatization of persons could be relation-specific, in that it always occurs in the relationship between the stigmatizer, or perceiver, and the stigmatized (Goffman, 1963, 1986; Link and Phelan, 2001, 2014, 2015), and also situation- and context-specific (Crocker, Major, and Steele, 1998). In other words, an attribute that is stigmatizing in one culture may not be stigmatizing in another culture (Jones et al., 1984), and that it is social relations and structures that facilitate stigmatization. This framework informed the objective of this study to examine through the lived experiences of persons with SCD what relational and/or contextual factors in the society facilitate stigma against persons with SCD. This framework informed the objective of this study to examine, through the lived experiences of persons with SCD, what relational and/or contextual factors in the society facilitate stigma against persons with SCD.
However, many current stigma researchers have used predominantly quantitative methods to investigate stigma including its relationship to SCD (Sartorius, 2006; Slade, Molloy and Keating, 2009). Their claims were that SCD leads to stigma which is different from the framework of Goffman who pointed out that stigma results from the breaking of physical, character and/or tribal norms/expectation. This quantitative approach limits the in-depth understanding of the research participants’ experience of stigmatization from their subjective point of view. And it is this more qualitative framework that has informed the course of this study. This study attempted to address the questions such as what were the norms/expectations that persons with SCD broke in social relations and context that facilitated stigma production against them. What were the actual experiences of the social stigma against persons with SCD? What did it mean to be stigmatized? How did they manage the presence of stigmatization in their interactions with others? How did they manage their spoiled identity in Goffman’s sense? In other words, this study explored from this perspective how the reality of stigma could be socially produced.

There is need for caution in this approach because, in the attempt to foreground and validate their experiences with possible cathartic effect of sharing, persons with illness might be emotionally overwhelmed and become disempowered and remain dys-abled. Hence, both positivism and phenomenology could equally be said to leave the persons living with a chronic illness such as SCD in the same situation as the researcher found them (see Oliver, 1992).

It is necessary to note that the use of ‘societal sickness’ in the third perspective has a potential double meaning. The first meaning is that intended by Kleinman. It means that by seeking medical help and attracting a medical label the persons who do so legitimize their illness experience by having the requisite high status person (a doctor) endorse their claim to be ill. This is not the meaning intended in this thesis. However, a second possible meaning, and one that is intended in this thesis is that a “societal sickness” could be taken to mean that there is something about society in general that is “sick” or “morally wrong”. That people living with SCD are faced with the societal sickness of disablism (i.e. being
discriminated against by others in society, these other social actors discriminate against persons with SCD or refuse to make reasonable adjustments to include them in society). Given that persons with illness having been faced with experiences found to be oppressive and in which they seem to be helpless, there is a need to work with respondents towards a resolution or at least a challenge to the existing situation in line with the social model of disability. The third level perspective via focus group discussion was designed to give further voice to the research participants living with SCD and to enable them to create a critical mass of persons to seek re-adjustments in the attitudes (and by extension actions via policies etc.) of others in the society such that they can be better supported.

**Research Strategy**

A systematic review of the literature on SCD and its relationship to depression and stigma within biomedicine and sociology was presented in the previous chapter. The early section of this chapter has highlighted the limits of biomedical ontology and argued for a consideration of sociological claims to complement the contributions of biomedicine to understanding SCD. The need to appreciate and explore alternative epistemological view of origins of distress in persons with SCD and depression is opened. This section in this present chapter seeks to highlight in a transparent manner the decision making processes that guided and led to the aims and objectives of this thesis.

Research strategies that could be potentially used as theoretical guides for the systematic enquiry presented in this thesis are reviewed in this chapter. In addition, consideration of the strengths and limitations of possible knowledge traditions that could underlie the understanding of the phenomena SCD and depression is made. In this discussion, the logical premises for the validated use of interpretative phenomenological analysis are laid out and justification for its use is revealed.

**Research paradigm**

In the systematic enquiry into the phenomena of SCD and depression, there are two most significant approaches that influenced the data collection in this study. These are positivism
and phenomenology and they tend to be associated with structured, quantitative and
naturalistic, qualitative data collection respectively. A discussion of the potential roles of
each of these epistemological positions follows with the aim of showing in which specific
area of my research each strategy might be preferred.

**Positivistic research strategies**

The assumption of this research strategy is from the epistemological position that both
social and natural worlds are made up of objective facts; that these are subject to the
fundamental natural laws, and that the revelation of truth in these worlds can be made
possible with research methods of the natural sciences (Bryman, Bell and Teevan, 2009).
Natural scientific methods are based on sensory experience (Christopher, 1985) and all true
knowledge is said to emanate from observation of sensory experiences of objective reality
(Crossan, 2003).

Within a positivistic framework subjective experiences can never be used to gain true
knowledge of reality. Therefore, subjective experiences are unwarranted in the pursuit of
generating testable hypotheses to allow for the explanations of the laws that govern social
world. The pursuit of understanding phenomena such as class, politics, society, and
communities that underlie individual perceptions of reality, which cannot be observed and
therefore cannot be adequately captured, and therefore explained, in purely objective and
statistical manner is therefore dismissed by adherents of this philosophy.

Social science has made attempts to use methods commensurate with positivist traditions to
attain “truth” as it relates to social reality but the results of these enquiries have been
inadequate (Muntaner, Lynch and Davey, 2001; Smith, 2001; Mahutga, 2008). For
example, the objective truth about the lived experiences of certain group of persons in a
society cannot be consistently be confirmed by objective senses alone (Reichardt and
Rallis, 1994). This is true because different experiences may hold different meanings for
different persons. This is understandable given that experience is relative to each individual
(Goffman, 1959) and specific to each individual’s social context (Giddens, 1991).
Therefore there are potential and valid variations or diversities of human experience that the positivist approach could not adequately account for (Thyer, 2009).

Social scientists have challenged the notion that facts “speak for themselves” and because of this there is a need for theory to interpret the social findings (Blumer, 1986). In other words, all observation is dependent on theory, as argued by Hindess (1974), such that one cannot test theory by observation since that observation is itself not theory-free. The obvious remaining possibility is that theory can only be tested or appraised by reference to other competing theories. In this epistemological perspective of phenomenology, there is the involvement of the researcher (contrary to positivistic independent distant relationship of the researcher to objective world) in making sense of the meaningful worlds of the social group that are being explored (Layder, 1994). Additionally, several authors (Sartre, 1957; Goffman, 1959, Merleau-Ponty, 1962; Blumer, 1986; Giddens, 1991; Crotty, 2003) have argued that human experience is embodied in the feelings, attitudes, normative social influences, behaviors and perceptions which positivism rejects and is therefore not objective.

Social reality, unlike physical reality, is multi-layered, multifaceted, not uni-dimensional, and associated with individual differences. Understanding this reality requires a credible and dependable account of human subjectivity together with a need to recognize that positivist methods are problematic when applied to explore and explain social phenomenon (Smith, 2009). When positivist methods are used to categorize, measure and analyze statistically lived experiences they are found to be problematic. This could be because there are no adequate tools and then the findings from analyses do not provide a complete or robust representation (Lincoln and Guba, 1985; Strauss and Corbin, 1990). In order to understand these social factors, it is therefore necessary to explore other epistemological alternatives in the discourse of post-positivism. In this thesis, the social phenomenon of lived experience of persons with SCD and depression are therefore determined beyond the confines of natural sciences. In other words, a positivist research strategy is inappropriate or limited as an approach in the pursuit of robust understanding of social experience of persons living with SCD as well as depression. In understanding the lived experiences of
persons with SCD and depression, there is essentially a need for an approach that will provide rich and detailed descriptions of their experiences which are collected as first-hand subjective accounts.

Phenomenological Approaches

Phenomenology defines both an ideology and a set of research tools to examine and comprehend human experience (Langdridge, 2007). The meaning of an individual’s experience of a particular event is revealed with phenomenological methods by paying particular attention to firsthand experiential account that is rooted in everyday life (Langdridge, 2007), for example the experience of living with SCD.

This phenomenological position contrasts with the biomedical understanding of a phenomenon where the emphasis is outside the person who lived with the experience. The philosophical principles of biomedicine might preclude persons, whose experience(s) are being investigated, from giving accounts that include a personal or emotional dimension of self that underlies understanding or the communication of experience (Heidegger, 1926, 1962). The phenomenological perspective recognizes the assumption that there exists reality independent of scientific measurement (Bhaskar, 2010), and conceives that some knowledge of “reality” is constructed based on human perception (Twomey Fosnot, 2005) and on-going socio-cultural interaction (Crotty, 2003).

These philosophical considerations guided this study to adopt a broad phenomenological focus that takes account of the need to make sense of people’s lived experience but also draws upon positions that developed out of phenomenology which orient this study to broader questions such as the existence of norms and stigma as well as systems of meaning that pre-exist and surround specific individuals, manifest in how these individuals are confronted with ascribed meanings by others and which shape their interactions.

One useful phenomenological tool is Interpretative Phenomenological Analysis (IPA). IPA aligns with the core principles of phenomenology because it gives considerable attention to an individual’s direct experience, and encourages individuals as research participants to
express their personal stories in their own words and with their frame of reference (Smith, Flowers and Larkin, 2009). IPA has inputs from phenomenology, hermeneutics and idiography. It pays respectful and adequate regard to core phenomenological understandings of lived experience as not only dependent on context, but also dependent on social meanings, historical context and cultural perspectives (Eatough and Smith, 2008; Smith, Flowers and Larkin, 2009). The IPA framework influenced this study to a large extent such that the lived experience of SCD and depression is understood as not only personally situated and based on idiographies, but also hinge on social interactions with others, and the prevalent culture of the society (Eatough and Smith, 2008).

Interpretation and phenomenology as presented in IPA are inter-dependent. Smith, Flowers and Larkin (2009: 37) neatly summarize this inter-dependency as follows: “Without the phenomenology, there would be nothing to interpret, without the hermeneutics, the phenomenon would not be seen.” Hence, IPA researchers do not strive to present an objective or definitive third person account of a phenomenon as earlier mentioned but conceivably declare access to a first-person version of the individual’s experience as this individual makes sense of his/her experience through his/her narrative account (Smith and Osborn, 2008).

When IPA researchers try to make sense of an individual making sense of his/her own narrative, there are identified levels of barriers such as accessing meanings that are hidden within the narrative, meanings of references that are metaphorical, and meanings of language signals (Smith, 2007). Smith (2007) also pointed out there could be another barrier if adequate attention is not paid to the temporal circumstances that could influence how the experience that is being narrated is perceived, interpreted and understood. The ‘biographical presence’ of the researcher (his/her own resources and experiences) provides another level of resistance (Smith, 2004: 45).

In order to avoid the barriers, the IPA researcher needs to pay attention to each of them. In order to resolve the barrier of biographical presence, Finlay (2008) suggested that an IPA researcher has to use of his/her own contexts to derive guiding insights and then s/he needs
to be clearly delineate the impact of his/her views on how the script is analyzed and interpreted. Some authors noted that preconceptions of the researcher may not be clear at first and may only begin to appear when the researcher engages with the text and s/he is willing to undertake self-reflection (Smith, Flowers and Larkin, 2009).

*Idiographic inquiry as part of IPA*

Idiography attempts to present credible experiences of people and highlight the specific contexts in which these experiences take place (Eatough and Smith, 2008; Smith, Flowers and Larkin, 2009; Smith, Harré and Van Langenhove, 1995). Each case is vital to the understanding of the phenomenon that is being explored. Consequently, the researcher endeavors to understand clearly and in-depth one case before (s)he analyzes the next case. The researcher maintains sensitivity to each case’s unique story by setting aside the findings from each case before moving to the next. This is achieved through dynamic bracketing (Smith et al., 2009). It is after each one of the cases has been studied in this step that a cross-analysis of the cases is conducted. However, even while a firm commitment to the dynamic bracketing is articulated (Smith et al., 2009), themes that arise from the analysis of the first case could also inform the analyses of the subsequent cases (Smith and Osborn, 2003). At this final stage of the analysis, the researcher tries to maintain credibility and dependability by illustrating the particular life-world of participants who related their experiences on one hand and illustrating more general themes on the other hand (Smith and Eatough, 2006). In this sense, the general as well as particular themes around the phenomena investigated are presented (Smith and Osborn, 2008). This is the approach used in this study.

With respect to the phenomenon of stigma, IPA could reveal insights into what were the actual experiences of the social stigma against persons with SCD and what it meant to be stigmatized. However, in exploring the other social accounts of stigma, such as the possible norms/expectations being broken by persons with SCD in their social relations and context that facilitated stigma production against them, there is need to consider another perspective. In other words, there are other versions of experience which could be
inaccessible using IPA. These versions of experience are understandable using a perspective, also derived from phenomenology, which captures forms of interaction order. This is Goffman’s perspective that unravels meaning in situation that is 'dependent on a closed, finite set of rules'. This method requires analysis that goes beyond the notion of bracketing (Goffman, 1963). IPA method is limited to enquiry and understanding self-other relations which do not capture this aspect of experience (Goffman, 1963, 1986). Goffman’s form of order framework would therefore be used in understanding how the reality of stigma in persons with SCD could be socially produced.

The Schutzian theory could also be relevant here. Schutz turned the emphasis of phenomenology away from traditional focus on consciousness to intersubjective world of everyday life (the life-world) (Ritzer and Goodman, 2004). He affirmed that people tend to view the world through the natural attitude and that, by bracketing the natural attitude, phenomenologists can study the properties of life-world that govern action, conceived of as the ordering of the world (Ritzer and Goodman, 2004). He posited that social actors in the life-world derive their knowledge from the experience of everyday life and an accumulated stock of life-worldly knowledge (Ritzer and Goodman, 2004). So the social perspective is different from the scientific perspective. The scientists (including biomedical adherents) draw what they know from the stock of knowledge of science. Schutz posited that science and everyday life are completely different worlds and ought to be considered as completely different worlds (Ritzer and Goodman, 2004).

Schutz argued that in everyday life, people rely on constructs or ideal types in order to interpret and grasp the relevant aspects of reality (Ritzer and Goodman, 2004). These authors highlighted that within the Schutzian paradigm, people would apply generic and homogenous constructs to make meaningful their experiences in the life-world. This type of application or engagement is called typification. Typification can take many forms such as labeling, and language, to mention a few. Through the process of socialization, typifications are learned. As such, typifications can be viewed as habitual or traditional tools for handling many situations and problems that emerge in everyday life. Schutz refers to some kinds of typifications as recipes, cookbook ways of handling experiences in the course of
everyday life, and that they may be modified or discarded if they fail to deal with the situation effectively (Ritzer and Goodman, 2004). As people go about their life-world without any challenges, they take their world for granted. However, this situation changes as soon as a problematic situation arises.

In understanding social reality, people use the concept of inter-subjectivity. Inter-subjectivity refers to anything social that a person uses to understand simultaneously another person's subjectivity and one's own (Ritzer and Goodman, 2004). According to Schutz, social reality consists of four realms: the future or Folgewelt, the past or Vorwelt, Umwelt characterized by “we” relations and Mitwelt characterized by “they” relations (Ritzer and Goodman, 2004). The future, or Folgewelt, is completely open-ended and therefore inaccessible to sociological analysis while the past, or Vorwelt, has already happened and therefore accessible to sociological study, even though it could be highly prone to misinterpretation. The Umwelt involves face-to-face rapport with others and is delineated by “we” relations, a term that represents a high degree of knowledge of those involved in these interactions. The interactions in Umwelt can be inferred by the use of rational models and ideal types. The Mitwelt (also amenable to sociological analysis) is described as “they” relations. This is the realm in which people deal with types of people and social structures. This study sought to understand how social relations and social structures create depression and stigma in those with SCD. Insights from Schutzian perspectives such as “we” relations and “they” relations would be useful in this study particularly in the social analyses of depression and stigma (regarded in this framework as problematic situations) emerge from social relations and structures in the life-world of persons with SCD.

Schutz argued that meanings refer to the ways in which people decide which aspects of the life-world world are important (Ritzer and Goodman, 2004). People therefore construe their reality through their own autonomous mental representations by using subjective meaning contexts (which is not unproblematic to study scientifically). For Schutz, the objective meaning contexts exist in society and are shared by all social actors (Ritzer and Goodman, 2004). These are therefore more accessible to scientific study. Schutz’s sociology suggests
Schutzian theory could thus be described as an endeavour to construct a theoretical perspective that highlights how social actors create their social world and how this social world impact on these actors (Ritzer and Goodman, 2004). In summary, the “We” relations, “They” relations, and objective meaning contexts are accessible to sociological investigation. In order to understand the lived experience of SCD, particularly the experience of stigma and depression, this study would attempt to investigate the “we” relations, the “they” relations and the “because motives” (accessible social factors that could highlight variations of experiences that involved the views of others).

The combination of perspectives enumerated above would yield insights into social relations that produced negative experiences of emotional distress, stigma and discrimination in persons with SCD but might not go beyond this to empower these persons. This study attempted to go beyond highlighting social factors in the production of negative experiences of persons with SCD. This is informed by the perspective of Michael Oliver (1992) who, after critical examination of phenomenological research, posited that it highlights the issues in social relations but thereafter leave social relations (i.e. disability discrimination) intact. It could be argued that Oliver (1992) used one of the insights of critical realism, namely that what is actually occurring does not exhaust the possibilities of what might occur were other structural arrangements in society to be changed. In this study, in line with Oliver's argument, phenomenological approach would probably highlight the social relations that produced negative experiences, stigma and discrimination in the lived experience of persons with SCD, but it would stop there, without considering what could change in social relations to make life better for persons with SCD. It is this critique that influenced this study to adopt Oliver's model of disability framework to ask questions such as what, if anything, persons with SCD may consider as oppressive about their social conditions, what could change in their social relations, how can change be negotiated, and how could help be given to others in similar social situations.
For this study, the strategy best suited was the mixed methods approach influenced by the combined perspectives as indicated above. According to reviews of mixed methods studies (Denscombe, 2010; Cresswell and Tashakkori, 2007; Tashakkori and Teddlie, 2003; Teddlie and Tashakkori, 2008), a mixed methods strategy provides a fuller and more complete picture of experiences of the issue at stake: in this research people with SCD who experience stigma and depression. The adoption of a mixed methods approach was reflective of the broader concerns that spanned a number of related but distinct theoretical positions in this study. A mixed methods strategy allowed for deeper and broader scope of different aspects of knowledge; avoided the potential criticism associated with single methods of data collection; and guided in the selection of respondents who participated in various stages of this research. The survey part of the research with mental health scales helped to contextualize the findings by permitting the readership of the research to situate the findings in relation to other research that has used formal depression scales in describing their research participants and/or their clinical clients.

In summary, the approach of this thesis views social reality as being multi-layered. It is better to understand that social reality depends upon which level one is looking at. At one level of social interactions between individuals, perceptions, meanings, emotions, viewpoints all make a difference to how people interact. At this level, phenomenology is quite a useful framework for research as it identifies, as discussed above, the “we” as well as “they” relations and “because motives” in line with Schutzian theory.

At another level, social reality is seen as what happens at broader levels of society (class, racism, the legal system, the capitalist mode of production, post-colonial relations between UK and Nigeria) where things transpire regardless of what people discern about them (Layder, 1997). This is also consistent with the “they” relations in Schutzian phenomenology. At the broader levels of the society, things develop for a number of reasons. First, it could be that what has set these developments is historical, or is in the past and is handed down to the current generation. Secondly, things can happen as a consequence of different contextual resources (power, income, capital), or thirdly because different groups have different capabilities for effecting what happens. Many individuals
have little or no authority over these broader contextual factors. In addition, a number of these broader contextual factors are beyond the knowledge/experience of many individuals (Layder, 1997). In other words, social structure or “they” relations may be beyond many people’s personal comprehension. It is in this sense that the particular use of mixed methods in this thesis attempted to connect personal troubles (expressed anguish of people with SCD at the level of individual phenomenological interviews) to their possible causes at broader societal levels (disablist attitudes; lack of a strong national health system that would identify people with SCD by newborn screening at birth and save their lives) thus contradicting the discourses of death that surround people with SCD in Nigeria; and lack of disability discrimination legislation and policy (that would reduce the amount of discrimination in the labour market against those with SCD). In other words, this approach could potentially show how things could be different.

Going further in this multi-layered perspective, one could argue that things should be different. For example, by allowing people in the same objective position (persons living with SCD in Nigeria where there are certain contextual factors many of which add up to them being discriminated against) to come together in focus groups, there is at least the possibility that their private troubles that they thought were a product of bad luck, personal failings, can be reinterpreted as being linked to these broader social factors, and an understanding developed that improving their lives depends on changing and challenging these broader contextual factors. Thus mixed methods allows a holistic view the social world of people with SCD, who are depressed; permits the understanding of the phenomenon of their lived experience; and could perhaps initiate an appreciation of the social relations that result in their relative exclusion from society.

**Research participants**

**Rules of eligibility in the study**

The following criteria were used to include participants in this study:

1. People with all forms of SCD (HbSS, HbSC, HbSThal) attending the outpatient sickle cell clinic of the Department of Haematology, Lagos State University
Teaching Hospital (LASUTH), Ikeja, Lagos. Despite the recognized difficulty with including heterogeneous genotypes in psychosocial research on SCDs, I was advised that this study would unlikely be able to recruit the desired sample size if inclusion was limited to young adults with homozygous SCDs (HbSS).

2. The target group is aged 16+ years because by the time they are 16 years and over, they will have some life experiences that may have affected their psychosocial state.

3. Consent by the person living with SCD.

4. Not currently acutely unwell (e.g. not admitted to the ward due to acute illness)

5. For stages of the research subsequent to the questionnaire, not experiencing severe or moderately severe depression

6. Adequate command of Yoruba (spoken fluently by the researcher) and/or English language to complete the questionnaires.

Ethical Issues

In thinking about the consequences of this research upon others and the establishment of clear lines of accountability for the redress of potential grievances, this research was situated within the guidelines of Social Research Association (SRA, 2003). It thus considered its ethical obligations to the society, academic colleagues and participants connected with the study. This research was also conducted within the moral and legal order of Nigeria; its methods, procedures and findings were open to collegial review.

In considering the nature of the subject being studied, due attention was given to aspects of intrusion of privacy, access to respondents, confidentiality and anonymity of respondents. SCD comes with the potential of stigma and this is more likely where depression is involved. Consequently, people with SCD and depression may tend to keep their lives from the public agenda (France-Dawson, 1986). This issue was addressed by giving information sheets to recruited participants, obtaining consent from them (at questionnaire stage leading up to the in-depth interviews and focus groups), assuring them of confidentiality at all stages of the research. In this instance it was felt that it would not be ethical to guarantee anonymity as this would leave a situation where a person had been identified as very
severely depressed, but where no specific help could be offered as there would be no way of identifying that person for help.

Autonomy of participants was been respected. However, exceptionally, consent forms for the questionnaire stage of the study outlined that those choosing to take part agreed to sharing of this clinical information with responsible medical professionals. The information sheets [see Appendix I] and consent forms [see Appendix II] were designed in the question-and-answer format used by UK National Research Ethics Service and translated into Yoruba. Audio-tapes of the information sheets were available in Yoruba.

1. Access to participants:
Access to participants was negotiated through the ethical clearance of the proposal by De Montfort University Ethics Committee (Reference number 910) and the Medical Ethics and Research Committee of Lagos State University Teaching Hospital (LASUTH); and through contact with SCD attendees of the Sickle Cell Clinic in LASUTH, Ikeja.

The urban clinic from which the respondents were drawn is a large clinic with over 500 registered SCD patients. The clinic is a government-run service and is therefore likely to attract people with SCD who are from lower and middle strata of society. More affluent people with SCD would be more likely to use the private, fee-paying clinics. By contrast the poorest SCD person would be less likely to survive into adulthood in the first place, and would be unable to afford even the minimal fees required to access the government-run service. The findings are therefore most likely to be applicable to lower/middle income urban groups with SCD. The poorest might conceivably experience even more extreme forms of social discrimination and pressure than the accounts given here. Whilst at first glance it might be assumed that the richer groups might experience fewer problems than the sample in this study, the nature of the discrimination described (being disowned by family members, hiding SCD from others, being caricatured as unable to achieve highly) might mean that such experiences persisted even in more affluent circles as people with SCD were presumed not to achieve the highly successful norms of rich Nigerians.
Access to participants for in-depth interviews and focus groups was negotiated through identification of consenting volunteers who volunteered on the basis of providing their name and contact details when they completed the questionnaire.

2. Anonymity and confidentiality:
(a) At the questionnaire stage of this study, it was anticipated that certain participants would fall into a level of severity of depression that, ethically, would require medical intervention. For the purposes of ethically addressing the clinical needs of those identified as severely depressed, there was confidentiality but not anonymity. The questionnaire was administered and completed in duplicate by consenting participants. The participants filled in their hospital numbers (which was known to them on their attendance slips at the sickle cell outpatients’ clinic); this aided in the identification of those with moderately severe and severe depression after the scores on PHQ-9 were entered and scored. One copy of the questionnaire was used for research while the other copy was given to the attending doctors for filing into each participant’s case record. Those with moderately severe and severe categories of depression were invited, if they wished, to be offered direct support in the mental health clinic of LASUTH, Ikeja. Of the 103 participants, two fell into severe categories, were therefore excluded from the study, but all of them took the offer for support in the mental health clinic of LASUTH.

(b) The questionnaire was designed to invite those who wished to be considered for interviews/focus groups to provide contact details. Of the 103, 74 had depression according to PHQ-9. All the 74 gave their contact details. The final 15 that were interviewed were chosen purposively from those who had mild to moderate depression (72) in order to reflect socio-demographic diversity. All of them could converse in English. For the interviews, the identity of those interviewed was known to the interviewer so confidentiality and not anonymity was guaranteed. Respondents were identified by codes in transcripts and links to names were only via separate list held on pass-word-protected computer at the LASUTH, Ikeja, Lagos.

For those who participated in focus groups, the identity of those interviewed was known to the interviewer so confidentiality and not anonymity was guaranteed. Respondents were
identified by codes in transcripts and links to names was only via separate list held on password-protected computer at the LASUTH, Ikeja, Lagos. Minimum ground-rules of respect for views of others and respect for confidentiality of the information were agreed by the group at outset of focus group.

3. Avoiding harm:
In addition to the support processes outlined above for those identified with severe depression, all 103 participants were given the name and contact details of another consultant psychiatrist at LASUTH, Ikeja, Lagos to whom they could self-refer or be referred if experiencing any distress. The interviews (in-depth and focus group) were, to an extent, found to mimic elements of non-directive counseling (Rogers, 1945). In this regard, the interviews formed the sounding board for people’s views and experiences potentially enabling them to become more reflexive of their situations and learn positively from them.

4. Health and Safety of Researcher:
Where interview was not at LASUTH premises, the interviewer carried a mobile phone and telephoned a colleague at LASUTH to confirm beginning and safe return after completion of interview.

5. Safe storage of data:
Data were from questionnaires, and tape recordings of the interviews and of the focus groups. All data were treated in accordance with the best practice as identified by the existing UK Data Protection Act (there being no equivalent legislation in Nigeria at the time of writing). All data were treated as highly confidential and kept (for hard data such as questionnaires, transcripts from audio-recordings) under strict lock and key in the hospital and in a pass-worded computer (for electronic data such as voice recordings, the quantitative and qualitative data on appropriate programmes i.e. SPSS and Nvivo) at the LASUTH, Ikeja, Lagos. Questionnaires were to be shredded at the end of the study. Original tapes would be erased upon completion of the study. Respondents were identified by codes in transcripts and links to names were only via a separate list held on password-protected computer at LASUTH, Ikeja, Lagos. Final transcripts and SPSS datasets were anonymized for identifying details and anonymized transcripts and datasets have been
stored on password-protected computers at DMU for 10 years in accordance with DMU policy on retention of research records.

Methodology

In order to investigate the lifeworld experiences of people with sickle cell disease SCD who have depression, their various strategies to legitimate their experience of the illness and re-negotiate their social identity, to explore what are oppressive about their social conditions, what could change, how change could be made and how to help others to re-negotiate their social identity, the appropriate research methods used within the perspective of a mixed-methods approach were: (1) Identifying people with SCD who have depression through administration of the validated Patient Health Questionnaire-9 [see Appendix III] to a cohort of 103 patients at a sickle cell outpatients clinic; (2) Conducting in-depth interviews with up to 15 people with SCD identified as having mild/moderate depression in order them to describe their lifeworld experiences; (3) Conducting three focus groups with two sets of five people to explore various strategies the participants employ to legitimate their experience of the illness and re-negotiate their social identity.

Using the paradigm of Kleinman (1988), the choice of these methods delineates SCD with depression as not only a disease (questionnaires within an established medical psychiatric framework) but also an individual illness experience (interviews, situating their lived experiences within their individual life-worlds) as well as a sickness in which individual experience is linked to broader social relations (focus groups, enabling a delineation of social relations experienced as oppressive and potentially group problem-solving as a resistance to these social challenges). Although the three stages are presented here as if distinct, it should be noted that they do not have clearly demarcated boundaries as each stage overlaps and interpenetrates the other stages.

For the first stage, the diseases examined within a biomedical perspective were: SCD and depression. This stage involved a cross-sectional study of persons with SCD with methods
that involved convenience sampling of participants with SS (their genotypes were confirmed from their case records). In order to characterize the people with SCD who have depression, the Patient Health Questionnaire-9 was used. The PHQ-9 is a self-report questionnaire contains 9 items and mirrors the DSM-IV criteria for major depressive disorder. It is purposely developed for use in primary care and is conventionally used in clinical as well as non-clinical practice and research. It has been reported to have good psychometric properties in both clinical and non-clinical practice (Kroenke et al., 2001; Lowe et al., 2004a, b; Adewuya, Ola and Afolabi, 2006). The scores on PHQ-9 ranges from 0 to 27 with scores of 5, 10, 15 and 20 representing mild, moderate, moderately severe and severe depression (Kroenke et al., 2001). The PHQ-9 can also be administered repeatedly with good reliability (because of its researcher-imposed structure) which can reflect improvement or worsening of depression in response to care. In terms of internal validity, the PHQ-9 has been demonstrated to closely reflect the actuality of depression (Kroenke et al., 2001).

The use of this questionnaire is appropriate because of (1) the need to obtain standardized data on SCD people with depression (2) the need to cover large numbers of people with SCD (3) the information required of respondents tends to be straightforward and (4) the researcher anticipated that most respondents would be able to read and understand the questions in English given the known characteristics of those attending the particular sickle cell outpatients clinic. In other words, the primary health questionnaire-9 was used in this stage first to identify persons with SCD who had depression, secondly to obtain standardized data on these set of identified persons and thirdly to prepare for the next stage of the study. The findings of this stage are presented in Chapter 4 in this study.

For the second stage, persons with SCD who had depression were asked about their lived experiences. This stage explored how depression and stigma could arise from the interactions of persons with SCD with others in their social world. An in-depth interview method was used here to explore aspects of participant’s life, experiences and relationships in terms of SCD, stigma and depression. First, a purposive sampling technique was used to
recruit 15 SCD participants identified with depression from the sample of 72 persons with SCD who had mild to moderate depression, and who volunteered for the interview stage of the research. This sampling was conducted to reflect diversity in terms of gender, socioeconomic status and ethnicity. Thereafter, in-depth interviews were conducted with the 15 participants. This method was guided by phenomenological insights of Husserl (IPA), and of Blumer, Goffman, Link and Phelan who adapted the phenomenological paradigm of Schutz, in order to unravel among persons with SCD the more complex and subtle phenomenon of depression as well as stigma, what is oppressive about their social conditions; and how they negotiate their social identity within the cultural, socioeconomic and institutional contexts.

In-depth interviews were conducted one-to-one basis on people with SCD living with depression. The format [see Appendix IV] was semi-structured in order to allow the interviewees develop ideas and speak more widely on issues raised. This interview explored the more complex and subtle phenomenon of the emotions, opinions and experiences of living with SCD and depression. It also explored sensitive issues such as stigma, what is oppressive about their social conditions; and explored privileged information (that can only be derived from these interviewees) on the experiences of living with SCD and depression, what strategies have worked and how they have been able to normalise their experiences within the cultural, socioeconomic and institutional contexts.

The combination of insights that guided this method was appropriate in the realization of the following objectives of the study, namely to: (1) ask people with sickle cell disease who have depression to describe their life world, (2) explore their perceptions of life and lived experiences with stigma and depression (3) explore what, if anything, they may consider is oppressive about their social conditions. In other words, the choice of this method was appropriate because of the depth of information to be gained, and because valuable insights into lived experiences with SCD and depression were more likely to be generated based on their priorities, opinions and ideas. The findings of this stage are presented in Chapter 5 in this study.
Phenomenological interviews enable researchers to understand what sickle cell feels like from the insider’s point of view. This is illustrated by one of the participants who said:

“They manage to take care of you, but most times, they grudgingly would give you education. You know that kind of thing that you may die early and the investment in you is wasted. Things like that. You are not given chance to be yourself, you are not allowed to play, you are shut out from friends and so many other things…no ice-cream.”

The interview method is associated with high validity and a high response rate. In-depth interviews also have a potential therapeutic nature for the interviewees in talking and airing their feelings and opinions to a person whose purpose is to listen and note the ideas without being critical (Rogers, 1945). In using this method, I was aware of the certain conditions that might affect the interviewer-interviewee relationship such as the gap between me and the interviewees in terms of age, social status, and educational qualifications. The possible negatives effects of these factors were offset by:

The way I presented myself – in a light which is designed not to antagonize or upset the interviewee (conventional clothes, courtesy; use of neutral and non-committal statements) and my personal involvement: I was inclined at some stages [where the aim was to help and empower the interviewee] to show emotion, to respond with feeling/empathy and to engage in a true dialogue with them. The following extract suggests that I was able to gain rapport with them:

“Remi: there is one doctor who works in a federal medical Centre; he used to be a good friend of mine, just like Dr. Ola to me now.”

The way I conducted the interview also tried to limit how my identity as a medical doctor would affect the interview. The following extract illustrates this methodological point:

“Researcher: in some ways why do you think the parents get afraid?

Participant: because you too you should know now, are you not a doctor? You know.

Researcher: can you explain this, describe it for me?
Participant: ha ha, it is very clear that sickle cell can take one’s life at any time. I don’t see many people with sickle cell…I have seen very few that have lived up till 70 years. But they are not too many. Many sickle cell patients live averagely like 20 or 30 years. You know you know what I’m trying to say.

Researcher: others without sickle cell die through accidents and die early too?

Participant: yes that happens. That is what my sister was telling me the other day when we heard the news about the DANA air crash. She said you see these are not people with sickle cell and they died. Anybody can die young and it is not just people with sickle cell, so people should forget about the idea that only some particular people with conditions of sickle cell can die young. Anyone can go at any time. We should care for each other and believe in God. We are all human beings created by God. God gives life and takes. So the attitude that people have to sickle cell patients is just not good. They even wish them death by their attitudes. When you expect death, death will likely come. You don’t do things to help them, you think if you do they would still die, so why bother. When people with sickle cell are in crisis it is not always good at all. I just saw one boy in the clinic now, his situation is very bad, I was just praying let God help this boy.”

My identity as a doctor could affect the interview, but when these moments arose during the interview, as the extract above shows, I persevered and did not allow the participant’s views to disappear behind the expression “you know”.

The internal validity of interviews is good in that it is close to the actuality of living with SCD and depression. Since this type of naturalistic inquiry uses less structure, the validity is increased, although the reliability is decreased. The reliability of the interviews was though enhanced by using a topic guide in order to ensure there is some level of consistency in terms of the range of experiences covered in each interview.

**Reciprocity in research**

An important aspect of research ethics is the rapport between researchers in social science and the people they study. The perspective has been that in the past such relationships have been at best unequal and at worst exploitative (Oliver, 1992). In other words, the social researchers take information from the researched and, whilst they eventually receive
professional advancement through journal publications and career development, the people who provided the information receive nothing for the quality time and useful information they provide (Baca-Zinn 1979: 209).

In order to correct the perceived power imbalance between the researchers and the research participants, and reduce possible exploitation there are various methods suggested in literature (i.e. Cancian 1992: 628). For example, the use of participatory methods has been encouraged. The salient features of this participatory interviewing are: disclosure of personal experiences by the interviewer, drawing on interpersonal skills of being approachable, sympathetic, and responsive; not trying to control the interview process; and promoting equality by presenting oneself “as one is” with study participants (Neuman 2003: 252).

In this section of the thesis, I describe my efforts to manage the power dynamics between myself and those I interviewed. This section is organized to highlight the two key stages that a typical researcher undergoes while conducting research: finding and recruiting research participants and establishing rapport with research participants.

Finding and recruiting research participants

I spent two months and three months conducting the in-depth interviews and focus group discussions respectively. As outlined above I administered a quantitative scale to find out among the attendees of sickle cell clinic those who would screen positive for depression. The participants gave consent to be screened and to be called for further interviews. In order to have a sample that reflected socio-economic diversity among the participants with SCD who screened positive for depression, I had to use purposive sampling. I called on mobile phones these persons who fitted the criteria for socio-economic diversity serially from the list of those who had administered the depression scale. All of them had mobile phones. I downplayed my professional identity (by sharing the information that I had a cousin with SCD whose death motivated me to search for alternative ways of making life
better for those with SCD) in these phone calls and focused on working with them even
after my research to address some of the challenges they might have been facing as persons
living with SCD. Three potential interviewees said they could not participate in interviews
because of commitments to travel back to (boarding) school, but the fact that they
expressed good wishes for my research suggests their withdrawal was purely on practical
grounds and not the result of any antipathy to the idea of participating in research.

One of the participants, Joke, illustrated the willingness to participate in the research thus:

   “I’m very happy for this opportunity, for the fact that there is privacy. If I
   want to talk about my condition in the public, I burst into tears. And I would
   not be able to say anything.”

Such comments suggest that the downplaying my professional identity and focusing on
listening and working with them, including beyond the formal stages of data collection
offered the participants a way to enter into a more equal relationship with me.

*Establishing rapport with research participants*
I conducted all the in-depth interviews and focus group discussions myself. This way, all
participants were presented with the same stimulus (me) (Lamont 2000: 255). There were
other important advantages, as well.

Self-Disclosure
I was able to follow participatory methodologists’ suggestions that encouraged
investigators to regard the interview process as a transaction, and to be ready to recompense
in ways acceptable to the interviewee(s) (Morgan, 2005). The majority of respondents
living with SCD asked me about my interest in sickle cell. I told them I had a cousin who
lived with sickle cell until 12 years of age before he died. I told them he was one of the
motives behind my engaging in this study.
Reciprocity

In my relationship with the participants, there were various attempts to ensure a degree of reciprocity in the research relationship. Participants were paid expenses, of sufficient value to compensate them for taking part in the research, while it was ensured that it was not their main motivation. In addition to re-imbursement of travel costs, the participants in the focus groups, also had a meal served during each of the focus groups. Equally important were the non-monetary forms of reciprocity which involved the researcher in giving his time on behalf of respondents.

One such example involved engaging in mediation on behalf of the research participant. One of the participants, Ope, had a leg ulcer and was admitted in order to treat it via skin transplant. However the father refused to pay for the procedure because he said it would not work. Ope called me to help. I offered to help and called the father for a chat after introducing myself as a researcher who was working with his son. He agreed to meet me outside the male surgical ward where his son was admitted.

When we met, his father told me of his dream about the surgery. This dream ended in blackness and he concluded from this dream that the outcome would be negative. He further revealed that he was told by the surgeons that another flap of skin would be taken from his son’s body to fix on the ulcer. He mused that the ulcer the surgeons wanted to treat started without any obvious wound and he found it difficult to believe that they would create another wound in order to treat the ulcer. He said that his son would likely have two ulcers rather than one especially if the surgery failed. After listening to him, I asked if I could get more information from the surgeons and he agreed.

When I met with the surgeons, I told them the possibility of creating two ulcers and the need to provide options that would reduce the likelihood of such. The surgeons consequently opted for a superficial graft rather than the deep graft earlier suggested. I presented this information to the father and explained further that this option is just like having a common bruise that would dry off without treatment. It was true that the son had such bruises like any other person before and no worries. In addition, I re-framed his dream
that the blackness was a sort of confusion that needed light of clarity which we had been able to find through this second option. He agreed with this perspective and gave the go-ahead for the surgery. The surgery was successful and the leg ulcer is now cured. In this way I was able to demonstrate an ongoing commitment to my research participants.

The in-depth interviews helped in giving people a voice and to get them heard in a way that their experiences are validated by others rather than listened to within an antagonistic framework such that the person is further alienated. For instance one of the participants, Ifeoluwa, said:

“She [her auntie] thinks I have a kind of affliction that could be washed away by prayers or by juju (traditional healing). She gives me money grudgingly. She does things like that and I don’t like them. It makes me very sad. I feel lonely. I don’t feel I am heard, I don’t feel she understand what I feel and go through.”

The purpose of phenomenological interviews could well be said to be to provide the people with an opportunity to communicate to others what she feels and what she goes through. Furthermore, the structure of the study was such that the research did not end with in-depth interviews where some of the participants, while sharing negative experiences, might be brought down or suffer reinforcement of their negative feelings. The study provided the opportunity for focus groups where they needed to share so as to see what they had in common but only share enough to get this sense of sharing experience in common and then try to move to making positive changes. This is illustrated in the case of Odekunle, who provided the rationale for not dwelling on the negatives in the focus group and for empowering the participants. Odekunle said:

“Nothing makes me depressed like frequent illness. I remember busting into tears as a young child of 13, 14 years, my mates were in the lower floor, I could hear them playing, frolicking, rollicking, and having fun, and here I was on bed, weeks and weeks on that same bed, I wasn’t in pain but I was just feeling weak, just tiredness, just tiredness, and I have been hospitalized and I was home. And the tiredness did not improve, so when I just thought of them, hearing them alone got me so sad that I started to cry. And then my mum came and saw me in tears and said oh why? Then she started to cry and my own tears increased. I’m almost crying now as I am saying that.”
In the in-depth interviews, Babalola mentioned some very distressing views such as “hang myself, poison myself”. This is an example of what Oliver (1992) refers to when he says a straightforward phenomenology might be interpreted as exploitative. In other words, the researcher obtains vivid data, but what does the researcher do to help? In this study, at the very least, as part of the ethical dimension of the research, it was ensured that there was an offer for those distressed in this way to be referred to the clinic for depression. In addition, this study was structured in such a way that, through focus groups, participants could come together and feel stronger through the possibility of mutual support.

I also attended to the right of the respondents. For example, Eniola said,

“They should not treat us like sickler. I know that I am not a sickler. I am not. I am better. I don’t want to talk again.”

I immediately respected her wish and closed the interview. Talking is not always experienced as a positive experience. It depends on the person and the context. Revisiting painful experiences when there is no apparent prospect that they will change may be further damaging.

In sum, the use of self-disclosure, as a method of handling power inequality (Oakley, 1981) or for the intention of building and sustaining a confiding relationship (Booth and Booth, 1994), was useful in this study. In addition, the considered use of in-depth interviews and focus groups sequentially, and the use of a variety of reciprocities apart from covering expenses, all tended to reduce possible exploitation of the research participants.

For the third stage, the reality of SCD and depression is assumed to be created in terms of broader social relations. This stage claims that persons with SCD could face challenges of depression including stigma because of the societal sickness of disablism. In other words, others in the society react against persons with SCD via discrimination and refuse to make reasonable adjustments to include them in society. This study, in understanding how broad social relations could place persons with SCD in challenging and oppressive situations, used not only the phenomenological perspectives of Blumer, Goffman, Link and Phelan
who adapted the phenomenological paradigm of Schutz, but also Michael Oliver’s social model of disability.

Focus groups [see Appendix V] were conducted with 10 out of the 15 participants who took part in the in-depth interviews. Five out of the 15 participants were unavailable for the focus groups either because of travels back to school or because of admission in the hospital. These ten participants formed two groups, with each group consisting of 5 participants [see Appendix VI]. On one occasion, in the second focus group, one of the participants did not attend because of rain. These focus group discussions were used to explore the attitudes and perceptions, feelings and ideas about SCD and depression; and gauge the extent to which there are shared views among the group of people living with SCD and depression. The interaction within the groups was used as the means of eliciting information about what the participants considered were oppressive about social relations, what could change and how the change could be initiated; and how to help others in similar circumstances.

In other words, the FGD was used to understand the difference in perspectives between those living with SCD and depression and others in the society. From the literature review, it was realized that the difference in views might cause such problems as stigma and depression. This method was also used to allow for the emergence of not only expressions of what persons with SCD consider oppressive in their social relations with others but also how they could begin to change these oppressive social relations. The use of this approach was to harness the advantage of a group that possesses the capacity to be more than the sum of its component parts and to show the kind of synergy that individuals alone do not have. As some participants answered questions, their responses would be cues for others to respond. This procedure helped to explore a range of perceptions about (1) practices of others without SCD that could be considered oppressive (2) strategies to negotiate change as well as help persons with SCD in similar oppressive situations and (3) how coming together in the FGDs felt for the participants.
The focus group was a single-category design in which two groups of persons with SCD and depression had each three sessions of FGDs. The choice of three sessions was considered adequate in line with the minimum number to reach a point of theoretical saturation in addition to the limited budget and timeframe for the thesis (Krueger and Casey, 2009). The participants were from the list of 15 respondents to the in-depth interviews. They were invited during the in-depth interviews and also by phone calls after the interviews. The meetings were set one at a time with each group with consideration for the convenience of the participants (date, time, and location). They each had reminder phone contacts three days before each of the meetings. There were also incentives (monetary incentives for their transportation and non-monetary incentives that were symbolic in the form of one, food that ranged from snacks to lunch meals and two, the purpose of the discussion, which covered issues such as challenging SCD discrimination, becoming more visible in Nigerian society, and working towards a better quality of life). In summary, the invitation to the respondents was framed in positive ways in that they had meals, transportation fares, and an opportunity to share ideas as incentives.

During the FGDs, questions were asked in a conducive environment in the hospital premises on weekends. The quality of the discussion was considered standard because the questions were made clearly understood by the respondents (no use of acronyms, and professional jargons) (Krueger, and Casey, 2009). In addition, the questions were kept short and were often open-ended. The questions were formulated in such a way to help create informal environment and stimulate spontaneous conversations. The respondents were also able to articulate their answers and the perceptions on the range of issues discussed. The issues discussed were guided by the research questions and the theoretical framework of Oliver’s Social Model of Disability. The questioning pathway followed sequentially: opening, introductory, transition, key and ending questions. The combined theoretical framework attempted to capture from the respondents’ reference possible areas of influence of social relations on the lives of persons with SCD, without which robust interventions to make a socially significant difference would be impossible. Examples of such questions were: (1) How do you as a group respond to how people treat you, what strategies do you
(2) What strategies could work well in responding to people and what would not work well to improve your life? (3) How do you think you can help someone living with SCD as a group?

The choice of this method relies on the depth of information to be gained that is a good measure of internal validity. Focus groups have the advantage of (i), highlighting the attitudes, priorities, language and framework of understanding of people with SCD and depression; (ii), encouraging a wide range of conversation among participants and gaining different aspects of understanding; (iii), helping to recognize norms in a group (a good measure of reliability) and provide insight (a good measure of external validity) into how social processes help in the production of knowledge (e.g. through the examination of what information is censured or muted within the group) and (iv), encouraging open communication about humiliating topics and facilitating the discussion and description of concepts and experiences that might be left unfinished in an interview (Kitzinger, 1994; Culley, Hudson and Rapport, 2007). The following quotation from one of the focus groups lends credence to the choice of this method. Focus groups create an opportunity for persons coming together to recognize that the problem could lie in others rather than in themselves.

“It is when I have started coming out and meeting with groups of persons with sickle cell that I myself knew that I do not have problems and they are the cause of my problems. I know that I am just as normal as others only that I need to take special care of myself. That’s all.”

This method explored further the following objectives: (1) explore what, if anything, they may consider is oppressive about their social conditions (2) explore what could change in their social relations, how change can be negotiated, and how to help others with similar social situations (3) assess the impact of research participation on people living with SCD. This third level of Kleinman’s framework was designed to give further voice to the research participants living with SCD and to enable them to create a critical mass of persons to seek re-adjustments in the attitudes (and, by extension, actions via policies) of others in the society such that they can be better supported. In addition, the use of focus groups was also meant to be a platform to facilitate forms of social support and empowerment that would
hopefully outlast the research. The findings of this third stage are presented in Chapter 6 in this study.

**Data Analyses**

The empirical data from the first stage was analysed using quantitative techniques in order to characterize the persons with SCD and depression in this study, and forms part of making the research generalizable, by proving the reader with context from which to judge the transferability of results to other situations.

Descriptive statistics were used for the socio-demographic data. Frequency counts were conducted for the categorical variables (gender, ethnicity, type of family, religion, language, level of education of fathers, mothers and the patient, who they live with, type of SCD, presence/absence of leg ulcer, experience of blood transfusion, family history of mental illness, and occupation of mothers, fathers and patients). For the description of depression, frequency counts were used to calculate the prevalence and also to enumerate categories of depression. Depression scores were also summarized with means and standard deviations.

For the continuous variables, they were described by mean, median, mode and range. These variables included age, household income, personal income, money spent on medications, number of days off work/school, age at diagnosis of SCD, number of days in pain per week, number of hospital admissions due to SCD in the last 12 months, and number of siblings.

Inferential statistics were conducted to explore the relationships between SCD and depression. For the socio-demographic variables (gender, ethnicity, type of family, religion, level of education of fathers, mothers and the patient, who they live with, type of SCD, present/absence of leg ulcer, blood transfusion, family history of mental illness, and occupation of mothers, fathers and patients), associations with SCD and depression were explored with Chi-square test while for the continuous variables (age, household income, personal income, money spent on medications, number of days off work/school, age at
diagnosis of SCD, number of days in pain per week, number of hospital admissions due to SCD in the last 12 months, and number of siblings), independent T-test was used to test for significant difference. All the tests were two-tailed and the level of significance was set at 0.05.

For the second stage, the qualitative data was analyzed using IPA processes but modified by insights from Blumer, Goffman, Link and Phelan. There are a range of research strategies for analysis of data gathered in the in-depth interviews within the multiple phenomenological paradigms that could reveal the lived experiences of persons with SCD and depression. Interpretative phenomenological analysis (IPA) is a major tool that is relevant in this study. Given below are the processes that guided the preference for the use of IPA over the grounded theory.

Grounded theory was developed by Glaser and Strauss (1967) with the purpose of becoming a credible alternative to positivism. It is thus represents a paradigm shift in which social data is obtained in a methodical way and analyzed to develop theoretical frameworks for the social phenomenon explored. The core elements of grounded theory are theoretical sampling (Glaser, 1978) and analysis (Denscombe, 2007). In grounded theory, the theory emerges from the social data obtained through sampling. The sampling allows the researcher to determine what data to collect next and where to find such data as s/he collects, codes and analyzes the preliminary data. The theory emerges as the researcher engages in these processes (Glaser, 1978). This kind of data analysis is therefore a continual process that spans preliminary data together with on-going data. This analysis requires the use of open coding as well as the application of continuous comparative methods. In this way, guidelines for gathering more data are provided. In addition, this continual process thereby facilitates conceptual identifications that are essential for moving from descriptive representations of live experiences to a more inferential analysis that provides explanations for discovered relationships between and across reported experiences (Glaser and Strauss, 1967). The theory that emerges from this procedure is valid when no new evidence develops from subsequent data analysis and this is referred to as the point of “theoretical saturation” (Glaser and Strauss, 1967: 61).
However, the primary aim of this study was to understand experiences of persons with SCD and depression as well as how meaning was ascribed by others rather than to provide an explanatory framework for these experiences. This aim is best explored under phenomenology and its modifications by Blumer and Goffman. This perspective provides a methodology that allows the experiences of persons with SCD and depression to be explored first, that is before an attempt is made to explain these experiences through theoretical abstractions. IPA is a useful tool to begin this exploration of what is this lived experience of SCD and depression. This IPA method was used in addition to analytical insights from the works of (1) Blumer (1986) and (2) Goffman, both of whom took some influences from phenomenology [especially Schutzian] and other aspects of sociology and psychology as noted above. Although these latter accounts go beyond the standard IPA, the first stage of analysis in this research was based on standard IPA principles.

IPA has phenomenological and interpretative aspects. The phenomenological aspect of IPA allows for the development of a pattern or structure of a particular experience (Smith, 1996, 2004; Smith and Eatough, 2006), which in this study was the experience of depression and SCD. The IPA interpretative aspect focuses on discovering meaning within this particular experience. In this IPA framework, there is engagement with life-world of an individual such that primal subjective understanding of lived experience is revealed, unlike the third person account knowledge that is revealed with positivism (Moustakas, 1994; Moran, 2000).

In addition, IPA methodology allows for transparency in research because it provides for the understanding of how the researcher, while engaging with the narrative scripts of those interviewed, might create a unique noetic picture of what the experiences of those interviewed are like and from this picture, how the researcher might develop a noematic interpretation. Within IPA framework, the researcher carefully attempts to bracket his natural assumptions about the narrated experiences. This careful attempt is referred to as epoche (Langdridge, 2007, 2008; Moran, 2002; Ricoeur, 2004) which allows the researcher describing an experience not only to avoid using any preconceived ideas that might
misrepresent the pertinent features of the experience but to actively endeavor to bracket such presuppositions out (Bernet, Kern and Marbach, 1999; Langdridge, 2008).

Another concept that IPA uses to gain understanding of the social world is physicality of the experience in the social world. Underlying this is the assumption that humans are not only self-conscious social beings, who seek meaning and engage with the world, but also create as well as re-create their consciousness constantly through lived experience (Sartre, 1957). In other words, Sartre (1957) conceivably argued that human consciousness is product of constant cycle of creation and re-creation enmeshed in lived experience. Within this framework combining several strands of phenomenology, it is argued that social actors in their pre-existing social world have the potential power to seek for meanings attached to phenomena and change those meanings as necessary (Sartre, 1957). This position underscores how persons could make sense of their experience (Smith, Flowers, and Larkin, 2009), and consider aspects of it that are oppressive (Oliver, 1992). Thus as individuals develop experiential relationships with certain phenomena in their social world, they make sense of their intentionality of this relationship and could develop the motivation to change it as necessary or applicable (Langdridge, 2008). In this study, by extending the foregoing, by responding to IPA/Blumer/Goffman/Link and Phelan’s questioning stance, persons with SCD and depression might overcome the socially constructed experience of depression and have the motivation to sustain this change as a demonstration of the nature of their consciousness.

In contrast to the positivist approach which assumes that general laws about social world can be revealed with statistical analysis of collective data, IPA proponents posit that the summarization of collective experience as a single obvious interpretation is problematic for understanding sociological phenomena adequately (Smith, 1996). In addition, IPA researchers argue that a positivist stance ignores the unique pertinent elements of individual subjectivist phenomenon and does not recognize that such subjectivist experience is a complex, relational phenomenon that is uniquely situated in an individual’s perspective (Smith, 1996). Furthermore, it has been argued that positivism manipulates sociological phenomena into numbers by the way it collects social data, transforms and analyses these
data. Such processes alienate the individuals who were the researched in the first place. IPA therefore seeks to highlight the essential elements of the individual subjectivist phenomenon in order to present a credible account of the particular experience of each individual in his/her social world and to be able to reveal something in detail about the whole group of such individuals (Rafael, Engel and Schutt, 2005) – a concept outside the epistemology of positivism. By so doing, and by using the analysis of individual cases based on a relatively small sample size, IPA thus arrives at more general claims with caution (Smith and Osborn, 2003; Smith et al., 2009). In other words, IPA allows the researcher to “delve deeper into the particular” in order to take his/her audience “closer to the universal.” This arguably can only be achieved by the use of a small group of people (Warnock, 1987 cited in Smith, 2004).

Within the framework of IPA, qualitative data analysis in this study applied principles similar to those of hermeneutics to interpret the textual data from the interviewees. Hermeneutic principles require that information about a person’s experience is written accurately and that there is committed engagement with this script in order to understand the mental processes of the person (Smith and Osborn, 2003). Each transcript in this study was analysed in a manner to demonstrate the conventions and expectations of the person’s mores that makes it possible to reveal the understanding of his/her lived experience based on the language (metaphors, key phrases, idioms of expression) s/he used. In engaging with this type of analysis, efforts were made to articulate each participant’s lived experience so that mutual understanding could be achieved (Smith and Osborn, 2003).

The analysis of data of this study was iterative. In other words, analysis moved backwards and forwards through different dimensions of understanding the narrative accounts of persons with SCD and depression in the study, and allowed the researcher to reflect on the relationships in the testimonials as well as his relationships with them (Smith, 1996). In addition to the iterative principle, eidetic reduction was applied. In eidetic reduction, emphasis is put towards the understanding of conscious experience of the person including the understanding of the wider context in which the transcript was originally produced without contrast or comparison with current knowledge (Gadamer and Linge, 2008; Smith
and Osborn, 2003; Smith, 2004; Smith et al., 2009). The perspectives of symbolic interactionism of Blumer (1986) and stigma of Goffman (1968) as well as modifications by Link and Phelan (2001, 2014) were also used to read critically into the experiences of persons with SCD and depression to understand (a) how they simultaneously ascribed meanings to themselves and understand how others ascribed meanings to them; and (b) what interaction order or sets of defined rules they break that puts them in situations of stigma.

Several authors have pointed out the merits and demerits of IPA (Giles, 2002; Finlay, 2009; Willig, 2009; Pringle and Drummond, 2011). The demerits are discussed below with attention to how these demerits are addressed. First, they noted that there is the danger in imposing interpretations on the experiences of others through interpreting them through the researcher's framework. The researcher in this study was aware of his medical training with its emphasis on a biomedical perspective. This biomedical disposition might bias the location of the problems of SCD within the persons who lives with SCD. This disposition of the researcher was discussed with the supervisors before and during data analysis such that bracketing was encouraged in the researcher throughout the period of analyses. Secondly, Giles (2002), Willig (2009) and Finlay (2009) point out that there is a necessary assumption of a degree of self-transparency. In other words, it is assumed that people (participants) are actually able to apprehend and put into language effectively all that is relevant to understanding their experience of a given phenomenon. The connected problem here is that there is lack of attention given to factors of power and social structures, as these often fail to show up in people’s discursive reflections. The researcher was able to use probes that reflected attention to these factors. Thirdly, the authors (Finlay, 2009; Willig, 2009) noted that IPA also limits itself to what emerges as an object of concern in people’s accounts, with the emphasis strongly on “what does it feel like” questions. In other words, IPA does not focus on what emerges from social relationships and especially social norms. This problem was addressed in this study by using in addition to IPA, Blumer and Goffman’s perspectives that were influenced by Schutz as well as psychological theories apart from IPA. Fourth, these authors noted that there is the possibility that the likely
explanation of the themes that emerge from the text will vary. This runs the risk that each
reader may construe findings differently since each reader are unique interpreters and may
not endorse or connect with the researcher’s interpretations (Pringle and Drummond, 2011).
In this thesis, this pitfall was minimized by using interview excerpts that are extensive in
order to increase the access of the reader to the actual words of the respondent(s). This
increases the transparency of the research by according the reader maximum opportunity to
consider alternative interpretations. Fifth, the discussions and conclusions that emerge from
the accounts of the social actors may not be definitive, as a researcher’s elucidations of
these accounts may vary over a period of time as his/her perspective widens and deepens
(Finlay, 2009). This pitfall was minimized by giving due considerations to the socio-
cultural contexts in which the respondents shared their experiences and also by having
feedback from a sample of respondent(s) on the emerging discussions and conclusions to
check whether or not they reflected their views. Sixth, IPA possesses so much flexibility in
its methodological process that might undermine its epistemological position (Giles, 2002).
This pitfall was minimized by adherence to IPA repertoire of strategies as shown in Table
3.1 (Smith et al., 2009: 79-80) such that microanalysis of each individual’s experience leads
in steps to more generalizable accounts.

While noting these limitations, it should be noted that in IPA the experiences of participants
in the interviews are given priority and that IPA allows primordial knowledge to be
obtained through detailed analysis of individual experience that takes cognizance of the
social, culture and temporal circumstances in the life-world of such individual (Smith et al.,
2009). In acquiring this first order knowledge, the development of second order knowledge
and the subsequent search of more generalizable accounts are allowed (Dilthey et al.,
1989). It is this merit along with the advantages of other strands of phenomenology that
forms the strength of this approach.

The analytic technique used an iterative inductive cycle as outlined in Table 3.1 (Palmer,
1969). The repertoire of strategies in Table 3.1 was used flexibly. For each case, in line
with IPA’s idiographic stance, each step of the analytical procedure is followed for the first
case before proceeding to the second and thereafter (Smith and Osborn, 2003). The
transcript that was first selected was based on the criteria of being the most detailed, and engaging among all the transcripts on cursory reading.

Table 3.1: the IPA iterative and inductive analytical cycle

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The close line-by-line analysis of the experiential claims, concerns and understandings of each person</td>
</tr>
<tr>
<td>2</td>
<td>The identification of emerging patterns within this experiential material, emphasizing convergence and divergence, commonality and nuance, usually for single cases and then subsequently across multiple cases.</td>
</tr>
<tr>
<td>3</td>
<td>The development of a ‘dialogue’ between the researchers, their coded testimonials and their sociological knowledge about what it might mean for people to have these concerns in this context leading in turn to the development of a more interpretive account.</td>
</tr>
<tr>
<td>4</td>
<td>The development of a structure, frame, or gestalt which illustrates the relationship between themes</td>
</tr>
<tr>
<td>5</td>
<td>The organization of all these materials in a format which allows for analysed data to be traced back through the process from initial comments on the transcripts through initial clustering of thematic development into the final structure of themes.</td>
</tr>
<tr>
<td>6</td>
<td>The use of supervision, collaboration or audit to help test and develop the coherence and plausibility of the interpretation</td>
</tr>
<tr>
<td>7</td>
<td>The development of a full narrative evidenced by a detailed commentary on data extracts, which takes the reader through the interpretation, usually theme-by-theme and is often supported by some form of visual guide (a simple structure, table or diagram)</td>
</tr>
<tr>
<td>8</td>
<td>Reflection on one’s own perceptions, conceptions and processes</td>
</tr>
</tbody>
</table>

Adapted from Smith, Flowers and Larkin, 2009: 79-80

The first step is reading and then re-reading. This step specifies that the researcher needs to engage actively with the narrative scripts (Smith, 2006). The transcripts were read over and over again with careful consideration in order to enter the reported life-world of the interviewees and comprehend how their narratives were used to highlight social meanings. This engagement allows the locations in the transcribed scripts of rich and detailed sections of similarities as well as sections of contradictions/paradoxes (Moustakas, 1994). The researcher is also able to think carefully about his techniques and then consider how the early interviews have helped in the process of developing his skills for later interviews.

The second step was to probe, at the initial level, the linguistic structure and language use. Here the researcher is required to keep an ‘open mind’ in order to discover anything of
interest in the transcripts (Palmer, 1969; Bailey, 1994; Clandinin and Connelly, 1998). This step allows the researcher not only to become increasingly familiar with transcript but also to identify a specific pattern configuration through which the researched thinks carefully and understands the lived experience. This stage of analysis is also iterative. For each cycle of analysis, a blank sheet was required and upon completion, such notes were compared with previous analysis to develop an understanding of the core essence of the accounts.

Caution should be and was exercised in order to stay close to the meaning inherent in the transcript. In other words, adequate care was taken to avoid making value based judgments or conclusions about what the respondents said or did not say. The systematic protocol to stay close to the meaning inherent in the transcript requires the identification of three different foci in the texts (Smith et al., 2009): the first focus identifies in normal font the descriptive comments that represented the context of what the respondent said and the subject of the transcribed account; the second focus identifies in underlined font the linguistic comments that focused on a particular use of language; while the third focus identifies in italics the conceptual comments that focused on concepts.

The printed copy of the each transcript had wide margins for the earliest notes that highlighted contents of the transcription that were descriptive, linguistic and conceptual. Each page and line of hard copy had a distinct number for unmistakable referencing and coding. After the analysis and coding of the transcription, a comprehensive expository note was made that contained similarities and differences. This allowed clear recognition of potential amplifications or contradictions in what the interviewee said. Thus the researcher employed the reflective use of analytical dialogue with each line of the transcript by inquiring what the word, phrase or sentence could mean in the prevailing social, cultural and temporal context (Flick, 2009).

The development of the emergent themes was the third step. Here the large amount of information from the comprehensive lists of exploratory comments of step 2 was reduced but only in terms of volume and not complexity. The reduction involved the depiction of interrelationships, connections and patterns among pieces of exploratory comments. This
entailed working with initial notes rather than the transcript. The hard copy of the transcript was formatted in columns that consisted: exploratory concepts, original transcript and emergent sub-themes. The emergent sub-themes were delineated as phrases which reflect the sociological essence of IPA inquiry as well as the analytic framework of Blumer and Goffman. This combined approach is also linked to the principles of hermeneutic cycle where pertinent sections of the transcript are interpreted in relation to the whole (Smith et al., 2009).

The step four sought for connections across emergent sub-themes. The set of sub-themes were arranged sequentially i.e. in the sequence of emergence from the transcript. Thereafter, the investigator developed a chart that illustrated how the sub-themes converged as themes (Smith et al., 1999). Here the researcher would reflect and attempt to identify common links between these sub-themes and then re-order them as emergent themes using analytical and theoretical framework of Link and Phelan (2001), Blumer (1986), and Goffman (1968) in addition to IPA analytic reflection (Langdridge, 2007). During this process, some sub-themes appeared to cluster while others would not and would require additional review and consideration. In this latter case, themes that appeared to be superordinate would be used to re-order and recode sub-themes. An example is shown in Table 3.2. Here theoretical and analytical framework of IPA as well as perspectives of Blumer, Goffman, Link and Phelan guided the development of appropriate themes. Each theme together with sub-themes was easily connected to the originating text via highlighted key words highlighted on page numbers.
Table 3.2: Illustrative examples of emergence of themes and sub-themes with key words

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-theme</th>
<th>Key phrases</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiencing Disapproval</td>
<td>Disapproval experienced from family member</td>
<td>“even when I feel like I can do these things, my mum was always like don’t do it”</td>
<td>129</td>
</tr>
<tr>
<td></td>
<td>Disapproval experienced from others in the community</td>
<td>“…they don’t give us a chance to live and to enjoy life”</td>
<td>138</td>
</tr>
<tr>
<td>We wished we were dead</td>
<td>Thoughts of suicide</td>
<td>“I feel like dying”</td>
<td>168</td>
</tr>
<tr>
<td></td>
<td>Attempts at suicide</td>
<td>“There was a day I took Lysol to kill myself”</td>
<td>170</td>
</tr>
</tbody>
</table>

The fifth step required movement from analysis to the testimonial stage. Here the cycle of steps one through four is repeated for the next testimonial. Each case was treated on its own term in order to do preserve its individuality (Smith et al., 2009).

The sixth step subsequently involved looking for patterns that cut across all cases (Smith et al., 2009). Here the researcher was required to reflect on the connections between the lists of themes/sub-themes identified in the step four and the way these identified themes and their sub-themes could illuminate different cases (Smith et al., 2009). Table 3.3 shows an example of this process in the form of a table of recurrent sub-theme for each person.
Table 3.3 Example of Recurrent sub-theme

<table>
<thead>
<tr>
<th>Interviewees</th>
<th>Disapproval experienced from members of family</th>
<th>Disapproval experienced from others in the community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aderonke</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Babalola</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Comfort</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Damilola</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Eniola</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Funke</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Gbenga</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Hannah</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Ifeoluwa</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Joke</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Ope</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Bolaji</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Niniola</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Adekola</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Odekunle</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Through iterative engagements in the analytic cycle, the researcher contemplated the primary research questions as well as the objectives. According to Smith’s (2004) guidelines, the researcher aimed to make sure that the answers to those research questions were essentially a true reflection of the people’s own accounts of their lived experiences. This act would ensure the development of robust comprehension of the meanings people attributed to their own lived experiences (Warnock, 1987 cited in Smith, 2004) and as this understanding grew, it allowed the configuration of the phenomenological script of the original testimony (Smith et al., 2009).

In the seventh step, the researcher used analytic induction to study the findings (Cassell and Symon, 2005) while looking for similarity across cases (Miles and Huberman, 1994). The objective here was to scrutinize a conceptual explanation of individual testimonies in order to highlight a clear relationship between sub-themes and emergent themes. To ensure that the conceptual explanation was true for all cases, each individual transcript was continually examined to locate common factors and provisional explanations. The conceptual model was continuously redefined and modified as new cases were examined so that divergent
explanations could be in consonance with the commonly recurring themes and accurately represent reported experience (Cassell and Symon, 2005). This is shown in Figure 1.

The eighth step is concerned with the presentation of findings. Here the researcher first attempted to describe the narrated account and explain, with regard to the context of experience, what this account could mean. Secondly, a detailed interpretation of the experience was depicted in order to discern what it all meant within the context of the overall study. In this step, an overview was given of what was discovered and thereafter, the essence of the related theme together with the sub-themes.

In the ninth step the marginalized or oppressed group is given a voice. Here the study brought to light issues with which persons with SCD and depression previously might not have had the opportunity to express or discuss. This step might highlight the aspects of structural disadvantage which impact on their poor quality of life (Yates, 2002). In this
step, this study gives a voice to these persons with SCD and depression who have hitherto been silenced by marginalization and bias as indicated in extant literature.

**Critical evaluation of the research process**

The orientation of IPA differs from the ideals of validity and reliability as prescribed in positivist research (Smith et al., 2009). However, it recognizes that there are analytical assumptions inherent in the testimonies provided. It also identifies possible methodological biases that could affect the research process and the findings which could emerge from such process (Smith et al., 2009). Furthermore, there is a discussion, below, to demonstrate the transparency for all decisions taken and the role that the researcher had in the methodological process. This is described to show that the thesis is committed to the tenets of quality and rigor (Flick, 2009).

**Reflections on the research strategy**

IPA application allowed a deep insight into the lived experiences of persons with SCD and depression. The analysis provided the framework that allowed the findings to be portrayed such that the nature of these experiences is revealed and the reader is given the chance to endorse them or share in them. Earlier in this chapter, three criticisms of IPA were listed (under limitations of IPA). While these concerns were engaged in previous discussions, this thesis is also able to identify a number of additional observations not covered in extant literature specifically about the use of IPA.

**Reflections on research methods**

1. The use of PHQ-9 as a scale to measure depression, a Western construct in a non-western setting, was carefully reflected on. It was noted in the literature review (Chapter 2, page 26) that the biomedical view of depression is problematic. In other words, there was a need to take into account the social meanings of depression in non-Western cultural contexts. However, it was argued later in this review of literature (Chapter 2, page 29; Chapter 4, pages 120-121) that even if when depression could be ascribed as a Western concept; its core symptoms remained
useful in describing a constellation of distressed states even in Nigeria. It is within this framework that depression was used in this study.

2. The reflection on the use of semi-structured in-depth interviews was also carried out. The use of this method was informed by understanding that depression and stigma among persons living with SCD could result not only from biological processes but also social process (Chapter 2, page 56-57). It was critically examined and noted that for persons with SCD, each of the conceptual dimensions of biology and social relations represents a facet of critical experiences for them. It was therefore necessary to examine not only one part of their trajectory such as the rise of the disease, but also the social creation of the illness (depression) (Chapter 2, page 59-60). In Chapter 4, a useful observation was made that quantitative analysis that followed traditional medical lines assumed a material reality to depression and produced such results in terms of association of measurable variables (page 120). The point was that the social meanings of living with depression and SCD could not be captured by positivist methods and, without exploring these social meanings, a robust understanding of the illness and critical points of social interventions could not be provided. Hence the need for in-depth, semi-structured, interviews, where the focus would be on one hand, the relation of “personal troubles” to public issues of social structure (Mills, 1959) and on the other hand, the impact of social systems as a whole on individuals with SCD who were enmeshed in them (Brown and Harris, 1978) (Chapter 2, page 31).

3. With regards to reflections on the need for the focus group discussions, there are limitations to merely describing the lived experiences of persons with disability, such as having their problems laid out but no consequential action (Chapter 2, page 51-53). The use of FGDs was to create, within the frame of reference of persons with SCD, favourable circumstances to initiate possible mechanisms that might formulate flexible policies and practices that not only prevent negative and discriminatory social exchanges but regulate positive and supportive social interactions.
The rationale for the focus groups was to go beyond laying bare the oppressive social relations from the point of view of persons with SCD and allowing persons with SCD to reflect on such social creations of depression and stigma in order to come to challenging them and addressing them in their own terms. In order to achieve this, the focus groups met on three occasions. Broadly speaking, in the focus groups, participants were meeting one another for the first time, and in general they corroborated views individually expressed in the in-depth interviews. In the first round of the focus groups, they gave similar accounts of negative experiences with other social actors in their life worlds. What each of them said individually in the in-depth interviews was shared with others for the first time in the early focus group meetings. They began to develop trust in each other and sense of belongingness. However, as was consciously planned, drawing upon Oliver’s social model of disability, the focus started to shift, from the negative voices, towards a consideration of what oppressive social relations could change and how such social re-arrangements could be negotiated in mutually agreed ways with others in the society. In other words, had there been but one focus group session, the findings would have been largely a repetition of the results of the in-depth interviews. Further sessions were based on the epistemological assumptions that, as they took time to recognize that they shared experiences, they needed to trust one another. Furthermore, guided by the social model of disability the researcher was also involved in active facilitation of the focus groups, and this prevented the group reverting over and over to their formerly expressed lamentations. So the procedure was to use theoretically informed probes to guide them beyond the lamenting and to consider suggesting solutions to socially constructed barriers of stigma and depression. In Goffman’s terms, the participants through the focus group sessions were learning how to prepare backstage, in order to challenge frontstage, out in open society, the broader social relations considered oppressive within their own frame and term of reference. In running the focus groups, these goals were met. In summary, the focus group discussions were used to go beyond the description of the socially created hurdles of stigma and depression in the lifeworld of persons
living with SCD and begin, within the frame of reference of these persons, social re-
arrangements that would not only challenge the socially scripted discriminatory
practices by others, but also social exchanges that permit nurturing and beneficial
interactions. The use of FGDs highlighted (see pages 276-279) how persons with
SCD who lamented their disadvantaged unequal status with others began to develop
insights into their collective and individual positive characteristics as against
individually accepted negative ‘deterministic’ perspective of others; began to
propose weighed strategies to end their separation from others and renegotiate their
positive identity with others; started to advance and propound the need to change
social arrangements by supporting themselves, parents and younger ones with SCD,
standing up for themselves, initiating favourable social policies and interfacing with
key stakeholders to gain their supports in making reasonable social readjustments
towards improving their living conditions and others in similar situations.

Reflections on analysis

Given that IPA as method for analysis for in-depth interview data of lived experience has
sufficient and robust theoretical foundation, but that its application to focus group data has
no similar theoretical status, there is a need to reflect on the use of IPA with focus groups in
other to consider pitfalls and potentials. Whilst Brocki and Wearden (2006) have noted that
IPA approaches are being combined with a variety of data collection methods and types,
some authors (Dowling, 2007; Smith, 2004) have raised concerns as to whether focus
groups could ever be phenomenological. However, other authors (i.e. Langdriddle, 2007)
have independently suggested that IPA was ripe for such detailed theoretical and empirical
exploration applied to focus groups. In this vein, this study used a modified IPA for
framing the questions in the focus group data collection, as well as focus group data
analysis. However, it was a modified IPA in that it was also influenced by the interactional
perspective of Goffman, as well as the social model of disability proposed by Oliver
(1992). The IPA analytic technique on the focus group data drew on group level patterns
and dynamics in line with suggestions of a number of authors (i.e. Dunne and Quayle,
2001, 2002; O’Toole et al., 2004; Vandrevala et al., 2006) and with the influence of the
disability rights perspective of Oliver (1992). These combined perspectives in data collection and analysis of focus group data helped in the exploration of the specific research questions, such as what persons with SCD consider oppressive in their social conditions, what could shift and change in their social relations, how these changes can be negotiated, and how they could help others in similar social situations. In other words, the challenges, concerning the dynamic between individual and group, and over whether individual or group is to be considered the unit of analysis in focus groups analyzed using IPA (Morgan, 1997; Wilkinson, 1998) were considered, and addressed by conceptualizing focus group discussions as representing trajectories from individual views, through “back-stage” rehearsals of groups views, through to anticipations of a “front-stage” challenge to societal attitudes in the mould of Oliver's social model of disability.

In presenting the analysis of focus groups, attention was given to the thematic synthesis stage, in addition to illustration of individual themes. Hence, thought was given to the problem of eclipsing individuals at the analytic stage in addition to the presentation of the results such that voices and perspectives of individuals were illustrated in individual themes. The analysis was transparent in retaining the sense of which individual contributed specific parts to the discussion, in order to exercise caution towards prioritizing the group over the individual, the general over particular or the whole over the parts. Caution was taken not to eclipse the individual. At the same time, the use of social model of disability mitigated the danger of privileging the individual over the group and this balanced the approach to the analysis of data (Tomkins and Eatough, 2010; Palmer, Larkin, and Fadden, 2010). In summary, this project used a pragmatic approach in combining theoretical perspectives of social model of disability, and Goffman’s interactionism, with a modified IPA to address focus group data analysis, whilst acknowledging the challenges of using IPA in focus groups.

Additionally, IPA has been criticized for lacking in scientific rigor because of the possibility for variant interpretation. IPA has been said to depart from the tradition where the researcher is responsible for achieving rigor but that it requires that such rigor must be evaluated by the readers who could determine whether or not the accounts and the
interpretations (findings) are credible based on the provided information. Through constant critical reflection on the research process, the study attended to key methodological criteria by which qualitative studies are appraised. These key methodological criteria of trustworthiness of the data include reflexivity, credibility, dependability and transferability. These are discussed in the following sections.

Reflexivity

This requires the researcher to engage in sustained self-criticism and self-appraisal about his role in interpretative analysis. The researcher has taken care to align with the protocols as laid out in the methodology. This demonstrated that the analysis of people’s accounts went through constant and critical review as each testimonial account was subjected to analytical procedure on several occasions throughout the 12 month period.

The chance to analyze each transcript from a new angle a number of times allowed possible presuppositions to be recognized and reduced. This process allowed a reflective recognition of a range of likely explanations made concerning the narrated accounts. Continual cycle of analysis also allowed for interpretations that precluded the initial biases that might have been applied.

The findings in chapters 5 and 6 demonstrated that the voices of the participants were enabled, and the participants discussed their challenges and proffered possible solutions in their own frame of reference. It is thus suggested that the audience, apart from their own interpretations, will be able to endorse and/or share the findings as well as the interpretations of what it means to persons with SCD and depression.

Credibility

This refers to the value inherent in the findings (Bryant and Christopher, 1985). This was achieved in this study through prolonged engagement with each testimonial. Rarely do social circumstances occur without there being counter-examples, or exceptions to the rule. In enhancing methodological criterion of credibility, the study also presented reports of exceptions to experiences shared by the majority of the respondents. For instance, Gbenga
[21, male, student, Christian], related his experience that could suggest that situations might be changing in contrast to the experiences of most others. Gbenga recounted that:

“For now, I think it is good now, it is much better than before. Some time ago, they used to believe that a child with sickle cell is ogbanje or a possessed being. But now more people know it is all fault of parents. They treat everybody well and the same. They treat everybody normally; they don’t excuse someone just because he or she has sickle cell…People outside the school also treat us better than before. They don’t look at you as if you will die the next day.”

IPA however recognizes that the lived experience can be multifaceted and that there may be endless meanings in a person’s constant interaction with the world and that these cannot be captured or described with complete certainty (Smith et al., 2009). The hermeneutic circle – where the understanding of parts change our understanding of the whole and which then changes our understanding of the parts, and on and on – comes to light here. For example, when persons with SCD reported that they worked hard in their workplace and their employers had more confidence in them compared with others, this was understood as playing positive role in the community development. However when some of them put the experience into their overall experience of trying to ‘work themselves to death’ because of rejection in the society, their engagement at work in some situations made more sense. In addition, the notion of the “double hermeneutic” is also relevant here where the researcher tries to make sense of the participant making sense of their experiences. There is no clear way out of this circle and this is acknowledged in IPA.

The researcher conducted the analyses in this study such that bias was limited and accuracy was heightened. However, the resulting conclusions were discussed with the supervisory team. The sub-themes and the themes in this study were arrived at on the basis of the investigator’s critical review together with mutual reflection.

Dependability

Dependability corresponds to reliability in quantitative research (Bryant and Christopher, 1985). Reliability generally refers to the degree to which the methods and findings of a study can be replicated under identical conditions by a different researcher. However,
reliability is difficult to ensure in IPA research due to its theoretical underpinnings such as intentionality and noema-noesis correlation. This is because the essence of an individual’s lived experience cannot be captured completely as interpretations and reinterpretations not only evolve but change (Langdrige, 2008). More so since the researcher’s developing and unique horizons, relationship with the people who took part in the study, together with his attributes and limitations, could not be included or described with precision. So the choice to apply IPA might limit the achievement or the use of dependability. However, even if dependability does not arise in IPA, there are methodological criteria that could serve as the equivalent to positivist reliability. In this study, the researcher was transparent by showing some of his ‘workings out’, to borrow a metaphor from mathematics, (see for example, Chapter 2, Table 3.2). Furthermore, the researcher was transparent with the readers about the time, manner, place and context of the study. These areas about the study are provided with sufficient contextual detail (for example, in Chapter 4: Section on the socio-demographic characteristics of the participants) that even if they could not replicate the study themselves (because the researcher’s/readers interpretations are unique), the readers have enough information about the processes and context of data collection to judge in what ways these might have affected the production of accounts from the respondents. Unless such interpretations are communicated and shared, there is no possibility of any notion of a collective body of knowledge. This provision of transparency of detail of processes and context is sometimes called providing an audit trail.

The researcher, in line with ethical requirements, prioritized the safety of each person, respected the participants’ reported experiences, and was also reflective, empathetic, sensitive and compassionate in order to gain confidential access to, and understanding of, the testimonies provided. These skills mentioned have been developed in the researcher over many years in his psychiatric practice and cannot be easily described for the purpose of dependability.

Transferability
This is a concept similar to applicability in the positivist tradition (Flick, 2009). The extent of similarity between contexts is taken as a measure of the transferability of the findings of a study. Hence the original context of the findings must be provided so that the judgment of applicability can be made for those persons with SCD and depression who did not take part in the study. In other words, this concept of transferability could be thought of as the equivalent of the positivist external validity or generalizability. Hence there would arise such pertinent question as: can the findings of a small group of people with SCD and depression (i.e. social discrimination contributes to poor mental health of this small group) be transferred to others incomparable social situations? And perhaps more importantly is the question: can social support through groups (group solidarity leading to challenging negative labels, identifying social sources of problems and beginning to form a group identity to challenge such discriminatory circumstances) be transferred to others with SCD and depression? The context of the findings is provided in this study (audit trail, as discussed above) so that the judgment of applicability can be made by the readers for persons with SCD and depression in comparable social situations.

This concept of transferability presents a number of challenges in this thesis. First the ethical requirements to omit the type of information that make transferability obvious such as locations and placement addresses. Inclusion of this information is seen as an unequivocal risk to anonymity such that participants could be recognized in their own community with consequent experience of ostracism and social alienation. In this study however, the clinic and the city where the respondents were drawn from were presented. This consideration is allowed to keep the criterion of transferability undiluted because it is not the name of the clinic, or hiding that name, that matters. It is that the reader is provided with a vivid picture of the circumstances of the research. The experiences portrayed in this thesis should not be regarded as absolute. However, this does not mean that the judgments or conclusions presented lack credibility. Instead, the interpretations should be considered as initial part of an enriching debate that should be developed and expanded in line with Husserl’s (1999) advice. The findings, in other words, are presented to open up issues for
the first time and provide the opportunity to develop a position that is able to bring about equality and social inclusion.

For the third stage, qualitative data was analysed using IPA processes as discussed above but modified not only by Blumer and Goffman but also by disability rights authors such as Oliver (1992) which was reflected in questions asked in the focus groups. The analyses of the FGDs followed a sequential process, and were verifiable. In being systematic, the audio-recordings were transcribed for each FGD. It is important to note that earlier FGD transcripts were read before the next FGD for the purposes of covering areas that were not covered previously. At the end of the FGDs for both groups, the transcripts were arranged in sequence in which the FGDs were conducted. There was individual analysis of each FGD before group cross-analysis was conducted.

For the individual analysis, the questions for each of the focus groups were listed and the researcher checked that they were answered or that the answers/comments were of different types. The comments were read to check if they were of importance about the research objectives and/or whether or not they reinforced what had been said earlier by other respondents. Comments that were alike were grouped together. Weights or emphases were given to comments depending on frequency, reinforcements by others, specificity to research objectives and emotional components. This process was similar carried out across the transcripts of the two groups.

The analytic framework consisted of looking for key concepts as well as critical incidents apart from the use of constant comparison. In looking for the key concepts, the objective of the analysis was to identify concepts that were of central importance. This allowed the researcher to develop understanding of how the respondents view about social relations that could change among other objectives. The researcher was able to identify a number of important similar ideas, experiences and preferences among the group. In looking for critical incidents, the objective of the analysis was to discover important events that shaped the orientation of the respondents’ actions later in the FGDs. The researcher was able to identify vital ingredients necessary to create the window of opportunity to initiate social
change for better quality of life for persons with SCD. This was useful in applying the principles of social model of disability to the community of persons living with SCD. In making use of constant comparison, the objective of the analysis was to identify regular occurrences of social patterns in the data and discover possible relationships between concepts of Social Model of Disability and comments by respondents. The research compared segments of the data with others to identify similarities and differences. The data that were grouped together had similar dimensions. Each dimension was given a name and became a category or sub-theme. The sub-themes are arranged in a relationship to one another such that a specific theme developed. In summary, to some extent, the analysis of themes of the FGs followed broadly similar principles to the IPA, but the differences were the particular types of themes that arose following the influence of Oliver and the social model of disability.

**Conclusion**

In this chapter the author has considered issues of method and methodology in researching people with SCD and depression. It has been explained that the data collected has been in three parts: a questionnaire helping to identify those who are moderately depressed; in-depth semi-structured interview with 15 people with SCD living with moderate depression and a series of three focus groups with five in each group. The data collection has mirrored the distinction drawn by Kleinman (1988) between a disease (depression as measured by a mental health scale); an illness experience (as articulated by 15 interviewees, using the combined phenomenological analytical approaches of IPA, and of Blumer, Goffman, Link and Phelan as appropriate to understanding the life world of those living with both SCD and depression) and a societal sickness (as articulated by six focus group discussions, using the combined analytical approaches of Blumer and Goffman inclusive of Link and Phelan, together with Oliver’s social model of disability (as appropriate to understanding disabling social relations and what could change in the life world of those living with both SCD and depression). The latter notion of sickness allowed the researcher to consider a more active intervention through focus groups, enabling sharing of experiences, challenging of negative labels and identifying structural challenges to the advancement of the collective cause of
those living with SCD. This reflects a view of research ethics that goes beyond the formal processes that have been documented in this chapter, to an ongoing ethics in which the researcher stays with the issues raised by the groups and offers some sense of reciprocity to those participating in the research. The evidence of distress and the possibilities for change are considered in the subsequent chapters 5 and 6, which look at the experiences of those living with SCD and depression. Before that a short chapter 4 reports on the initial questionnaire using the mental health scale.
CHAPTER 4: FINDINGS 1 – RESULTS OF QUANTITATIVE DATA

Introduction:

The previous chapter described the processes that were used to identify a sample of people living with SCD who are depressed on a validated psychiatric scale, to explore the life-world experiences of these persons living with SCD with a view to identifying social structures that are associated with their depression and to possibly empower these persons as a group to consider changing these aspects of the social structures in a way that could improve their quality of life. This chapter presents the findings from the quantitative data. The socio-demographic characteristics of all the participants in the study are presented. The rates of different categories of depression among these participants are presented with descriptions of other illness related variables. A comparison of socio-demographic variables was carried out between participants that were depressed and those who were not to highlight possible variables associated with depression among persons with SCD.

Socio-demographic characteristics of the participants:
One hundred and three questionnaires were administered to outpatients who were living with SCD at the SCD clinic at LASUTH. None of the approached persons declined to be recruited. The socio-demographic characteristics of the participants are shown in Tables 4.1a to 4.1d. The average age of the participants was 25.3 (± 7.7) years. A higher
proportion of the participants (73.8%) were from monogamous families. The majority (61.2%) were females. Ninety (87.4%) were from Yoruba ethnic group. Sixty five (63.1%) were Christians, 36 (35.0%) were Muslims and two (1.9%) were members of Eckankar. The highest proportion (89.3%) had Yoruba as their first language, while 102 (99.0%) had English as their second language. The majority (55.3%) were students. The students’ mean age was 20.4 (± 3.5) years. Seventeen participants (16.5%) had vocational jobs and 12 (11.7%) were petty traders.

Fifty five (53.4%) lived with both parents, 18 (17.5%) lived with only mother, 9 (8.7%) lived alone, 4 (3.9%) lived with their spouse, and 4 (3.9%) lived with their grandparent. Fifty six of them (54.4%) had at least secondary level of education. A higher proportion of their parents had at least secondary level of education and majority of the parents were petty traders. The median number of siblings was 4 with a mode of 3. The range was 0 to 15. They had few half-siblings, a range of 0 to 3.

The household income per month of the participants ranged between 5000 and 400,000 naira with a median of 30,000 naira (At the time of the research one British pound sterling was equivalent to 250 naira). Personal income per month ranged from 0 to 150,000 naira with a median of 3,000 naira and mode of 15,000 naira. For those who are students, the median personal income was 5,000 naira with a range of 3,000 to 30,000 naira. It should be noted that the minimum wage in Nigeria is 11,000 naira per month.

For the whole cohort, the median money spent on SCD medications per month was 3,000 with a range 0 to 30,000. The majority of participants spent at least 1,500 naira per month. For those who are students, the median amount spent on SCD medications per month was 2,500 naira with most students spending 1,500 naira per month. Thus it is worth noting that people with SCD are spending between 20 and 50% of their income on treatment for their SCD, an important contextual consideration when assessing the personal experiences of people living with SCD as will be carried out in Chapter 5.
Table 4.1a: Socio-demographic variables of all respondents

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
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</tr>
<tr>
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<td>Female</td>
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<td>Total</td>
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<td>100</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
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<td></td>
</tr>
<tr>
<td>Yoruba</td>
<td>90</td>
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</tr>
<tr>
<td>Ibo</td>
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<td>1.0</td>
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<tr>
<td>Hausa</td>
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<td>1.9</td>
</tr>
<tr>
<td>Urhobo</td>
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<td>1.0</td>
</tr>
<tr>
<td>Ibira</td>
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<tr>
<td>Eshan</td>
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<td>100</td>
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<tr>
<td>Eckankar</td>
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</tr>
<tr>
<td>Total</td>
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<td>100</td>
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<tr>
<td>English</td>
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<td>89.3</td>
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<tr>
<td>Edo</td>
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<td>1.9</td>
</tr>
<tr>
<td>Urhobo</td>
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<td>Ibira</td>
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<td>1.0</td>
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Table 4.1b: Socio-demographic variables of all respondents

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<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
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<td><strong>Level of Education</strong></td>
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<td></td>
<td></td>
</tr>
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<td>Mother</td>
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<td></td>
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<tr>
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<td>Primary</td>
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<td>12.6</td>
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<td>Tertiary</td>
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<td><strong>Who do you live with</strong></td>
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<td>53.4</td>
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<tr>
<td>Mother only</td>
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<td>17.5</td>
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<tr>
<td>Father only</td>
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<tr>
<td>Spouse</td>
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<td>3.9</td>
</tr>
<tr>
<td>Uncle/Aunt</td>
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<td>4.9</td>
</tr>
<tr>
<td>Sibling</td>
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<td>4.9</td>
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<tr>
<td>Grandparent</td>
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<td>3.9</td>
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<tr>
<td>On my own</td>
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<td>8.7</td>
</tr>
<tr>
<td><strong>Type of SCD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SS</td>
<td>101</td>
<td>98.1</td>
</tr>
<tr>
<td>SC</td>
<td>2</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>Leg Ulcer (lifetime)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>22</td>
<td>21.4</td>
</tr>
<tr>
<td>No</td>
<td>81</td>
<td>78.6</td>
</tr>
<tr>
<td><strong>Blood transfusion (lifetime)</strong></td>
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</tr>
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<td>Yes</td>
<td>66</td>
<td>64.1</td>
</tr>
<tr>
<td>No</td>
<td>37</td>
<td>35.9</td>
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<tr>
<td><strong>Family History Of Mental Illness</strong></td>
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<td>4.9</td>
</tr>
<tr>
<td>No</td>
<td>98</td>
<td>95.1</td>
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Table 4.1c: Socio-demographic variables of all respondents

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td><strong>Father</strong></td>
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<tr>
<td>Vocational</td>
<td>14</td>
<td>13.6</td>
</tr>
<tr>
<td>Petty trading</td>
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<td>43.7</td>
</tr>
<tr>
<td>Administration</td>
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<td>7.8</td>
</tr>
<tr>
<td>Teaching</td>
<td>5</td>
<td>4.9</td>
</tr>
<tr>
<td>Clergy</td>
<td>4</td>
<td>3.9</td>
</tr>
<tr>
<td>Armed Forces</td>
<td>7</td>
<td>6.8</td>
</tr>
<tr>
<td>Banking</td>
<td>4</td>
<td>3.9</td>
</tr>
<tr>
<td>Accountant</td>
<td>3</td>
<td>2.9</td>
</tr>
<tr>
<td>Engineering</td>
<td>11</td>
<td>10.7</td>
</tr>
<tr>
<td>Retired</td>
<td>2</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>Mother</strong></td>
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<td></td>
</tr>
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<td>Vocational</td>
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<td>2.9</td>
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<tr>
<td>Petty trading</td>
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<td>72.8</td>
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<td>Administration</td>
<td>7</td>
<td>6.8</td>
</tr>
<tr>
<td>Teaching</td>
<td>8</td>
<td>7.8</td>
</tr>
<tr>
<td>Nurse</td>
<td>5</td>
<td>4.9</td>
</tr>
<tr>
<td>Doctor</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Clergy</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Armed forces</td>
<td>2</td>
<td>1.9</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Patient</strong></td>
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<td></td>
</tr>
<tr>
<td>Vocational</td>
<td>17</td>
<td>16.5</td>
</tr>
<tr>
<td>Student</td>
<td>57</td>
<td>55.3</td>
</tr>
<tr>
<td>Petty trading</td>
<td>12</td>
<td>11.7</td>
</tr>
<tr>
<td>Administration</td>
<td>4</td>
<td>3.9</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
<td>1.9</td>
</tr>
<tr>
<td>Teaching</td>
<td>5</td>
<td>4.9</td>
</tr>
<tr>
<td>Accountant</td>
<td>4</td>
<td>3.9</td>
</tr>
<tr>
<td>Nurse</td>
<td>2</td>
<td>1.9</td>
</tr>
</tbody>
</table>

**Illness related variables:**

This is shown in Table 4.1d. One hundred and one (98.1%) had sickle cell anaemia (HbSS) and 2 (1.9%) had haemoglobin SC disease (the HbSC genotype). As leg ulcers are a physical symptom associated with more severe experiences of SCD, and receipt of blood
transfusion is a service utilization indicator of more severe forms of SCD, these two characteristics were included in the questionnaire. Twenty two (21.4%) reported that they had leg ulcers before or at the time of the study. Sixty six (64.1%) said that they had received blood transfusion in their lifetime. Five (4.9%) of the participants reported a family history of mental illness.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (S.D)</th>
<th>mode</th>
<th>Minimum</th>
<th>Maximum</th>
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<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (n=103)</td>
<td>25.3 (7.7)</td>
<td>16</td>
<td>16</td>
<td>50</td>
</tr>
<tr>
<td>Students (n=57)</td>
<td>20.4 (3.5)</td>
<td>16</td>
<td>16</td>
<td>28</td>
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<tr>
<td><strong>Household income (n=32)</strong></td>
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<td></td>
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<tr>
<td>Total (n=80)</td>
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<td>15,000</td>
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<td>150,000</td>
</tr>
<tr>
<td>Students (n=43)</td>
<td>5,000</td>
<td>3,000</td>
<td>0</td>
<td>30,000</td>
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<tr>
<td><strong>Money spent on SCD medications</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (n=103)</td>
<td>3,000</td>
<td>1,500</td>
<td>0</td>
<td>30,000</td>
</tr>
<tr>
<td>Students (n=57)</td>
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<td>1,500</td>
<td>500</td>
<td>30,000</td>
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<tr>
<td><strong>Number of days off work or school Per month due to SCD (median)</strong></td>
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<tr>
<td>Total cohort (n=103)</td>
<td>7</td>
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<td>Students</td>
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<td>120</td>
</tr>
<tr>
<td><strong>Age at diagnosis of SCD (median) year</strong></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Total (n=102)</td>
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<td>1</td>
<td>0.3</td>
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<tr>
<td>Students (n=56)</td>
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<td>0.3</td>
<td>22</td>
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<tr>
<td><strong>Number of days with pains per week</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (n=103)</td>
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<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Students (n=57)</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td><strong>Number of Hospital admissions due to SCD in last 12 months</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (n=103)</td>
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<td>0</td>
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<tr>
<td>Student</td>
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<td>3</td>
</tr>
<tr>
<td><strong>Siblings (median)</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
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<td>3</td>
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<td>15</td>
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<td>Brothers</td>
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<td>7</td>
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<tr>
<td>Sisters</td>
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<td>0</td>
<td>5</td>
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<tr>
<td>Half-siblings</td>
<td>0</td>
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<td>0</td>
<td>3</td>
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</tbody>
</table>

The median age when diagnosis of SCD was made was 5 years for the whole cohort. Some participants were diagnosed at a year while some had the diagnosis at 26 years of age. For
the student population, the median age at SCD diagnosis was 5 years. Among these students, some had the SCD diagnosis made at about a year old while some had it at 22 years of age.

The participants, including the subset of students, reported having pains at the median of one day a week. The range was 0 to 7 days per week. The median number of reported admissions due to SCD in the past 12 months was one with a range of 0 to 3, including the student sub-group. In the past 12 months, while the whole cohort median number was 7 days per month off work/school, with a range of 0 to 365 days, the students had a median number of 5 days per month off school with a range of 0 to 1 school year.

Prevalence of Depression:
This is shown in Table 4.2. The average PHQ-9 score was 4.29 (± 4.16) with a range of 0 to 15. Twenty nine (28.2%) of the participants did not have depression while 74 (71.8%) had one form or the other of depression according to the scoring of the PHQ-9. Twenty three (22.3%) had minimal depression, 42 (40.8%) had mild depression, 7 (6.8%) had moderate depression and 2 (1.9%) had moderately severe depression. Those who had moderately severe depression were offered referrals to the mental health services of LASUTH for support. They both took up the offer of support. The 72 respondents with recorded depression as mild (23) moderate (42) or moderate severe (7) were considered eligible for inclusion in the subsequent interviews. As described in Chapter 3, above, fifteen of these 72 were selected for interview based on generating a sample with as much diversity as possible in terms of gender, ethnicity and socio-economic status, and these 15 comprised the sample for the interview and subsequent stages of the research.

Table 4.2: Frequency Distribution of persons with SCD with depression as measured by PHQ-9

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>23</td>
<td>22.3</td>
</tr>
<tr>
<td>Moderate</td>
<td>42</td>
<td>40.8</td>
</tr>
<tr>
<td>Moderate Severe</td>
<td>07</td>
<td>6.8</td>
</tr>
<tr>
<td>Severe</td>
<td>02</td>
<td>1.9</td>
</tr>
<tr>
<td>Normal</td>
<td>29</td>
<td>28.2</td>
</tr>
<tr>
<td>Total</td>
<td>103</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Comparison of those with SCD who are depressed with those with SCD who are not depressed according to PHQ-9 on socio-demographic dimensions:

This is shown in Table 4.3. Persons with SCD are dichotomized into depressed (score ≥ 5 on PHQ-9) and not depressed (score < 5 PHQ-9) and are then compared on the socio-demographic variables in order to explore factors that might be associated with SCD and depression. There were no significant differences on many of the variables except:

1. Age, where those depressed are significantly older than those who are not depressed (F = 0.322; df = 80; p = 0.014).
2. Number of hospital admissions in the last year, where those that are depressed had significantly more hospital admissions than those that are not depressed (F = 7.967; df = 80; p = 0.007)
3. Lifetime experience of leg ulcers, where those who are depressed had significantly more lifetime experience of leg ulcers compared to those who are not depressed ($\chi^2$ = 3.900; df = 1; p = 0.031)

From the bivariate analysis above, it seems that the older a person with SCD is, the more disrupted the life trajectory of a person with SCD is, such as number of hospital admissions, or the more visible the stigmata of SCD is, such as having leg ulcers, the more likely a person living with SCD would be to suffer depressive symptoms or depression. This “truth” as revealed from the biomedical perspective is not the whole “truth” given the limitations of biomedical science (positivism). It might be assumed from these findings that social factors do not have a role, given that gender, ethnicity, religion, family type and family history of mental illness did not show significant associations with persons with SCD who are depressed. It could be argued however that associations (or lack of associations) between broad social categories (such a family type or religion) and depression might miss the point because, even if they were associated, this still would not reveal specifically what it is about religion/ethnicity/family type that is creating a pathway to depression.

In other words, it should be noted that association is not causation. For example, having leg ulcers might “get someone down” and lead to moderate depression or, alternatively, being
depressed might mean less self-care leading to leg ulcers, or a third factor (i.e. relative poverty) might lead both to poorer self-care because they cannot afford treatment and to more depression. In addition, even if these associations could be shown to be both causal, and be shown to be causal in the direction of causing depression, this would not be surprising since both pain (leg ulcers) and hospitalization are known to be associated with depression. An inclusive view highlights that it is not so much that a biomedical perspective is untrue; so much as it is limited in what it can tell us, and perhaps just as importantly it does not necessarily tell us where the possible points of intervention in people’s lives are that might make a socially significant difference.
Table 4.3: Comparison of those with SCD who are depressed with those with SCD who are not depressed according to PHQ-9 on socio-demographic dimensions

<table>
<thead>
<tr>
<th></th>
<th>Not Depressed</th>
<th>Depressed</th>
<th>Value</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>21.93 ± 7.86</td>
<td>26.44 ± 7.63</td>
<td>0.322</td>
<td>80</td>
<td>0.014</td>
</tr>
<tr>
<td>Number of hospital Admissions</td>
<td>0.25 ± 0.52</td>
<td>0.74 ± 0.85</td>
<td>7.967</td>
<td>80</td>
<td>0.007</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>16 (25.4)</td>
<td>47 (74.6)</td>
<td>0.610</td>
<td>1</td>
<td>0.435</td>
</tr>
<tr>
<td>Male</td>
<td>13 (32.5)</td>
<td>27 (67.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yoruba</td>
<td>23 (25.8)</td>
<td>66 (57.1)</td>
<td>1.713</td>
<td>1</td>
<td>0.188</td>
</tr>
<tr>
<td>Others</td>
<td>6 (28.2)</td>
<td>74 (71.8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Type</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monogamous</td>
<td>21 (27.6)</td>
<td>55 (72.4)</td>
<td>0.039</td>
<td>1</td>
<td>0.843</td>
</tr>
<tr>
<td>Polygamous</td>
<td>8 (29.6)</td>
<td>19 (70.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christianity</td>
<td>20 (30.8)</td>
<td>45 (69.2)</td>
<td>1.318</td>
<td>2</td>
<td>0.517</td>
</tr>
<tr>
<td>Islam</td>
<td>8 (27.2)</td>
<td>28 (77.8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eckankar</td>
<td>1 (50)</td>
<td>1 (50)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father’s Level Of education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>2 (16.7)</td>
<td>10 (83.3)</td>
<td>0.000</td>
<td>1</td>
<td>0.995*</td>
</tr>
<tr>
<td>Primary</td>
<td>5 (38.5)</td>
<td>8 (61.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>11 (32.4)</td>
<td>23 (67.6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>11 (25.0)</td>
<td>33 (75.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother’s Level Of education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>2 (26.1)</td>
<td>17 (73.9)</td>
<td>0.020</td>
<td>1</td>
<td>0.886*</td>
</tr>
<tr>
<td>Primary</td>
<td>3 (23.1)</td>
<td>10 (76.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>15 (36.6)</td>
<td>26 (63.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>5 (19.2)</td>
<td>21 (80.8)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Leg Ulcer</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2 (9.1)</td>
<td>20 (90.9)</td>
<td>3.900</td>
<td>0.031**</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>27 (33.3)</td>
<td>54 (66.7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood transfusion</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>15 (22.7)</td>
<td>51 (77.3)</td>
<td>2.676</td>
<td>1</td>
<td>0.102</td>
</tr>
<tr>
<td>No</td>
<td>14 (37.8)</td>
<td>23 (62.2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family history of Mental Illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1 (20.0)</td>
<td>4 (80.0)</td>
<td>0.000</td>
<td>1</td>
<td>1.000***</td>
</tr>
<tr>
<td>No</td>
<td>28 (28.6)</td>
<td>70 (71.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Linear by Linear Association test; ** Fisher’s Exact test; ***Continuity Correction test

Mother’s occupation Likelihood Ratio test 10.141 df 8 p 0.255; Pearson’s Chi test 9.967 df 8 p 0.267; Father’s occupation Likelihood Ratio test 10.504 df 9 p 0.311; Pearson’s Chi test 7.963 df 9 p 0.538.
Thus far the analysis has followed traditional medical lines in assuming a material reality to depression and producing results in terms of association of measurable variables. However, we need to address the very validity of the concept of depression. At the very least we need to consider if the concept of “depression”, identified and developed under the auspices of western psychiatry, can be legitimately transferred as a concept to other cultures, including in our instance, to early 21st century urban Nigeria.

Hence, the limitation of depression as a Western concept needs to be highlighted against the backdrop of its usage in this stage of the study. The dilemma of “Western depression” and its use in other cultures reflects problems with the reliance of mental health research on (1) identification of symptom clusters that show underlying disease located in person(s) (with no consideration of wider and integral social contributions) and (2) potentially different idioms for expressing mental distress in different cultures (Iley and Nazroo, 2001). Kleinman (1987) described this problematic reliance as a ‘category fallacy’. He argued that the use of research in a Western culture of a category of illness and its application in another culture may fail to identify many to whom it can apply because this category lacks coherence in the other culture. Moreover, the idioms of distress in the non-Western researched group could be different from those used in the Western research tool.

In other words, the use of Western depression in Nigerian culture could possibly have its disadvantages. Reference to the work of Jadhav (1996) becomes relevant here. Jadhav (1996) has described the historical and regional development of ‘Western depression’ which led him to suggest that this apparently universal disorder could be culturally specific. However, there has been limited empirical research to generate robust data to support this position. It is important to note however that some authors (i.e. Fenton and Sadiq-Sangster, 1996) have reported that some idioms of distress in non-Western culture correlated strongly with most of the standard Western symptoms of depression. This suggests, contrary to Jadhav (1996), that there is a considerable overlap between expressions of distress in different cultures such that notions of depression remain useful in describing a constellation of distressed states.
However, and in contrast, Fenton and Sadiq-Sangster (1996) also highlight the absence of some standard Western symptoms of depression from non-Western cluster of idioms of distress. The impact of this argument is possibly that the form that a disease takes in one culture will be different from another culture, and that depression might be fundamentally different from illnesses in other cultures. Having said this, it has been noted in this study that the all participants shared similar idioms of distress in the form of sadness while a majority (eleven out of the 15 participants) expressed or hinted at suicidal thoughts/attempt. This cluster of symptoms has been reported to correlate strongly with symptom profile of ‘Western depression’ in a non-Western culture of South Asians (Fenton and Sadiq-Sangster, 1996) and it is with this in mind that it is argued that depression is used as a legitimately relevant concept with some validity in this thesis.

In conclusion, this chapter has presented the findings from the quantitative data. These findings include the socio-demographic characteristics of all the participants in the study, rates of different categories of depression among these participants, together with a description of other illness related variables and a comparison of socio-demographic variables that highlighted possible variables associated with depression among persons with SCD. A critique of the use of depression as a Western concept in a non-Western culture with highlights on its relevance in Nigeria ended this chapter. The next chapter presents the lived experiences of 15 persons with SCD and depression in Nigeria who took part in-depth interviews. In contrast with the disease perspective captured in this chapter, the next one describes the illness experience of these persons with a view to understanding how social interactions could underlie problems faced by persons with SCD and depression in Nigeria.
CHAPTER 5: FINDINGS 2 – RESULTS OF IN-DEPTH INTERVIEWS

Introduction:
The previous chapter presented the socio-demographic characteristics of all the participants in the study, the ostensible rates of depression among them as assessed using standardized scales, and significant correlates of depression among these persons with SCD. While this perspective is important, it does not capture possible points of impact on the lives of persons with SCD, that is, what Kleinman (1988) calls their illness experience, and without an understanding of such illness experience, it can be argued that it would be difficult for interventions to make a socially significant difference. This present chapter describes the findings generated from the in-depth interviews with 15 persons who live with depression and sickle cell disease in Lagos State.

The Study Sample: Socio-demographic characteristics of respondents

A total of fifteen persons with sickle cell disease were interviewed individually. These participants in the in-depth interview represents about 15 percent of those who had
consented to have questionnaires administered to them, and constitute about 20 percent of the seventy four persons with sickle cell identified with PHQ-9 as having some level of depression. A heterogeneous sample of respondents was generated based upon sampling for diversity. There were varieties of respondents in terms of age, ethnicity, religious, cultural and socioeconomic backgrounds (Table 5.1). Women and people of Yoruba ethnicity were overrepresented in the individual interviews. Eleven of the participants were single, one was a widow, two were married, and one was divorced. Nine of the participants were living with their parents, one lived with his sibling, two with extended family having become orphans, two lived with their nuclear families and one lived alone. Nine of the respondents are from monogamous setting while six are from a polygamous setting. Among the participants one was currently unemployed, while ten were underemployed. Three were students, and one was an apprentice. The sample has many advantages due to the heterogeneity of the group; however, the sample did not have a balanced representation of gender, ethnicity and religion. However, the researcher acknowledged the biases that the sampling strategy might introduce into this study. This may mean that the emerging themes might not fully reflect the experiences of male participants, participants from other religions or ethnicity. Nonetheless, it seems that the approach used in this study is one of the best options to generate adequate and diversely rich sample of participants in order to gain broad and penetrating first hand insights into the possible social origins of depression and stigma in those living with SCD in Lagos, Nigeria.
<table>
<thead>
<tr>
<th>Fictitious Names</th>
<th>Age</th>
<th>SCD Type</th>
<th>Sex</th>
<th>Ethnicity</th>
<th>Marital status</th>
<th>Education</th>
<th>Domestic circumstances</th>
<th>Employment</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aderonke</td>
<td>43</td>
<td>SS</td>
<td>Female</td>
<td>Yoruba</td>
<td>Widow</td>
<td>Tertiary</td>
<td>Widow w children</td>
<td>Unemployed</td>
<td>Christianity</td>
</tr>
<tr>
<td>Babalola</td>
<td>22</td>
<td>SS</td>
<td>Male</td>
<td>Yoruba</td>
<td>Single</td>
<td>Secondary</td>
<td>Polygamous home</td>
<td>Artisan</td>
<td>Islam</td>
</tr>
<tr>
<td>Comfort</td>
<td>42</td>
<td>SS</td>
<td>Female</td>
<td>Yoruba</td>
<td>Single</td>
<td>Tertiary</td>
<td>Lives alone</td>
<td>Secretary</td>
<td>Christian</td>
</tr>
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<td>Damilola</td>
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<td>Female</td>
<td>Yoruba</td>
<td>Married</td>
<td>Tertiary</td>
<td>Pregnant</td>
<td>Seamstress</td>
<td>Christianity</td>
</tr>
<tr>
<td>Eniola</td>
<td>23</td>
<td>SS</td>
<td>Female</td>
<td>Yoruba</td>
<td>Single</td>
<td>Secondary</td>
<td>Single mother</td>
<td>Student</td>
<td>Christianity</td>
</tr>
<tr>
<td>Funke</td>
<td>32</td>
<td>SS</td>
<td>Female</td>
<td>Yoruba</td>
<td>Single</td>
<td>Tertiary</td>
<td>Polygamous</td>
<td>Teaching</td>
<td>Christianity</td>
</tr>
<tr>
<td>Gbenga</td>
<td>21</td>
<td>SS</td>
<td>Male</td>
<td>Yoruba</td>
<td>Single</td>
<td>Tertiary</td>
<td>Polygamous</td>
<td>Student</td>
<td>Christianity</td>
</tr>
<tr>
<td>Hannah</td>
<td>27</td>
<td>SS</td>
<td>Female</td>
<td>Yoruba</td>
<td>Divorced</td>
<td>Secondary</td>
<td>Father died</td>
<td>Trading</td>
<td>Christianity</td>
</tr>
<tr>
<td>Ifeoluwa</td>
<td>23</td>
<td>SS</td>
<td>Female</td>
<td>Edo</td>
<td>Single</td>
<td>Secondary</td>
<td>Living with auntie</td>
<td>Student</td>
<td>Christianity</td>
</tr>
<tr>
<td>Joke</td>
<td>39</td>
<td>SS</td>
<td>Female</td>
<td>Yoruba</td>
<td>Single</td>
<td>Secondary</td>
<td>Father dead</td>
<td>Catering</td>
<td>Christianity</td>
</tr>
<tr>
<td>Ope</td>
<td>24</td>
<td>SS</td>
<td>Male</td>
<td>Yoruba</td>
<td>Single</td>
<td>Secondary</td>
<td>Living with parents</td>
<td>Signage</td>
<td>Christianity</td>
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<td>Bolaji</td>
<td>25</td>
<td>SS</td>
<td>Male</td>
<td>Yoruba</td>
<td>Single</td>
<td>Tertiary</td>
<td>A National Youth Service Corps member</td>
<td>Accountant</td>
<td>Islam</td>
</tr>
<tr>
<td>Niniola</td>
<td>25</td>
<td>SS</td>
<td>Female</td>
<td>Yoruba</td>
<td>Single</td>
<td>Tertiary</td>
<td>Monogamous</td>
<td>CHEW</td>
<td>Eckankar</td>
</tr>
<tr>
<td>Adekola</td>
<td>28</td>
<td>SS</td>
<td>Male</td>
<td>Yoruba</td>
<td>Single</td>
<td>Secondary</td>
<td>Orphan</td>
<td>Tailor apprentice</td>
<td>Islam</td>
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<td>Odekunle</td>
<td>50</td>
<td>SS</td>
<td>Male</td>
<td>Yoruba</td>
<td>Married</td>
<td>Tertiary</td>
<td>Monogamous</td>
<td>Journalist</td>
<td>Christianity</td>
</tr>
</tbody>
</table>

*Note that all names are pseudonyms*
‘Pen-portrait’ of the Fifteen Respondents

Aderonke is a 43 year old female of with two children, a male that is 17 years old and a female that is 12 years old. She is a widow. She is Yoruba from a monogamous family with two siblings, an orthodox Christian of Methodist tradition, and a graduate of Economics from University of Lagos. She is unemployed till recently when she started to trade in water sachets and provisions. She lives with her parents in their accommodation in the city. She has nieces and nephews who have sickle cell disease. She was interviewed in Medical Research Council building of LASUTH.

Babalola is a male who is 22 years of age. He is a twin and a Muslim from a polygamous home and the only one with sickle cell disease among 10 siblings. He has been suffering from sickle cell disease for the past 10 years. His parents are both petty traders. He is a student in a tertiary institution and presently lives with one of his full siblings. He was interviewed in the sickle cell clinic, LASUTH.

Comfort is a 42 year old Christian female who is the only one with SCD in a monogamous family of four. She is from Yoruba ethnic group and is single. She is a graduate of secretarial studies and works as a secretary in a local government secretariat in the city. Her parents were both petty traders. She lives alone. She was interviewed in sickle cell clinic, LASUTH.

Damilola is a 29 year old graduate of Mass Communication from the Ogun State University. She is Yoruba and married to a Yoruba man. She is a Christian of the Redeemed Christian Church of Christ. She is into fashion design but presently off work because of pregnancy. She is 7 months pregnant. She is from a polygamous family with 15 siblings. There are 10 half-siblings. She had another female full sibling who had sickle cell disease. She lives with husband in a rented apartment in a town. She was interviewed in sickle cell clinic, LASUTH.

Eniola is a 23 year old Christian of the Yoruba ethnicity. She is a pre-degree university student. She lives with a single mother in their own house. The father divorced the mother because of her frequent illness. She is the last born and the only one with sickle cell in a family of seven siblings. She was interviewed in sickle cell clinic, LASUTH.
Funke is a 32 year old teacher in a school founded by her family. She is Yoruba and single. She is a Christian and from a polygamous home. She is only one with sickle cell in her family of 8 siblings. There are three full siblings and 5 half-siblings. She lives on with her parents. She was interviewed in sickle cell clinic, LASUTH.

Gbenga is a 21 year old student. He has been suffering from sickle cell disease for the past 12 years. His parents are both petty traders and he lives with them in a rented accommodation. He is single and the only one who has sickle cell in his polygamous family of 7 siblings. He has one sister and five half siblings. He is a Yoruba and a Christian. He was interviewed in the sickle cell clinic, LASUTH.

Hannah is a 27 year old female Christian with junior secondary school certificate. She is Yoruba and from a monogamous family. Her father died when she was 3 months old. She has 5 siblings. She is not the only one with SCD; her younger sister also has SCD. She was a petty trader but presently has no capital to continue the trade. She is separated from her husband with whom she has a son. She lives with her mother in their own house. She was interviewed in the sickle cell clinic.

Ifeoluwa is a 22 year old who completed secondary school education. She is Edo. She is an orphan and now lives with her auntie in a rented accommodation in the city. She is from a monogamous family and has one sibling. She is the first born and the only one with SCD. She is a single and a Christian. She was interviewed in the sickle cell clinic.

Joke is 39 years of age and is a caterer with secondary school education. She is Yoruba and a Christian. She is from a monogamous family of seven siblings. Two had died of complications of SCD and she is the only one alive with SCD. Her father is late and she lives with her mother in a rented apartment. She is single. She was interviewed in the sickle cell clinic.

Ope is a 24 year old male from Yoruba ethnic group. He is a Christian of the Cherubim and Seraphim denomination. He has junior secondary school education and has vocational training in signage and painting. He is from polygamous family with 3 full siblings and 3
half siblings. He is the only one with SCD. He lives with his parents in a rented accommodation in the city. He was interviewed in the sickle cell clinic.

Bolaji is a 25 year old graduate from a private university and currently engaged with National Youth Service Corps. He is the only child in a monogamous setting. He is a Muslim. He lives in a rented apartment in the city. He was interviewed in the sickle cell clinic.

Niniola is a 25 year old Community Health Extension worker. She is Yoruba. She is an Eckist and from a monogamous setting. She lives in a rented accommodation in the city with her mother who is divorced from her father. She is the only child with SCD out of 4 siblings. She was interviewed in the sickle cell clinic.

Adekola is a 28 year old male tailor apprentice who had secondary school education. He is an orphan who lives with a relation. He is single and a Christian from the Yoruba ethnic group. He is a Muslim from a polygamous family and is the only one with sickle cell among 4 siblings. He lives in a rented apartment with a relation in a city. He was interviewed in the sickle cell clinic.

Odekunle is a 50 year old sociologist who works as a journalist. He is Yoruba and a nominal Christian who prefers to be referred to as a free thinker. He is the editor of a magazine “African Sickle cell”. He is from a polygamous setting and is the only one with SCD among 30 siblings. He is married and has four children. He lives in a rented apartment in a city. He was interviewed in the sickle cell clinic.

**Themes**

The analysis generated seven themes and 18 sub-themes in total. These main themes are: experiencing disapproval, experience of disbelief about pain from significant others, experience of stigma, ‘I am a different person’, thinking and talking about death, ‘we wished we were dead’, and coping with SCD. The themes and their sub-themes are presented in Table 5.2.
Table 5.2: Overview of the themes and sub-themes that emerged in this thesis

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Table 5.2 above shows the overview of the themes and the sub-themes that emerged from the interpretative phenomenological analysis of the 15 transcripts from the in-depth interviews. The discussion of the themes along with the sub-themes is given below with illustrative quotations from across the breadth of the participants.

**Theme I: Experiencing Disapproval (Judgement)**

Negative social experiences were central to many of the participants’ accounts. The participants related experiences of their behaviors being disapproved of by others in the society on different occasions, and by different members of the society such as family members, including relatives, friends, neighbours, and teachers/peers in school setting. Disapproval was experienced by ten of the fifteen participants in the context of family interactions, by thirteen of the participants in the context of friends, by nine of them within neighbourhood, by seven of them in school premises, by ten of them in hospital settings and by the whole fifteen from others in the community.

*Sub-themes*

1. *Disapproval experienced from members of Family*

The participants described negative social responses they encountered with family members including close relatives. They described disapproval in connection with household chores, sickness, outdoor activities with friends and schooling. In the family context, Damilola [29, female, graduate, Christian] recounted her experience with her mother and siblings:

“I just grew up knowing that I can’t do things that my sisters do. There is this exception for you when they are asked to do household chores. Even when I feel like I can do these things, my mum was always like don’t do it. Don’t do it. Don’t sweep, don’t bend down, and then so, and then I grew up knowing that I’m sort of like the weakest person in the house. I come from a very large household including our extended family. And everybody treats me as if I was an egg, and I could break at any point in time. I see myself as being spoilt (laughs).”

In her lived experience, she explained how she has come to accept that she is a weak person. She lived in a very large household where they treated her as someone who could
not do things. Her siblings and other relatives disapproved of her doing household chores and this was with the consent of the mother. She pointed out that they felt she could break at any point in time. Damilola further stressed in her experience of disapproval how her parents would only reluctantly allow her to go to school. She recalled being denied the opportunity to play with others, the chance to get to savour ice-cream and many other opportunities. She said:

“They [parents] manage to take care of you, but most times, they grudgingly would give you education. You know that kind of thing that you may die early and the investment in you is wasted. Things like that. You are not given chance to be yourself, you are not allowed to play, you are shut out from friends and so many other things…no ice-cream.”

Because it is feared that the coldness of ice-cream might precipitate a sickle cell crisis, the denial of ice-cream seemingly comes to encapsulate the unwarranted limitations her family imposes upon her. In describing her experience with her parents, Damilola pointed to the possibility that she broke the societal expectation of living a long life and thus they hesitated to give her the opportunity to go to school. They thought she would die early, and so if they sent her to school it would be of no benefit. In her words, ‘the investment in you is wasted’.

Niniola [25, female, Community Extension Worker, Eckist] described how her elder sister disapproved of her in when she fell sick. She recounted:

“I only had problem with my elder sister then, my elder sister most times when I fall sick, she would just get angry. She is like, “is it only you, is it only you; why is it that you are always falling sick, can’t you just take care of yourself? Are you not old enough to know what to do?”

She described how the disapproval was expressed by her sibling whenever she fell sick. The elder sister could not understand why Niniola was the only one always falling sick. She expressed her disapproval with anger and would tell Niniola that she was falling sick because she was not taking care of herself. Niniola did not meet the social norm of being able to take care of herself in order not to fall sick frequently.
Hannah [27, female, student, Christian] described how disapproval from other family members was too much to bear. She said:

“The suffering is too much…The prayer is that the child should grow up and take care of his parents. My case is not like that…my mother’s family rain abuses on me. They say I am the cause of my mum’s debt and may likely cause her untimely death. They also say I am “agbana” [Yoruba term meaning wasteful spending] that is once you have a person like me, there is no savings for you. All you have will be spent on sickness, and nothing to invest for the future. They would say she has started her rituals again, when it is time, you will get up and face reality. You don’t know other than to put your family in debt. We don’t know why your mother did not abandon you at all, they would say…when she dies (that’s me), we would tell her (my mum) now what have you achieved, nothing.”

She mentioned that the relatives from her maternal side did not approve of her behaviors. She noted that they believed she was the cause of her mother’s debt and that she was purposely falling sick to put her family into debt. They dismissed of her sickness as a ritual to impoverish the family and cause the untimely death of her mother. They found her unacceptable and wondered why her mother had not abandoned her. Feeling judged this way is too much suffering for her. Four out of the fifteen participants reported similar negative comments from their own mothers. This suggests the possibility that family members, a potentially key resource in being protected from depression, may in fact themselves be implicated in the genesis of distressed feelings. It is interesting to note that the people (mothers or fathers or relatives) who could conceivably perform the role of protecting these persons are the ones who stigmatize them. On the contrary, if there is a close confiding relationship, usually with the mother, these persons might have had a form of insulation against the risk of emotional problems such as depression.

2. Disapproval experienced from friends

The participants also shared experiences of disapproval from family friends. These experiences occurred during most interactions with friends and ranged from being called bad names such as “sunwonna (waste of money)” [Eniola, Joke, and Adekola], “abiku (die soon)” [Hannah], labelled lazy [Eniola, Hannah and Ifeoluwa] and being excluded from
playtime activities with friends [Babalola, Niniola and Gbenga]. Some friends of Eniola’s parents disapproved of Eniola [23 years, female, student, Christian]. The mother disapproved of her undertaking in household chores and this became known to others including her mother’s friends. She described how her mother’s friends would engage in discussion with her mother up to the point they disapproved of her being fit for education. She recalled:

“For me at home, my mum does not allow me to do anything. She does not allow me to cook except I just feel like cooking. She does not allow me to wash; she does not allow me to do anything. Anything! She would call the...because we have one boy that is helping us. She would just be calling that one, go and do this, go and do that. She does not allow me to do things. Now people say I am lazy, she has turned me to a lazy thing. They say I don’t want to do anything. That I don’t want to work...they say it in ways that are not kind. In fact, my mum’s close friend was advising my mum not to send me to school. She asked ‘what would she even do with her certificate?’”

Eniola was describing conscious attempts by her mother and family friends to limit her independence (i.e. some house-keeping activities such as cooking, washing, sweeping or mopping the floor, and then schooling as a possible future source of livelihood). It seems that when the mother did not allow her to engage in house-keeping, she became inactive. Her inactivity was subsequently seen by others, including the friends of her mother, as being lazy. She noted that they saw her as someone who is lazy. Being lazy is a behavior that is disapproved of. She is then considered not worthy of being sent to school. It seems Eniola has broken an expectation that a child who is actively engaged in house work is hard working and will do well in school. A child that is not hard working at home might not be hard working in school and it would probably be a waste sending such a child to school. It seems that the family acquaintances have low expectations of her capacity for housework, but this has the knock-on effect of creating a self-fulfilling prophecy in which her perceived laziness is taken as evidence of her unsuitability for schooling.

Bolaji [25, male, fresh graduate, Christian] described how he felt when his friends did not accept him but rather passed disapproving remarks on him:
“I felt so bad, I felt so bad because some of my friends usually insult me that look at this sickler, you cannot do this, you are not complete, you are too fragile, you are not mature and negative things that will make you very sad…I became very cautious in having friends. I can play but I do not tolerate when you abuse me that I have sickle cell, or when you will not play with me because I have sickle cell. I will not be your friends any longer. My parents have been so good to me. But when I remember how my friends dealt with me I feel so bad. I felt so bad then. Friends are supposed to support, they are supposed to help and make life easier for you but they did not. What comes out of their mouth is so terrible. I felt so bad”.

Bolaji recalled the feelings of sadness when he had encounters with his friends. He further noted how these encounters have made him cautious in making friends. He also mentioned that he would not be friends again with someone who abused him. He equates friendship with support and things to make living easier. Feeling judged this way led him to feel both morally bad and emotionally sad. The people with SCD seem to be confronted with an invidious choice. Even their “friends” are often disapproving, meaning that people with SCD may be compelled to choose between accepting stigmatizing attitudes from others or not having any friends at all, with the possible negative consequences for lack of social support that a lack of friends would entail.

3. Disapproval experienced in the neighbourhood

Nine of the fifteen participants went through disapproval from their neighbours. These individuals shared experiences that included jest making and negative expectations from neighbours. Babalola [22, male, artisan, Muslim] described encounters with his neighbours:

“They did not treat me well. They would say terrible things about me at my back. They sometimes say look at how his belly is protruding. They make jest of my body. They laughed at me. That time my belly was really big. They would say it even to my face. They don’t care at all. I would be hearing them talk about me. That was very painful because I was forced to stay in-doors. I became afraid at times to go out and play or take fresh air. Sometimes I would hear them when I was about getting out of the door. I used to tell my parents what they say. But later I stopped because they did not stop. I would rather stay in the house. I was afraid if they saw me they would start the talk again. I usually had anxiety when it came to leaving the house.”
Babalola went through many instances of rejection by his neighbours. He recounted the terrible things they said behind him such as how his belly was protruding (a bodily sign of SCD based on an enlargement of the spleen) and how they disrespected him face-to-face by laughing at him. He experienced these disapproving acts of his neighbours as painful. Feeling judged in this manner on several occasions, he became afraid to go out, and helpless, even with his parents being there. He said that most times he would have anxiety when he had to leave the house. References to both anxiety and increased social isolation are consistent with the possibility that actions of neighbours are contributing to poorer mental health. It seems he does not have enough cultural capital necessary to negotiate acceptance in his neighbourhood such that he was relegated to the status of a poor and unwanted person in their neighbourhood. He had negative emotional experiences as a result of the discrimination and loss of status others in the neighbourhood subjected him to.

With respect to Eniola’s [23, female, student, Christian] experience of her neighbours’ disapproval, she shared that on several occasions her neighbours would call her unpleasant names, and even wondered why she was allowed to exist. She described her experience with her neighbours thus,

“Most people [neighbours] will make jest of you. Where I was living before, before my mum had to change environment because of me. Because we had to change environment because of the jest stuff all the time, they laugh at me, some people will call me names that my mum does not call me. Some people will call me Ogbanje [malevolent spirit], aje [witch], emere [malevolent spirit], witch, kininkan [something]…waste, sunwonna [burning money]. All those names on several occasions... But what will I do? When I fall sick, they would even ask my mum why she never aborted me. My mum just had to change the environment because of me.”

Eniola said her mother had to move from her away from the neighbours who looked down on her on many occasions. She described a feeling of helplessness. The repeated occurrence of negative name calling was too much for her to bear. As moving home is a life-stressor, doing so to escape the vitriolic comments of neighbours appear to be doubly stressing, both in and of themselves and in causing the family to move. Eniola is possibly seen as discredited and the neighbours’ vitriolic comments (Ogbanje, aje [a witch], Emere
[embodied spirit], and kinikan [something]) were like deafening shouts to drive her away from the neighbourhood. She becomes helpless as she sees herself as unwanted and undesired. She has to change her environment, but not in the positive disability-rights sense of changing the social environment by reducing discriminatory attitudes, but in the negative sense of her family feeling compelled to move geographic neighbourhoods to escape the discrimination.

In Hannah’s [27, female, student, Christian] case she gave an account of how her neighbours, some of whom were related to her husband, disapproved of her marriage, and of her getting pregnant. She recalled that:

“After some time, I met the person who was the father of this little boy here. I explained to him that I was a sickle cell patient and would he want to marry me. He first went away because he was afraid. He also believed he was entering into trouble. So he ran away at first. His family lived close to where I was living. His family told him it was not a good thing to marry someone with sickle cell since he would be the one to bury the person. He would bear the burden of caring for her in illness most of the times. He would spend his money on illness and not on better other things. They told him that even if he had kids from me, he would become worse for it since I would die and leave him with the care of the children. When I got pregnant and it was visible, people in my neighborhood were saying who did this to her. This is debt, this is danger, and this is bigger problem. They increased my fear of pregnancy and child birth. They killed the hope I had in me. They replaced it with fear or terror. About a week to my expected day of delivery I was so sick I nearly died. My neighbors said did we not tell her never to try that sort of thing. She wanted to kill herself. That is why. Emere, they called me. You know “emere” people die during ceremonies like weddings or around child birth when people should be happy. I am ashamed of myself. My neighbors have nothing good to say about me. They avoid me if they can. They are distant from me. They send those who are interested in me away. They abuse me with the illness. For example, if I was with a person, just hanging out, they would call out, you had better not touch her, and she could pass out just like that. Don’t allow her to carry that load, if she did now, tomorrow she might not be able to stand up and she would be in the hospital. I cannot obey the norms of society. For instance, if an elder is with luggage, you are supposed to take it away and help carry, but in my case, they would not allow me to do that. The elders would say, thank you, please don’t bother, I don’t want to be responsible for your admission or death. They say words that would send you reeling backwards in shame and that
sear through your heart. You would want to die instantly. They make me think I should die. I am not wanted around. It pains me.”

In her account, she described how her neighbours who were relatives of her husband disapproved of her being considered for marriage. She narrated how these persons tried to discourage her husband from going ahead to marry her. They expected that she would die early, and put the burden of fending for their children onto the man alone. She also described her feelings when she was pregnant in the neighbourhood. She said they killed the hope she had in herself and replaced that hope with terror and fear. She felt shame from their disapproving expressions and actions. They avoided her and kept distance from her. She said she could not act according to societal norms and help the elderly because of disparaging comments from these neighbours. She links the disparagement of other community members to her breaking of societal expectations/norms.

4. Disapproval experienced from Teachers/Peers in school setting

In the school setting, persons with SCD went through experiences of disapproval from their classmates as well as their teachers. Niniola [25, female, Community Health Extension Worker, Eckist] described her experience:

“Because I could not stand with my mates, I could not do the things they do [run, and jump]. I was really sad about that…And some even because of that decided to scold me. They made fun of me because of that. I even remember a particular boy in my school then, he is always making fun of me then. ‘You that you can’t do anything. You will break into two,’ something like that. It is like whenever he scolds me like that I really get sad. At times I just burst into tears and I will start crying.”

Niniola recalled that her classmates disapproved of her because she could not do the things they could do such as run, jump and engage in sports. They also made fun of her because of this and she had feelings of sadness. At times she would burst into tears and cry. She has linked their negative reactions to her inability to run or jump like they could. In other words, her classmates had possibly seen her as unfit and discreditible since she lacked the physicality to engage in activities of running and jumping – an assumption that had become their expectation/norm.
Funke [32, female, teacher, Christian] felt lonely when her mates in school did not want to play with her. She recalled:

“When I was in secondary school, people don’t want to make friends with me. They do not want to be playing with me because I was not strong and I fall sick frequently. So I used to be alone. So I normally felt so bad. Each time I get home, I will start crying...Even the teachers did not help. They would say try and be strong, you cannot be falling sick like that. When people are rejecting you, what is left for you outside, there is nothing to gain in the outside world. So let me stay at home and be indoors all the time. I would not want to go to school.”

Funke recounted her feelings of sadness each time her mates in school did not allow her to play with them. She said it had come to feel ‘normal’ to feel bad, and she did want to go to school because of the negative reactions of her mates. She also mentioned that the teachers did not help and she felt the rejection. She expressed hopelessness in the outside world and preference for being alone and indoors. She experienced not only emotional hurt, the isolating effects of the disapproval (which caused her to wish to stay away from school) but also the hurt at the lack of support from significant others, namely the teachers. The teachers who are expected to comport themselves as if they were the parents for the purposes of caring for and offering support to a child at school are not doing so. It seems that these persons with SCD in their lived world at school have illustrated experiences of rejection, sadness, and cries with tears following interactions with their peers and teachers.

5. Disapproval experienced in the hospital setting

Damilola [29, female, graduate, Christian] related how she experienced disapproval in the hospital. She went to the hospital with some fear that, for a woman living with SCD, becoming pregnant is like signing a death warrant and this was worsened still further by the negative attitudes and actions of the nurses. She said:

“There is this fear that pregnancy with sickle cell is like signing a death warrant. I was really scared especially when I went to the general hospital. The female nurses were not really nice, their attitude changed when I told them I am a sickle cell patient. They started telling me I should have registered early, you this lady you are joking with your life. Things are not done this way. It was like I told you before, we are weak people…”
She recalled the sarcasm in the statement: ‘you, this lady, you are joking with your life.’ The disapproval she experienced in the hospital reinforced her opinion of herself that she is a weak person, and more probably that she has signed her own death warrant by becoming pregnant. She is already scared of death and the reaction of the health workers further confirmed this. The effect of this discrimination is that she is then liable to withdraw from using formal maternity services, with the consequences that she will place her own physical and mental health at even greater risk.

6. Disapproval experienced from others in the community

All the participants shared experiences of how other people in the community expressed disapproval of them. Aderonke [43, female, Christian, trader] mentioned that persons with SCD are not given recognition. She emphasized that others in the society have been unfair to persons with SCD. She said,

“SS patients need a lot of help it’s just that people, society are not recognizing them. But in so many cases the society has not been fair to SS patients. In quote they are not fair. They don’t, they are not ready to…how do I put it…to help them. They are not ready. They are not ready to help them.”

Aderonke recounted that others in the society are not ready to help persons with SCD. Rather, they disapprove of them. Damilola [29, female, Christian, graduate] noted the manner of death that some people attributed to persons with SCD. She said:

“They tell stories of how some of them [those with SCD] die just like chicken or like cockroach”

Her shared insights illustrates how others in the community put people with SCD into a “less-than-human” category (chicken or cockroaches) and rationalize their discriminatory behaviour. Funke’s experience further illustrates how others in the society do not give persons with SCD a chance to live well and contribute to the society. She recounted:

“They don’t treat them well. They treat them as outcast or these groups are not human beings. They are not human beings. Because each time they see us, they say what is wrong with this one, go and sit down in one place or corner. Are you supposed to participate in this or that? But people forget that
among us there are some who have aspirations to be important people, some like me would also want to contribute to the welfare of the society. They want to contribute to a good cause. But people in the society do not give us a chance. We don’t exist sort of. Some SS also want to be doctors, lawyers and so on. They want to be in good professions. But the way the society treats them, such ambitions would disappear. It dampens their spirit. Like me now, when I was small, a kid, I wanted to be a nurse. But as I grew older I saw that I might not be allowed to go into nursing because of my health. They would say my health could not get me through the training and all sorts. I gave up the ambition. In fact if I went ahead I know that nobody would assist me if I needed any assistance during the training. There would not be any special treatment for me. Immediately they see that you are an SS, they would not want to attend to you, they won’t answer you. This sort of reaction from the society kills the skill and spirit in people with SS. They don’t treat SS well at all.”

Funke expressed the desire of how others like herself would want to contribute to the society. She wanted to be in a good profession, but she expressed the opinion that society did not give persons with SCD a chance, and noted how persons with SCD are non-existent in society. She then described how she gave up her ambition of becoming a nurse when others placed limitations upon her by their attitudes. She described her thoughts that if she persisted she would not have had any support, how others would not assist her in reaching her goals if they knew she had SS. Yet in Nigeria there are nurses with SCD, and indeed one of the participants in this study is herself a community health worker. This evidence highlights that it is likely that there is an element of self-fulfilling prophecy in societal expectations that people with SCD cannot undertake professional occupations.

The mechanisms through which a person with SCD might come to view him/herself in a negative way have been illustrated. Others in their lived world avoided, excluded, disliked, limited and threw insults at people with SCD. The experience of disapproval by different segments of the society led many participants to report feeling “sad” [Eniola], “bad” [Babalola], “helpless” [Hannah], “uncomfortable” [Damilola], “no chance to live and enjoy life” [Aderonke], “like dying” [Funke and Babalola], and “unwanted” [Ifeoluwa].

The significant others in the family of persons with SCD who could conceivably perform the role of protecting these persons are among the ones who stigmatize them and exposed
them to the risk of emotional problems such as depression. The family acquaintances also seem to have low expectations of persons with SCD with regards to capacity for work including housework such that this has the knock-on effect of creating a self-fulfilling prophecy in which perceived laziness is taken as evidence of unsuitability for schooling. When significant others disapprove of them, they leave them with unpleasant and difficult choice either to accept stigmatizing attitudes from others or to go without any friends at all, with the possible negative consequences for lack of social support that a lack of friends would entail. With regards to neighbours, persons with SCD could be seen as lacking social capital necessary to negotiate acceptance in the neighbourhood such that they could be isolated. For example, Eniola was probably discredited and experienced vitriolic comments that drove her away from the neighbourhood feeling helpless. The disparagements of other community members could possibly be linked to persons with SCD breaking societal expectations/norms. These persons with SCD could experience not only the isolating effects of the disapproval but also the hurt at the lack of support from significant others. There was evidence that, among persons with SCD, there were those who held professional jobs, and this highlights the risk of a self-fulfilling prophecy occurring if societal expectations that people with SCD cannot undertake professional occupations prevail.

The participants have had encounters of disapproval from significant others including parents, relatives, friends of family, their neighbours, their peers and teachers in schools, health professionals in health institutions, from leaders in religious homes and from others in the society at large. They seem to experience frequent and regular disapproval from each and different segments of their social world at various times that it could be perceived as a “chorus of disapproval”. This concept of “chorus of disapproval” will be discussed in more detail in chapter seven.

**Theme II: Experience of disbelief about pain from significant others**

Twelve of the fifteen participants related experiences where significant others, whether family, community members, or professionals, did not believe that they suffered pain. They
were ignored or frowned at for not doing what they were supposed to do such as household chores.

Sub-themes

1. Experience of disbelief about pain from family

Gbenga [21, male, student, Christian] explained how his father did not believe he was indeed sick,

“For my father, he does not understand much and sometimes, he would think I was pretending or I was just being lazy to do the work he gave me to do and I am not sick. He would then scold me. It bothered me at times, but many times I don’t bother because I have my mum and sister to back me up. They know that it is because I can’t do the work and it is not because I am lazy.”

Gbenga’s experience illustrates the importance of having someone to buttress their status or support them. This alleviates his feelings of sadness and allows him to possibly shift his focus away to more positive things. Adekola [28, male, student, Christian] showed how he experienced disapproval with one of his siblings when he narrated that:

“My brothers would say when I have crisis that I have started to pretend again, it is because I want to take things like milk, ice-cream and chicken. I take things that they would not get from our parents normally. I would cry and cry and they would not console me…I don’t want any of their friendship. I would be indoors so that when the crisis starts, I would be alone and cry and cry and nobody to wipe my tears away.”

So Adekola would cry and cry indoors because his siblings did not believe he was actually sick. They would prefer to think he was acting just to get good treatment from their parents. This lack of understanding has made him to say he did not want their friendship since he did not believe from their actions that they were supportive and friendly. When he cried they would not even console him. He bore his pains alone with no one to wipe his tears away. He seems to doubt that his siblings could support him, and he therefore would not solicit their support. He prefers to be alone and would not call for help in times of crisis. His network of support has reduced and he would probably not call for help and receive
help on time if there is a need for such intervention with subsequent negative consequences in terms of health including his mental health.

Odekunle [50, male, Christian, Journalist] recounted his shock at the disbelief exhibited by his brother when he was not feeling alright at home. He said:

“This would be around 1980; I was always having fatigue, always tired and tired, so I would lie on bed all day long I would be on bed. I didn’t go to the hospital. I had my daily chores to do at home like going to throw away the refuse, and other little things you had to do within the house. So one of my brothers said to my sister ‘look this is something that Odekunle should do but you see he has been lying down all week all day, why don’t you do it.’ You know what my own brother said, he said he is malingering. He is not ill, he is just malingering. Up till today when I think of it, it happened 1980, when I think of it, I want to shed tears. How can my brother say I didn’t want to work that I was malingering. So up till today when I see that my brother it reminds me of that incident. That simple statement: he is malingering. When your brother can talk like that what would an outsider say?”

It is interesting that even discrimination that happened a long time ago continues to resonate even decades later. The negative effects of discriminatory remarks on mood and possibly on mental health are therefore possibly long-acting. In these experiences, the participants expressed disbelief that their significant others such as hospital health care workers, and their siblings responded to their pain or sickness episodes as illegitimate. This illustrates how these persons with SCD went through crisis and the prices they paid such as social isolation, and role tension, leading to sadness. Fear of damaging relationships led some of our participants to conceal their true feelings. Odekunle [50, male, Christian, Journalist] said,

“If it is just pain that I can bear, I don’t tell her or any other person because telling her or them would give me more problems than when I keep quiet about it.”

And Hannah [27, female, Christian, divorced] expressed a similar situation,

“Why I become sad at times is because I would be having pains or my body just does not feel alright and I know that my mummy does not have enough money to take care of me. If you asked me then, what was the problem, I
would not answer. I would just be staring into space. I would be irritable; I would stay in one place for some time.”

In other words, these persons with SCD would tend to conceal their pains in order to avoid the problems of going through sadness in response to the disbelief of significant others. There is a possibility that this attitude might serve to increase the belief of significant others that there was nothing wrong after all.

2. Experience of disbelief about pain from professional workers

Funke [32, female, teacher, Christian] remarked on how professional workers (nurses and doctors) thought she was pretending when in pain. She recalled her encounter with hospital staff and said:

“I’m the one that knows what is happening to me. You don’t know what I’m feeling now. The pain is just too much, just too much. That’s all, I use my drugs, and then I took a lot of water. Then I pray that God should guide me and give me long life. The people who take care of us in the hospitals don’t even know what we go through. They think we are pretending. They can’t understand the type of pain that we go through. Except you are SS, you can’t understand this kind of pain. It is just too much…”

The significant others in the hospital who are doctors and nurses do not understand what persons with SCD could be going through. They would even think that these persons were acting up. This reaction adds to the pain they go through and they noted that the pain is “just too much”. The hurt from the reactions of those charged with the care of those with SCD who render instead a dis-service is enough to create distrust with the health system and a reluctance to use such a system. The persons with SCD seem to be ostracized by the social reactions of others and are prone to further abuse, neglect and a negative spiral of emotional disturbances.

Eniola [23, female, student, Christian] described how sad it is to go through such experiences where health professionals did not believe her. She described her experience thus:
“It is very sad. People think you pretend when you are in pain. Even doctors and nurses! They would shout at you. They would say you are too timid, you are too weak. Your mates can bear this pain. Can’t you withhold little pain? Is it every time you must use drugs for pain? And all these nurses too, they need education. They say that is how you people behave like witches. You people behave like witches.”

The nurses made accusations of low pain thresholds in Eniola. The nurse looked down on her as having broken an expectation of bearing what she termed “little” pain and as having broken the expectation of the proper timeline for using pain medications. Eniola was seen as timid and weak. She lacked the physicality of a normal patient. She recalled the lay belief that persons with sickle cell behave like witches (witches pretend to be innocent in a bad event, whereas they are responsible for the event). The nurse was holding Eniola responsible for the pain she had and the exaggeration of the pain. Eniola is prone to further emotional abuse, neglect and mismanagement in the context of negative reaction from a nurse who is supposedly charged with the duty to care for her clients.

3. Experience of disbelief about pain from community members

Funke [32, female, Christian, Teacher] described in her experience the reality of the pain she went through in crisis, and how she tried to bear the pain to avoid disturbing others. She spoke thus:

“For me to cry out that I am having pain you suppose to know that this pain is getting too much. I am a kind of person who has high threshold for pain. Anytime I am in crisis I don’t let people know. But when it becomes too much, you will see it in my face. It is not that I wanted to cry but tears will be coming out and running down my face. Then they would be asking what is wrong with you again? But they don’t understand. Try and bear it they would suggest. They don’t know, have I not been bearing it long before they saw it on my face. Assuming they know they would not say that. It is like your life wants to disappear, your life is about to leave your body. That’s why I think about death. Even if it is death, then let me die.”

She said in her experience of pain that others did not know what she went through. She would only let them know she had pains when it was too much for her to bear. She noted how she would not want to cry but that tears would come out involuntarily. She said others do not know and it seemed she thought they could not empathize. She therefore tried to
describe how it feels and said “it is like your life wants to disappear, your life is about to leave your body”. She tried to spark the imagination of others with this illustration. She linked her experience of pain with the thought of death, and felt death might be a better experience than the pain. The lack of empathy perhaps leads to hiding pain and to thoughts about death. A person with SCD therefore would have the double pressure both to bear pain and to hide pain. The experience of pain, the pressure of hiding the pain without much success and the lack of empathy of others could possibly lead to thoughts of death. The pressure of hiding the pain without much success and the lack of empathy of others could derive from the negative reactions of others.

Persons with SCD gave accounts of concealing their pains to avoid negative comments from others. This resultant behaviour of persons with SCD might serve to increase the belief of significant others that there was nothing wrong after all and create a vicious cycle. The hurt from the reactions of those charged with the care of those with SCD who render instead a dis-service through disbelief of their pain is enough to create distrust with the health system and reluctance to use such system. The persons with SCD seem to be ostracized by the social reactions of others and are prone to further abuse, neglect and negative spiral of emotional disturbances. For example a nurse held Eniola responsible for the pain she had and the exaggeration of the pain because she believed Eniola as a person with SCD was behaving like a witch (i.e. acting innocent, but not innocent). Eniola is prone to further emotional abuse, neglect and mismanagement in the context of negative reaction from a nurse otherwise charged with the duty to care for her clients. The lack of empathy in significant others perhaps leads to hiding pain and to thoughts about death. Again a person with SCD therefore would have the double pressure both to bear pain and to hide pain. The experience of pain, the pressure of hiding the pain without much success and the lack of empathy of others could possibly lead to thoughts of death. These pressures seem to derive from the negative reactions of others.
Theme III: Experience of stigma

The participants in this study also shared experiences where they encountered persons who discredited them because they did not meet certain expectations. These expectations could be in terms of physical appearance, economic independence/provision, or physical capacity/capability. Twelve of the fifteen participants were discredited because of their physical appearance, ten of them because of economic independence/provision and eight of them because of their physical capacity/incapacity. These experiences are highlighted to present ways in which others in the social world of the respondents take them through various components of stigma according to Link and Phelan.

Sub-themes

1. Physical appearance:

Odekunle [50, male, journalist, Christian] described how people reacted to him because he had somatic features of sickle cell. He recalled the how others thought he was smallish, and how the more a person has certain physical characteristics, the less they would want to deal with him/her. He said,

“So the way people react, they look at you as a small person, as someone who is thin and not fit, the more it shows on you, the less people want to deal with you or to relate with you.”

Eniola [23, female, student, Christian] talked about her childhood experiences with her peers, where her peers would label her a sick person because of how she appeared physically. She recounted:

“People would be asking me are you SS? Are you a sickler? Then it is glaring, it is obvious, people would see it that I am a sickler. I was short, very thin, my eyes were yellow and my belly was protruding. They would even be the ones to tell me to go and check my blood. They would say this one looks like a sickler. Then if I hear my friends and other people telling me that, I would just go down, I would cry, I would feel sad, I feel bad, I feel depressed.”

Eniola recalled having these experiences and how she would cry, feel sad, bad and crucially, in her own words, depressed in response to these encounters. Her friends and
others would refer to her as “this one”, thereby depersonalizing her, separating her from them and then they would ask her to go and check her blood. Her friends noted that she was short, thin and had yellow eyes. These are human differences that are significant for labelling. They asked her if she was a “sickler” because the pervading beliefs that associate these undesirable physical characteristics with being a “sickler”. These supposed friends then had the power to call her a sickler. She looks like one and thereby enough power to place her in distinct category (stereotype) and then separate her (them) from themselves (them). She gave accounts of her feelings of sadness, and depression which are likely disadvantages consequent upon the loss of status and discrimination she suffered from them. Joke [39, female, caterer, Christian] narrated her experience of being discredited because of her leg ulcer when she was in a relationship with a friend:

“But along the line, I met a guy and we started on a good ground. He even followed me to my church and had some interview like that. One morning, it was 2000, no, it was in the afternoon, I went to his place. I went inside his room and discovered that all my photographs in his room are no longer there. I asked him what happened and he lied he wanted to fix some things. I shrugged my shoulders. But when I started putting pressure on him that he has changed, he now said that he cannot marry me because I have a leg ulcer. And this man I am talking about, their second born, a girl, his half-sister, they have same father but different mothers; this girl is a sickle cell too. So he knows about people with sickle cell...It was later I knew that it was the step mother (the mother of the sickle cell half-sister) that influenced him to break the relationship. The woman surprisingly told him there are better girls outside without sickle cell than this one that has leg ulcer. But that time, I nearly ran mad. In fact, I thank God. I told him he could go and it is not his fault and I don’t blame him. I said despite my condition that I am a sickle cell, if I have money he would marry me. If I had money, I would not have leg ulcer and I would be able to take care of myself very well. I would not be trekking when I should take bus or cab.”

Here Joke in social relations with her boyfriend gave account of the components of stigma. The boyfriend saw her leg ulcer as a significant human difference sufficient for labelling. And she becomes undesirable as a result of the leg ulcer having an association with being someone with SCD, which he has learnt from the dominant beliefs in the society. She therefore is different from others (us) in the society and is separated. She consequently suffered a loss of status and discrimination: she cannot be his wife. However, Joke could
not believe that her friend would act in such manner because he had some knowledge of sickle cell and experience of living with a half-sister who had SCD. Furthermore, she could not believe that his step mother, who had a child with sickle cell, would support him in taking that decision to cut off relationship with her merely because of her leg ulcer. She expresses her distress through the phrase “ran mad”. However she mentioned that this sort of reaction would not have happened if she had enough money and she was able to prevent the leg ulcer, suggesting that her breaking of the norms of the body is partially associated with socio-economic circumstances.

Babalola [22, male, artisan, Muslim] then talked about health professionals who would abuse them because of their different body parts. He said:

“Some doctors are there and some would not treat you well at all. Some would even use your eyes or other body parts to abuse you.”

These participants with sickle cell who had experienced stigma because of their physical appearance described experiences of shock, sadness, depression and mental torture when they went through such experiences. It could be likely that the social reactions in the experiences of the participants were linked to this focus on bodily expectations. Persons with SCD were smallish and skinny as opposed to tall and well-built respectively. To conform to social norms, they would need to have unblemished skin as opposed to broken skin, and to smell clean, as opposed to exuding smells as in leg ulcers; have white eyes as opposed to yellow eyes. Such are the bodily norms that persons with SCD are held by others to break.

2. Economic independence:

Ten of the fifteen interviewees shared experiences wherein they were seen as sources of economic loss by significant others in their life-world. Hannah [27, female, student, Christian] shared her experience with one of her siblings:

“It was my younger sister that told me that she planned to buy a car with that particular savings. She said you have come and spoilt the plan now. She said our mum had told her that if her savings reached up to this amount, she would use it to buy a car. And now you have come and messed up her plans.
You are the one who has been preventing my mum from buying her car. I started to cry. But I cannot blame God. If it is possible to blame God, I would certainly do so. But I cannot. If it is possible to call God and ask why He made my person like this, I would have called Him long time ago. But it is not possible. What will one do? One does not know why God acted like that. It is too much.”

Hannah described how she was been portrayed by her sister as a source of financial burden to their mother. She saw this as a burden that was too much to bear, and would have wished to know why she had to undergo such treatment. She was seen as being the one ‘preventing’ the mother from buying a car. She had made their mother incapable of affording a car because of her frequent sickness. She cried and experienced sadness. The car represented an important source of status that the mother, as a tribal chief, was expected to be able to afford. She broke this norm and the sister was therefore perceived as continuing to frustrate her mother’s aspirations to car ownership through requiring payments to cover her frequent illness. Another participant, Babalola [22, male, artisan, Muslim] said of one of his aunts,

“I remember a time that one of my aunties said I was a kind of basket where my parents pour in water to save. I was a leaky pocket for my family she said. All the money they spend on me is a kind of waste. This is what I heard her say. She said the drugs I was using were too costly. She said I would die today and wake up tomorrow. She said my trick was to deplete the whole family of money. I was not happy throughout that day, I was shocked.”

Babalola expressed his experience of shock and unhappiness when he was referred to as a kind of waste. He described how his aunt saw him as continuous financial drain in the family. He also described how his sickness was seen as a switch, with on and off cycle, with the purpose of depleting the family of money. There seems to be a social selection of human differences: his sickness is chronic, in that, unlike the sickness of others, spending money does not stop the sickness. These are significant enough for Babalola to be labelled, for him to be seen as separate from others in the family (us) and belong to the undesirable category of those who prevent progress in the family (them). In this experience, and the previous one, it is clear how someone with sickle cell experiences stigma because he or she is thought not to be able to contribute to, but is rather assumed to drain, the economy of a
Eniola [23, female, student, Christian] recounted the effect this view could have on persons with SCD when she said,

“What I would say is: some people don’t have any idea of what we go through; some people don’t believe in it at all; they believe we are wastes of money; they don’t give us a chance to live and to enjoy life.”

She noted that the society does not give persons with SCD a chance to live and enjoy life. These participants experienced these social reactions and such reactions could be linked to their breaking of certain expectations/norms. Babalola and Eniola broke the norm of the children as a source of economic provision. The Yoruba name “Babalola” literally means the “person who has wealth” and the name “Eniola” literally means “this person is wealthy”. In this way the people with SCD are not only breaking social norms and expectations, but are doing so in a manner that contradicts their very names within the naming system of their culture.

3. **Physical capability/capacity**

Eight of the fifteen participants shared experiences where they encountered others who discredited them because they did not meet up with expectations of normal physical capacity or capability. In Ope’s [24, male, Sign writer, Christian] account, he talked about his experience of a neighbour saying that football was not good for him. He said:

“Anytime I go out…I can remember some time when I was small, I was different from others, my friends were bigger than me. Sometimes I ran out of breath when we played and they do not. So I was playing football with my friends outside in the neighborhood. A woman came to me and asked me what I was playing football and whether my parents allowed me to come and play football? She asked me to leave the place and go and do other things. She said I cannot play football and it was not good for me. That day I felt bad. I did not like what she did to me.”

He said the woman stopped him from playing football because it was not good for him. He noted that the woman wondered if his parents had allowed him to come and play football. He described how he felt bad, and that he did not like what the woman did to him. He described how he was not able to run like others did and was also smaller in stature to them. He noted this, but would still go to play, but it seemed the woman stopped him
because she deemed that his physical capability might not be sufficient to engage in such play.

Another participant, Gbenga [21, male, student, Christian] said of his classmates in the university:

“It is just that some of my classmates, I don’t like their behavior. They see me as someone weak and not lively. And they don’t interact with me. And I don’t like that. They are very rugged, stubborn and do activities that I would not be able to cope with. They go out at night, drink beers and travel. These are things that if I do them I know I will suffer the consequence. Then most of them would not come to me, share thoughts with me, they would not answer me if I called them for help. It is not worth it to ask them for help. You will know by just looking at them.”

He said they looked at him as weak and not being able to engage in activities like they do. He further said they thought he was not lively. Others applied the label of being weak and unlively to him. He was therefore seen as separate from them and consequently he lost social status and experienced discrimination. He thus described how they would not come to him to share thoughts with him and support him, even when he called them, because of their view of him as being weak and not lively. He did not meet their expectations, specifically of young men, to be physical and tough (rugged); to socialize without becoming tired (go out at night); to consume alcohol and not to avoid it for their health (drink beer) and not to curtail their geographical range in order to be close to support if falling ill (travel).

In a slightly different way, Niniola [25, female, Community Health Extension Worker, Eckist] described how she anticipated the experience of being discredited by others in the secondary school because of physical incapacity or incapability. She said:

“When we are having PE (physical education) in school, maybe I was supposed to go and participate in some sports such as run or other things like that. I know I cannot do those things because I don’t have the energy. So that was the first thing that came to my mind and I was sad. It was really sad because I know that these things, if I can’t do them like others, they will begin to wonder that how come I cannot do things like them. As children, you know, they like to come together and do things together. But the
moment they know that I step aside, they would be like, what is the problem, what is wrong with you? Then I fall sick often and often then.”

Niniola was describing how she felt different and then sad when she thought she might not be able to participate in some sporting activities unlike others. She said she did not have the energy but was sad particularly because other children would ask what the problem was, and what was wrong. She anticipated being treated differently and noted that she was falling sick often then and so it would not be difficult to notice the difference.

In her workplace, Comfort [42, female, Christian, Secretary] experienced some discrimination because she was considered weak and sickly. She described how others said she could not cope with the energy demands of work. She recounted that:

“It is difficult getting job as a person with sickle cell. For me, it was difficult. Even when I got the job and I fell sick, my colleagues were saying among themselves whether this one [Comfort] could cope with the work. They wondered why I even bothered to look for job. It was to the extent that my boss was telling them he doesn’t think I could work or cope with the demands of work [secretariat job]. Someone there now answered him and said that [because I work for Lagos state] the governor has not said that sickle cell people cannot work again. Until there is a pronouncement like that people with sickle cell should be allowed to work. Anyway, it is like some unwritten rule that people with sickle cell are not considered favourably when it comes to giving them job or helping them to stay on the job when they have employment.”

Comfort showed in her experience how she was considered unfit for work. She went on to describe how persons with SCD were unlikely to get job placements because of the belief that they might not cope with the physical demands of the job. She did not meet the expectations of others at work: not falling sick frequently in other to meet job demands (becoming ill and not fulfilling expectations). This experience is similar to that of Aderonke [43, female, Christian, trader] who recalled that:

“There is little I can do as I don’t have a job, because I say I want to work they are not ready to employ me because I’m an SS patient. They believe that their work will not move on fast. So as my experience from day one, struggling for life, struggling to make ends meet has been a problem. That is my number one experience. Nobody wants to employ an SS patient except
you don’t give them your medical records. Nobody is ready to employ an SS patient.”

She said others would not employ her because of the belief that the work would not move fast. In other words, she would not cope because she would be slow and not energetic as others. She could only get a job if she did not disclose her SCD identity. She struggles to make ends meet because she could not work. Persons with SCD are seen by employers not to have the physical capacity or capability to meet the demands of job [she had hip problems]. If persons with SCD are not given job opportunities they possibly would struggle to cope in life.

Aderonke [43, female, Christian, trader] related her experience in the church and pointed out how the church members would discriminate against her because of her weakness in physical health.

“And em…the times are when you are been separated from others especially in the church, they feel you cannot do what others are doing. Because we are not…em…we are not em…nobody is perfect. In the church, in the midst of your people, your…in the congregation, in the midst of your Christian sisters and brothers, you feel depressed at times, when you are supposed to go somewhere, they would say no, no, you don’t need to go because of your health and you’ll feel like going there, you’ll feel somehow.

She used the word ‘separation’, and because she was separated from others, she felt somehow (unwanted and rejected), and she had a feeling of depression. She noted that the church members would anticipate that she could not do what others could do, but then cautioned that nobody is perfect. To them she could not meet their expectation of a person who moves about and who does not fall sick. In such ways are people with SCD are presumed not to have certain physical capacities and are discriminated against on the basis of these imputed/virtual identities.
4. **We don’t live long enough**

The participants mentioned in their experiences how others discriminated against them because of the belief that persons with SCD die young. Comfort [42, female, Christian, Secretary] shared this view when she recalled that:

“I have heard some people talk about them. That thing they say, they don’t live long and all sorts. Things like that, they don’t regard them as complete children, they expect they would die before their parents die, they pity the parents, you know feeling for them. No parent would want to use his/her hands to bury his/her child. Nobody prays for that kind of a thing. So people with children who have sickle cell are seen as incomplete family. The society thinks such family has no child at all. That is why I say incomplete children. The child with sickle cell should not be relied upon as a child because he or she can die any time.”

Comfort remembered hearing others mention that persons with SCD die early and that they are not complete children. She described how others would pray not to have such persons as their children in order to avoid witnessing the death of their own child. From her understanding of the perceptions that other people have of people with SCD, persons with SCD should not be relied on to outlive their parents. Once they saw a person with SCD, others associated them with the cultural beliefs that they don’t live long and they cannot be relied on to take care of their parents in old age. This enables them to see these persons as separate from them and be pushed down the social hierarchy. Damilola’s experience is similar; she had observed that others would look at someone with SCD as if they would die before their father. She would not disclose that she had sickle cell for this reason. Once it is disclosed, she would experience pity, people’s attitude towards her would change and they would act in ways that would make her think she would die before her parents. She recalled:

“I do not tell people that I have sickle cell though, because the pity and the negative attitude you get from the people, they treat you differently, they look at you in a way you don’t like, and they treat you as a weak person. I don’t want all that. These used to get to me when people knew and treated me like that; I get depressed and would think I won’t get as old as my dad or something.”
She noted her view to withhold her identity as a sickle cell person to avoid thoughts of dying before her parents and feeling depressed. Other participants went through the experience where people thought they would die young especially when it came to a job or employment. Five of the fifteen participants described that persons with sickle cell are not likely to get employed because others believed they could die young. Damilola [29, female, graduate, Christian] gave an account of how passers-by talked unfavorably about persons with SCD:

“People say they [persons with SCD] have a very short life-span. And you are not supposed to have a long term arrangement with them. They can just die like a cockroach. People are not even ashamed of saying it in your presence. They say it without fear or bothering about how you feel. If for example there are like four people here, someone can just get up and run his or her mouth about people with sickle cell and would not think that there might just be one or two persons with sickle cell here or who has relations with sickle cell in their family. They run their mouth about how they die and are going to die. They tell stories of how some of them die just like chicken, like if life can be snuffed out of them easily. People say a lot of horrible things about us. And I think you are supposed to be considerate. If they discuss sickle cell on the radio and I know that someone who knows I have it is around I feel a lot uncomfortable. They don’t present us well. For most time when people discuss it, they discuss the bad part of it. How they are going to die, they are not treated well. It makes me very uncomfortable. You just ruin my day if you do that… They really overdid things.”

Damilola described how others in the society were inconsiderate about how persons with SCD would feel if they heard all that they said about them. She talked about how they expect them to die early and in a disgusting manner (like a cockroach or chicken). She expressed that she would feel uncomfortable when others knew she had sickle cell disease. She mentioned that others did not discuss the good aspects of sickle cell disease, but rather put emphasis on the bad aspects, and how this overdramatized behavior makes her very uncomfortable. She said when people do that they ruin her day. Damilola further narrated that:

“Ha! Like I said before, the belief is they die young. So if you employ them, you have employed nobody. Your job is left hanging. Who would employ you? They are not supposed to have any long term contract with people with sickle cell. It is rather unfortunate. Even in the sickle cell clinic, I have not
seen a doctor or nurse who said they have sickle cell disease. Are you saying there are not doctors or nurses with sickle cell or they could be any staff in the hospital? I think people with sickle cell are not given consideration in employment or even in business.”

Damilola felt that people with SCD are not given jobs because others do not believe they can engage in a long term contract with them. They are expected to die young. She said this was rather unfortunate. She felt that even in hospital employment there is such discrimination against people with SCD and that is probably why she has not heard of any doctor or nurse with SCD working in healthcare institutions.

This feeling is validated by Funke [32, female, Christian, Teacher] when she said:

“My fear is that I don’t want them to know I’m SS because when they know you are finished, there is even no work for you. They treat you as if you are not alive or that you can die anytime and why rely on you.”

Funke described her fear of disclosure because of this behaviour from others. Others expect that those who have jobs would live long and that those who do not live long should not have jobs.

Seven of the fifteen interviewees made mention that they experienced discrimination in marriage because others believed they could die early in life. Aderonke and Babalola shared their experiences in this regard. Aderonke [43, female, Christian, Trader] said:

“An SS patient is not easy to marry for them as well (laughs). It’s easy for the men because they can still get a lady that is ready to…to be for them. But in the case of the women, so many people are running away from an SS patient. When I got…when I wanted to get married, my husband’s friends told him that you want to go and marry somebody that would die early. They told him that don’t you know that they used to die. They don’t make it up to…they even told him that they don’t make it up to age 30, that the least of their age is 35…they would die.”

Babalola [22, male, artisan, Muslim] added that:

“They are against people marrying people with sickle cell. They would say who would give his or her daughter out for a sickle cell person to marry. It is like a taboo to marry someone with sickle cell disease. They would ask who would let his or her child marry these ones who die today and rise up
tomorrow and die fast. God would not allow this kind of mistake they would pray.”

Babalola described how it was a taboo to give one's daughter to someone with SCD for marriage. The belief is that persons with SCD die early. It is because of this belief that persons with SCD possibly experience difficulties in getting married.

Odekunle [50, male, Christian, Journalist] recalled an account where an insurance company debarred him from insurance. He reported that he was denied insurance because of sickle cell. He recalled,

“But they won’t give us insurance. From my own personal...well maybe that was a long time in the nineties, I tried to get personal insurance but I was denied because of sickle cell. The company said, sorry, we can’t give you insurance. They don’t give insurance to people with sickle cell, I believe up till today. They are thinking you won’t live long, why do we want to waste money on you? Yes, in the 1990s, when I was working as a journalist with a newspaper, an insurance man used to come to my workplace. I collected a form from him, I never had an inkling (of idea), I never thought I would be rejected because of sickle cell. When I got to the final stage and they discovered I was with SS, they said no, sorry, we can’t give you insurance.”

Odekunle said that it was possible he was denied insurance because they thought he would die early as a person with SCD. The representatives of the company thought it would be a waste of money for the company. He also said he believes up till today that persons with SCD are not given insurance. The consequences here go further than disapproval in wider society. There are in addition real material and economic consequences, including being discouraged from jobs and denied insurance.

The participants shared experiences where they were discriminated against because they did not meet up with certain expectations in terms of physical appearance, physical capacity or capability, economic independence, and long life. These experiences occurred in various facets of their lives including homes, workplaces, churches, schools and society in general. However, it is important to note the view of one of the participants, Gbenga [21, male, student, Christian], whose experience could suggest that things might be changing. Gbenga expressed that:
“For now, I think it is good now, it is much better than before. Some time ago, they used to believe that a child with sickle cell is ogbanje or a possessed being. But now more people know it is all fault of parents. They treat everybody well and the same. They treat everybody normally; they don’t excuse someone just because he or she has sickle cell. For example in sports, they don’t discriminate again. They will ask you if you can and if you say you can, they would allow you to participate. They would not first say you can’t participate just because you have sickle cell. People outside the school also treat us better than before. They don’t look at you as if you will die the next day.”

He noted that the situation is better than before and others in the society do not share the expectation of early death, and weak physical strength. Persons with SCD are not separated as used to be the case. In his view, persons with SCD are probably being supported more than before.

5. *Policing of behaviour by others*

Five of the fifteen participants reported that others would tell them stay within certain limits of behaviour. At other times, others would police them to maintain moral boundaries. This informal moral policing took place in the context of school, church, and hospital. The components of stereotyping, separation and discrimination featured in this sub-theme. Joke [39, female, caterer, Christian] also shared her experience in the church, where the pastor tried to enforce decorum in the church despite being aware that she had sickle cell. Joke described the message she got from the looks of the church members. She said:

“Like myself now, I don’t attend church regularly. I go when I feel like. I cannot be complaining to people that it is because I have crisis I did not attend church. Some of them in the church would look at you that you are not serious. Some believe that when you say you have given your life to Christ and you are born again, you must not fall sick, you must not lack anything, you cannot be having sickle cell or crisis. With their entire attitude like that, I am not even in the mood to go their church regularly. It is when I have money to give offering and would like to worship my God outside my house that I go to the church now. Sometimes when I go to the church even when I am a little down, they would be conducting a praise worship service; while people stand up, I would sit down. When they notice some people are sitting down when others are standing up, they would then say everybody should stand up. They don’t appreciate that people have different needs, not everybody is strong or weak. They make it look as if it is because you are
arrogant or pompous that you are not standing up to praise God. So I would rather sit back at home and say my little prayer to God."

In her description, she said they looked upon her as if she is not taking her commitment to church seriously. She also mentioned that they expected her not to fall sick frequently, not to have frequent crises and not to lack anything, since she had given her life to Christ. Even when she could not stand up during certain aspects of the church service, they would police her to stand up by emphasizing the word ‘everybody’ or by their castigating looks. She described her reluctance to join in church activities because of these acts of moral policing.

In the context of child rearing, the society tries to monitor and limit the number of children persons with sickle cell have. One of the participants shared her experiences in this regards. Aderonke [43, female, Christian, Trader] described her own experience with significant others thus:

“And experience even as a woman, giving birth is another experience that I don’t like. It’s not easy for an SS patient to give birth. That is why you have to stop it at 2 not more than 2. It is enough for an SS patient. It’s only an SS patient that doesn’t love his or her life, that would go for 3 and 4. My mother did not want me to have more than one baby. She said it was dangerous. The consultant also told me it was dangerous but I insisted I would have two children, one boy and one girl. The only thing I did was to give them gap.”

Aderonke described how others have stipulated the number of children that a female person with SCD should have. She mentioned that it was dangerous if someone with SCD did not stay within such limits. In her experience, her mother and the consultant tried to enforce such limits, but she insisted. Furthermore, she developed her own strategy for having two children, by planning a birth gap between each one.

The social reactions in the experiences of the participants were probably linked to focus on expectations. The expectations could be in terms of body, where persons with SCD were smallish and skinny as opposed to social expectations to be tall and well-built; having unblemished skin as opposed to skin broken and exuding smells as in leg ulcers; having white eyes as opposed to yellow eyes (caused by the jaundice sometimes associated with SCD). Other expectations could be in terms of physicality specifically of young men to be
physical and tough (rugged); to socialize without becoming tired (go out at night); to
consume alcohol and not to avoid it for their health (drink beer) and not to curtail their
geographical range in order to be close to support if falling ill (travel). Other expectations
are of economic provision where, for example, Babalola and Eniola both of whose names
mean “someone with wealth” fell sick frequently such that the family became broke. Some
others such as Hannah, with her frequent illness episodes, prevented her mother from
buying a car, which is an important source of status for the mother as a tribal chief. These
norms/expectations could be broken in churches, workplaces, schools and in the wider
society. In some instances, the consequences of social reactions go further than disapproval
in wider society where they have real material and economic consequences, such as being
discouraged from jobs and denied insurance.

Others without SCD selected certain human differences in persons with SCD that they
deemed significant enough to be fit for labelling such as distinct physical appearance,
economic dependence, physical incapacity, and short life expectancy. With these
undesirable characteristics, they were labelled and were separated with consequent loss of
status and discrimination. The disadvantages they experienced included unemployment,
lack of insurance, inability to marry, shame and depression.

Theme IV: I am a different person

Nine of the participants described their understanding of themselves in relation to others in
the society. Some saw the difference in terms of three parameters: strength,
sickness/tiredness, and capability.

Sub-themes

1. Difference in terms of strength

Aderonke [43, female, Christian, trader] saw herself as being different from others. She
gained this impression of difference in relation to growing up, going through and coming
out of school, and living within the larger society. She said:
“The experience has not been favourable going through school, growing up and coming out of school, in the society especially, the experience you have with other people, the people you see are more stronger than you, you want to be like them...you feel like being part of them when you see them moving about, doing what you actually desire to do as well...so that’s part of the way I see it.”

She used the phrase ‘has not been favourable’ to describe the difference with others. She said others are stronger than herself, they moved better, and do things she could not do but would love to do. She wanted to be like others in growing up, in going and coming out of school and in moving about and doing things. She noted that this is just part of the way she sees her world. At this stage, within the context of an individual interview, Aderonke conceptualizes the issue in terms of her own bodily limitations and does not frame the issue as one that could be ameliorated by adjustments in the social environment.

Babalola [22, male, Muslim, artisan] also shared how he experienced being different from others. He found he could not match the strength of others in walking or running, he would run out of breath. He used these instances to draw on the fact that he was different. He did not observe that others had similar experiences as his in these instances. He recounted:

“What I thought was I was different from others. When for example we were going to a place and we needed to run, I would not be able to run like my friends. I would be panting up and down. Even when we got to the place or we even walked down to the place without running at all, after getting to the destination, I would be breathless for like 20 minutes. I would be breathing hard and my chest would be making noise and people could hear the heartbeats in my chest. I saw that my friends were different from me. They did not have such experiences. Even my younger twin brother Taiye is different from me. He is twice as big as me. He is about your size. I would look at them and look at myself and cry most times. I would be very unhappy.”

Babalola feels that people could hear heartbeats in his chest (even though in practice this is unlikely) and this is what gives him the fear that his difference will be revealed to others. In addition he even has a direct comparison of himself to his twin brother in terms of size. He would look at others and reflect on these differences and would be sad and cry. He did this frequently. It is worth noting that the participants, on one hand, related disapproval from others because of these are the same types of thing but here, on the other hand, it is they
themselves feeling the lack. This could be argued to be connected to the social reactions of others and social norms. It could equally be that, since they have been continuously being put down into such class by others, they have accepted it to be their regular position and see themselves as different from others. In other words, they can conceptualize their differential relationship to others in terms of their own bodily limitations and do not see it from a different perspective, namely that these could have resulted from negative social arrangements that could be ameliorated by adjustments in the social environment.

2. Difference in terms of sickness/tiredness

For Damilola [29, female, Christian, tailor], her difference is a reflection of becoming sick frequently and being tired when involved with lots of activities in comparison with others. She recalled:

“...You get sick a lot of times. You run out of breath like all the time. Lots of things like you get tired a lot. You are just different from everybody. You are very different. You are just like the weakest person in the group.”

Damilola also noted running out of breath all the time and mentioned being the weakest in the group, different from everybody else. She said being sick often, being tired often, and being out of breath often in comparison to others are signs of being different. At this stage, within the context of an individual interview, Damilola conceptualizes the issue in terms of her own frequent somatic limitations (frequent sickness/tiredness) and does not frame it as a socially created issue that could be addressed by social re-adjustments.

3. Difference in terms of capability

Ope [24, male, Sign writer, Christian] in his description noted he was different because he could not do what others could do. He also noted that this happened in the rainy season. He said:

“I knew I was different from others and I could not do what others can do. I also see them play around laughing and jumping about and I cannot do all those things. This also happens when it is the raining season and I could not go out and play with my friends. They say we need to stay indoors and not
Ope talked about activities as separating him from others and especially in the raining season. He felt that he could not go to school because of this difference. Endurance in physical activities is a key in what they noted as marking them as different. Another one is their capacity to endure the temperature changes that occur during the rainy season. In the perspective of Hannah [27, female, Christian, divorced] her experiences with respect to others are in the opposite. She therefore said she was different. She said:

“I realized I am different from others. People might be complaining of heat, I would be complaining that I am cold. They would be feeling hot, I would be catching cold. Rain must not beat me, I must not be exposed to fan. I am different from other people. I must not have urge to drink cold drinks, it would be a disaster. What kind of disease that separates you from the rest of mankind? You must not use all your money to eat; you must save money for sickness and not for other things. When there is party and people are enjoying themselves, I would be indoors, shivering and covered up.”

Hannah illustrated how different she saw herself from others. When it related to weather, she experienced it differently. She would be cold when others are warm and vice versa. She also noted that her sickness was more frequent, such that she needed to save money for sickness while others saved money for other things. She saw a difference in her priorities from others. She noted this difference as a disaster. Her expression of what kind of disease separates you from humankind suggests a feeling of sadness and isolation. Several participants including Aderonke, Babalola, Damilola, Ope and Hannah conceptualized an aspect of living with SCD as disapproval from others, while in another instance they saw it as being different from others. In order to make living with SCD more manageable, it might be that they, having been continuously being put down into such class by others, have accepted this position and thus perceive themselves as different from others. This framework locates the problem in themselves and does not frame the problem as located in the social arrangements.

This view of the problems located in themselves could also be seen as self-stigmatization. The respondents could have developed these conceptions about themselves as persons with
sickle cell as part of socialization into their culture. Their conceptions could lay the foundations for their expressed lay theory about their view of themselves in relation to other people. These persons could therefore have presumptions such as they would experience rejections from others (be it friends, employers, or neighbours). Such ideas could then become part of their world view. Once they lived in the society with the disruptions of their illness they encountered negative social reactions from others that would reinforce their views. Their belief that they are different, and the consequent expectations and fear of rejection, may lead to constrained strained social interactions. They thereby live in restricted social networks, develop depressive symptoms and experience unemployment.

**Theme V: Thinking and talking about death**

In Chapters 3 and 4, it was acknowledged that there is a conceptual issue at stake in the degree to which a Western concept of depression can be taken from its location of origin and applied to a new cultural context, in this case urban Nigeria. An accepted corollary of more extreme forms of depression is that such people may be prone to suicidal thoughts or suicidal actions. It is therefore important to note both the number and the intensity with which respondents spoke regarding this domain of experience. Eleven of the fifteen participants related experiences that revolve around the discourse of death and wish to die. Five of them shared how the view of others could affect their experiences of death, while eleven of them related that they had on several occasions wished they were dead.

**Sub-themes**

1. **Others make us think of death**

Comfort [42, female, Christian, Secretary] described how others in the society through their negative attitudes (for example the names attributed to them such as Emere, sunwonna, and that they don’t live beyond twenty) wish persons with SCD an early death. She said:

“So the attitude that people have to sickle cell patients is just not good. They even wish them death by their attitudes. When you expect death, death will
likely come. You don’t do things to help them, you think if you do they would still die, so why bother.”

She underlined how the attitude of others could itself have undermined the will to live in those with SCD. She described how death could result when persons with SCD were not given any help or consideration. The attitude of neglect or emotional coldness in others to persons with SCD could even account for some actual deaths of people with SCD in her view.

Gbenga [21, male, student, Christian] showed in his narrative that significant others thought that SCD was almost a sentence to death. He recalled the reactions of his mother:

quoted text here...

He noted that this negative view is recurring in the mind of his mother. He experienced this as she would continue to pray and fast for him. She often would pray that he should outlive her. He recalled how she was afraid and confused at the news he had SCD.

Aderonke [43, female, Christian, trader] talked about situations that could cause persons with SCD to die early. She mentioned that:

quoted text here...

It seems that participants are saying the view of significant others and others in general that SCD ‘is’ an early death sentence puts persons with SCD at greater risk of thinking more about death or dying by undermining their will to live. In addition, because of such ‘deterministic’ social expectations, members of the society do not provide necessary funds to assist persons with SCD in times of need. The perception of others appears to be that
there is probably no need, since the outcome could not change whether or not funds were made available.

2. **We experience the fear of death**

Damilola [29, female, Christian, tailor] related how thoughts of death crossed her mind on several occasions. She said:

“It is like when at times somebody just dies and I also feel maybe I will also die soon too. At times when I look at my niece and I would think that maybe when this is girl is about 15 years, I would not be there, I would be dead. And at times when we talk and they say when Cole [name changed] is 30 or wedding, I would be like I won’t be there. I mean it is like it happens almost every day of my life. It happens like 5 to 20 mins every day of my life. I will just think maybe I won’t be still alive when this or that happens. Like my friends when they are talking about 40th birthday, I will be depressed when I think I may not be alive by then. We have been planning for things like going to the Bahamas, but I’m like I may not live to see this. So why am I stressing myself to plan with them? It happens all the time. Making lots of plans like investing is difficult for me because I would be thinking “why can’t I enjoy my money now?” I may not live to reap the investments. It is a major part of my life. I just try to push it out of my mind…but the scary part for me was when people were always talking about how you would die young and then you would not grow as much as normal people. Most times, they don’t know I have it but they just talk about how people with sickle cell die young and you are not supposed to grow old. And for me, it was a bit depressing but there was nothing I could do about it.”

Damilola expressed that these thoughts of death made her to feel depressed and also made it difficult for her to have a long term plan for herself. She noted it is a major part of her life. Her life is themed with such thoughts of death and spending her money without saving it.

Funke [32, female, Christian, Teacher] also shared how she came to live with thoughts of dying early. She recalled that:

“When I was small, I normally heard that at the age of 18 or at the age of 20, various young ages, that sickle cell they don’t last long, they don’t live long. Well, when I was in secondary school, I know a guy that we were in the same class. He too is SS but he has died maybe at SS 1 or SS 2 (senior secondary school is SS). He died at that young age and so I started fearing
that am I not going to die? My thought was that even if I finish secondary school I know that I am going to die not long afterwards. So there is nothing I can do about it.”

She had been living with this fear of early death in her mind after she heard on several occasions of early death of persons with SCD and she witnessed a person with SCD that died at a young age. Here participants with SCD attributed their experience of fear of early death to all that they heard from others in the society. When these persons witnessed the death of others who had SCD, they think that this is confirmation of this view shared by others in the society. Members of the society probably hold the belief that there is no cure and nothing could help the SCD situation. However, as mentioned above, social adjustment via making funds available could have had positive impact, according to Aderonke. It is therefore possible that a negative outlook derived from interactions with others began to be shared by the person with SCD themselves, with the result that this might then preoccupy a person’s mind with negative framing of events so that they cannot enjoy life, plan for the future, or keep things in perspective. Being made to fear death may lead people to restrict their ambition or curtail the extent to which they focus outwards to others in society. It is even conceivable that the constant focus on early death predicted by others may itself contribute to low mood and ultimately depression.

**Theme VI: We wished we were dead**

Eleven of the participants had experiences of suicide that ranged from thoughts of suicide, self-conscious risky behaviours and attempts at suicide. Eleven interviewees had thoughts of suicide, two had self-conscious risky behaviours and another two recounted specific attempts at suicide including preparing to take insecticides and antiseptic solution. They all looked at the different situations they found themselves in and on many occasions when they considered different degrees of suicidal experiences.
Sub-themes

1. Thoughts of suicide

Eleven recounted having thoughts of suicide. The sickness, the pain and the lack of support provided the context in which such thoughts of suicide emerged. Funke [32, female, Christian, Teacher] related how she felt with her lived experience as a person with SCD. She said:

“And my experience has not been good at that. Any time I’m sick, oh God…I feel like dying. So I don’t feel like staying in this world. I don’t have support from my friends and my relations are also not caring. I would be like the pain is too much, too much.”

Her sickness and pains make her feel like dying. While she noted the physicality of the pain associated with her SCD she also links the experience to a lack of social support from relatives and friends. She is thus drawing attention to other factors beyond her SCD in the genesis of her suicidal thoughts.

2. Self-conscious risky behaviours

Two of the participants went further than ideas of suicide and reported engaging in behaviours that were risky and that, directly or indirectly, could result in death. Damilola [29, female, Christian, graduate] recalled that

“Life is short so why should I care less. I did anything that I wanted to do and I was not afraid of dying. I was reckless. And there is anything you asked me to do that I will be afraid to do. I would say what’s the big deal and I would go ahead and do it. Life is short for me. I took risks. I took to smoking and drinking. I smoked more than half a pack of cigarettes a day at times, and would go on drinking spree in parties. I would travel at night between 9pm and 1am. I was just not afraid of anything. I used to be afraid of dying but after a while I said to myself let me enjoy the little time I have, if I fear death, it would not make me die older, so I am not afraid and I would enjoy before I die.”

Damilola said she took risks and she was conscious of these acts. She engaged in smoking and drinking, she undertook journeys when it was not safe. She expected to die early and so why would she take precautions against dying? She wanted to enjoy life as much as she
could within the small time frame she thought she had. There is something here about a trade-off between short-term enjoyable activities (enjoyable in their own right and because they signify acceptance into a circle of people who drink, smoke and stay out late, and thus signify being part of, not excluded from, usual peer friendship groups) and long-term physical harm to health (and indeed short-term physical harm to health for someone with a chronic illness like SCD for whom smoking, alcohol and exhaustion are known triggers to illness episodes).

Joke [39, female, Christian, caterer] also talked about what self-conscious risks she took in fearless anticipation of early death. She recounted:

“I threw caution to the winds. I did anything I liked. I even stopped my medications because if you use them, they say you will still die at young age and if you don’t use them, what does it matter? In 1993/1996, I experienced this recklessness. I wanted to go to school, and the family said you will die young…I just took a job in a factory. Inside the cold room, I worked and worked. I resumed 8am and would come out 5pm. I would not leave for break. I would continue to work and work. I did not care if I died of cold or not. Anyway life was going to be short for me. It was in this cold room I developed this leg ulcer that has refused to heal. I believed that anytime I can die. I used to go to parties too. I would spend to whole of the night there; I would dance and do a lot of terrible things.”

Joke said she acted in a completely reckless manner. She said she did extremely bad or serious things that could cost her life. She went to all night parties and spent her time there without caring what would happen. She took a job in a cold room and exposed herself to cold for nine hours every day without going on break. She stopped her medications, she developed a leg ulcer but still did not take caution which she said she threw to the winds. In her words, she experienced ‘this recklessness”. She believed she could die anytime and so why bother to care for herself. She had no support from the family to remove this fatal belief and so plunged herself deep into extreme cold, extreme dancing and partying, extreme non-adherence to medications.
3. Attempts at suicide

Two of the participants described their experiences of attempts at committing suicide. Eniola [23, female, Christian, student] recounted the day she decided to take her life. She made a choice to die and begged God to take her life. She was in great ordeal. However she considered asking for help, and made some attempt using her possible network of support. When there was no forthcoming support, she made the attempt. She recalled that:

“I would pray to God to please take my life. I would prefer to be dead. There was even a time I took Lysol, you know Lysol? It is for wound. It is poison. My mum bought it for a cousin of mine to use to treat her hand wound. When I took the Lysol, I wanted to drink it and I wanted to die. I was in serious pains. I called my brother on phone; he said he had no time for me. I don’t even want to call mum because she would not be able to leave where she was at that time. She was busy with her boss. My brother refused to come. I opened the Lysol and was about to take it that was when my brother came in. When he saw me, he started to beg me not to kill myself.”

Eniola showed some reluctance to commit suicide as suggested in her consideration of God, her call to God, her call to her brother and the consideration of her mother. She mentioned her brother’s refusal to come and support her as well as the futility of having the support of her mother in that moment. In addition to the pains, she sensed lack of support and she felt it was better to take the poison.

Babalola [22, male, Muslim, artisan] looked at how he had been in life moment by moment and he expressed thoughts of suicide in stronger terms. He recounted:

“I am sad and life is just treating me badly. But what can I do? Sometimes I think maybe I should go and hang myself. I also think there is no God. I am sad; there is not a time that I am happy. These thoughts are always with me and they make me sad unhappy. I am not always happy. There is no day in my life that I can remember that I was happy. I would think sometimes that maybe I should go and poison myself. I would see my friends; they would have visitations from their girlfriends. For me, I don’t have any girlfriend.”

Babalola in his description noted a need to have support. However there was no social support and he felt it was better to die. He reiterated that his interaction with life puts him
in bad state and he was not always happy. He later recalled a day he made an attempt at suicide,

“I remember the day that I wanted to swallow poison. I was given a net to use to cover some chemicals at home. That day I was in pains, I had back aches and from inside the bones. I could not stand, in fact when I wanted to go to toilet, people had to carry me. I was alone at some point in time, so I dragged myself to where the chemicals were. They were chemicals to spray on nets to prevent mosquito bites. I opened the chemicals and was about to put it on my lips when I thought it was not necessary to do this. I thought God would punish me more if I did it. So I dropped the chemicals and left.”

In their thoughts of suicide, they highlighted their experience of a lack of social support from relatives and friends. This draws attention to other factors beyond their SCD in the genesis of suicidal thoughts. They initially showed some reluctance to commit suicide, but this reluctance yielded to suicidal attempts when social support could not be gained. With the absence or no expectation of social network and support, it was better to die. It is notable that they even made attempts to gain social support with a trade-off between short-term enjoyable activities and long-term physical harm to health. The participants conceived this recklessness as suicidal too. When there is social support, it is gained at their health expense and when they do not have this support; it is lost at their expense too.

Theme VII: Coping with SCD

Thirteen of the fifteen participants described how they coped with SCD. Ten of these thirteen coped by being careful and staying within their physical limits while the other remaining three coped by being careful and frugal with money.

Sub-themes

1. Being careful and staying within your limits

Ten of the fifteen participants realized that if they could stay within their limits they could still participate in activities that would allow them to fit into the society. Damilola mentioned she would want to part of her friends’ network and be like them. To fit into that framework would mean going to parties, dancing and some loss of sleep during that time.
These demands could be too much for her but she had learnt through experience that she could fit in by engaging in those activities in a different way. She said:

“You know I just want to be like my friends. I still do those things, but what I now try to do is that when I go to parties, I dance less, I sit down more frequently. Then when I get home, instead of sitting down to gist with my friends, I go to rest and drink plenty of water. I sleep more. I know I won’t stop doing those things. I just knew I had to put some things in place to make me balanced. If I know like I have stressed myself for like 2 days, I put in more rest, more sleep, and drink plenty of fluids. I stay indoors for like 3 days and rest and then I feel better... I do things I could do in the house; I don’t do things that would stress me out. I know what I could do. The amount of clothes I could wash at a time. The buckets of water I could fetch in a day. I know and I don’t go beyond my limits. You can’t even force me to do that. After school, I just go straight home and I sleep. I sleep not less than eight hours every day. When I don’t have lectures in school I don’t have to go to school. I stay at home and I rest. I make sure I get plenty of rest. That cannot also be compromised. No way. These are things that work for me.”

She knew the amounts of clothes she could wash at a time, the buckets of water she could fetch and the amount of sleep she would benefit from. She also described how staying at home and resting enough could not be compromised. They are all components of her functionality in her world. Bolaji [25, male, Christian, fresh graduate] also noted that being careful and avoiding stress could help in fitting into the society.

“But I have been taking this drug but it has not really helped me. So what I discovered was that if I keep away from stress, I don’t feel the pain. Anything heavy, I don’t carry. I don’t walk long distance. Anywhere I go to, I take bike or bus. Even if it is not far, I take a ride. I avoid stress most of the times. If I do them, I can visit and play with friends.”

Bolaji had shown that he could do things normally by staying within his capacity. He would therefore not carry heavy loads; walk long or seeming short distances. These aspects of his behaviors allow him to sustain his friendship. In both instances, the behaviour is also oriented to “fitting in” to being part of a group to being accepted by peers.
2. *Being careful and frugal with money*

Three of the participants described how they were able to fit into the society when they managed their finances appropriately. Funke [32, female, Christian, teacher] said she saw herself as normal as others as long as she took her medication and cut on her expenses to save money. She made efforts to save money to enable her to take her drugs regularly. She did not prioritize purchasing dresses (a socially valued activity she enjoys) over drugs. If you “cut your coat according to your cloth” you only buy things you can afford, and here Funke extends the metaphor by suggesting she only remains alive to buy the cloth to fit her body by restricting expenditure on parties and dresses in the first place. Funke said:

“So I see myself as normal people as other people as AA or as AS, so for the fact that I’m taking my drug and even taking my drug regularly, I think I can even live longer than the age that I think. I think I can live longer than the age expected of SS. It is just that this thing it includes a lot of money. It costs a lot. That’s why me personally I normally cut some things maybe the money to make party, dress; I don’t put myself in that kind of situation or my money on it. I see myself like let me take care of myself, if I can take care of myself and I can stand the world and I can stand outside and that me too I’m a normal person, of course, I would still be able to buy that cloth that would fit my body. If I don’t do it that way, the cloth would not fit me [I won’t fit into the normal stereotype of a normal person in the society]. By doings things this way I fit into the society and I don’t think I’m an SS anymore… There is nothing. Use herbs, use drugs, there is nothing. Me too I want to feel among. I don’t want people to reject me. I don’t want to hear people say I can’t be seen with them or that I am not okay. I want to feel among like others. So there is nothing we can’t do as work, though there are some jobs that we may have to do in small measured ways. We would not use the strength all at once. We would do it in graded manner. So it is not as if we cannot do any work. Even all my friends that I move with now; I tell them that it is only if I tell you that you will know that I am a sickle cell patient. Even when they do hold parties, I normally attend. I would help in the cooking, arranging tables, many activities to make the party go well.”

In addition to buying the metaphorical cloth, Funke stayed within her limit of physical capacity.

She did not use all her strength at once. And in this way, she could fit into the society by engaging in jobs, in parties, in cooking and other things to ensure that parties are held and
others enjoyed themselves. She therefore did not experience discriminatory remarks or reactions from her friends to the extent that she made adjustments to her way of living.

Gbenga [21, male, Christian, Student] talked about balanced diet in order to act normal in line with others in the society. He had observed that when he ate sufficient protein and took plenty of water, he had no pains and people were not able to tell whether or not he had sickle cell. He said,

“They say we should take enough of protein and just little of carbohydrate. This is because of the shape of the sickle cell. Some people without asking them, by just looking at them, you will know they have sickle cell. Some have swollen fingers, swollen stomachs, and their eyeballs too are very yellow. To avoid these, we are told to take plenty of water and enough of protein. And little of carbohydrate should be taken. If we do all these, we are going to be healthy and live long. I eat plenty of proteinous foods, plenty of fruits and little carbohydrate. I have little or no pains throughout the year. If you look at me, you won’t be able to tell if I have sickle cell or not. I am like any other human being.”

Participants at this stage of the interview could be seen to have framed SCD as a problem within themselves, and thus accepting the responsibility for adjustments by policing themselves to stay within their limits of physical and financial capacity. In other words, they seem to renegotiate their social identity by policing themselves.

**Conclusion**

In this chapter we have outlined some of the main features of the accounts given at interview by fifteen people living with SCD and depression. We have seen that the majority report disapproving remarks from a wide range of others: family, friends, neighbours, teachers, school peers, doctors, nurses, potential employers and even from individuals or groups in the street who do not know them, but feel they have a right to comment negatively on the life of someone with SCD. The fact that this experience permeates so much of their lives, so frequently, and with such intensity, and that they themselves associate these negative experiences with lowering their mood, suggests such social discrimination might conceivably be implicated in the genesis of depression. The participants shared experiences that suggest frequent and regular encounters of disapproval
from various aspects of their social world extending from basic unit of family to the wider society. These overlapping instances of disapproval, which could be conceptualized as a “chorus of disapproval”, place them in a difficult position where they are subject to negative experiences of sadness, depression and shame.

They recounted experiences of being held responsible for painful crises, and the exaggeration of pain, in such a way that other social actors portrayed them as wicked and undeserving of support and care. The participants highlighted areas of neglect and abuse which, if prevented through social re-arrangement with support and care, would allow possible shift of focus to more positive achievements for persons with SCD. The social reactions of others arguably derive from the social expectations that persons with SCD break as well as negative ascriptions being made due to identification of participants as having SCD and the effects of this as a stigmatizing label in itself and not the SCD per se.

In order to make living with SCD more meaningful, and possibly avoid the chorus of disapproval, through others policing them and through learning from early life what SCD means, have accepted their position and thus perceive themselves as different from others. This framework locates the problem in themselves, and does not frame the problem as located in the social arrangements. The present social arrangements with pervading beliefs also preoccupy the mind of persons with SCD with negative framing of events so that they cannot enjoy life, plan for the future, or keep things in perspective. For example, being made to fear death led some participants in their accounts to risky behaviours (and could potentially lead others), and to restrict their ambitions or limit the extent to which they focus outwards to others in society. It is arguable that social arrangements which focus disapproval onto persons with SCD, and the constant focus on early death predicted by others might contribute to low mood, depression, and ultimately to suicidal thoughts or suicidal actions. In their thoughts of suicide, they highlighted their experience of a lack of social support from relatives and friends which draws attention to other factors beyond their SCD in the genesis of their suicidal thoughts and other negative experiences.
One potential source of social support is of course the company of others living with SCD, and the potential dual purpose of focus groups (as both data collection method and an opportunity for people living with SCD to network with one another and offer mutual support) was a preconceived part of the overall research strategy. In the next chapter we examine more closely the testimonies of people with SCD, but this time in the context of speaking together in groups.
CHAPTER 6 - FINDINGS 3: RESULTS OF FOCUS GROUP DISCUSSIONS

Introduction

The previous chapter presented the findings of the interviews, which highlighted that illness experience could not be simply reduced to the biological disease, but that discriminatory social structures might be contributing to the challenges facing people living with SCD. In this chapter, it will be noted that many of the themes that were presented in the previous chapter resurfaced during the first round of each of the focus groups. These repeated themes are experiencing disapproval, experience of disbelief about pain from significant others, experience of stigma, I am a different person, thinking and talking about death, we wished we were dead, and coping with SCD. This Chapter 6 does not focus on these themes because they formed part of the process of people with SCD, who did not previously know one another, getting to know one another, and because in Chapter 5 there was a detailed exposition of these themes so there is no need to repeat them in detail here in Chapter 6.

This chapter presents the findings of six focus group discussions which sought to understand how the discriminatory social structures that might contribute to the challenges of the participants can be confronted. Apart from the new themes that emerged from the focus groups it is notable to highlight that the participants in the focus groups engaged with
one another with confidence, they interacted with openness, validated and affirmed their experiences, challenged each other with a view to making life comfortable for and beyond themselves, and they gave support to one another. Their interactions seem to underlie the development and reaffirmation of social interests held in common among themselves. The process of coming together in a supportive group with other people with SCD itself is arguably a catalyst for different kinds of conversation and action that will help persons with SCD renegotiate their identity. Being in groups is most likely to create the right conditions to validate their experiences, and share insights into what could be oppressive in these experiences. In the process of interaction with similar others, while identifying negative social processes, the possibility of making attempts to challenge them is high. In line, they will begin to realize the need to support one another and think of extending this to others with SCD including next generation with SCD against some of the impacts of negative social reactions. By initiating the creation of a network of support or something like peer communities, this will begin to lay the foundation for a positive sense of self for persons with SCD with stigmatized identities.

The profile of the participants in the focus groups:

There were 15 individual interviewees and ten out of these participated in the focus groups. The six that were lost from the study were not available because of resumption of their studies in school outside of Lagos or they were ill and admitted into hospital. These five people were not different in any way in their views from the remaining ten who took part. Focus Group A consisted of five participants: Eniola [23 years, female, Christian, student/Radio Presenter], Odekunle [50 years, male, Christian, Journalist], Niniola [25 years, female, Eckist, Community Health Extension Worker], Ifeoluwa [22 years, female, Christian, Student] and Aderonke [43 years, female, Christian, Widow] and met three times (FGA1, FGA2 and FGA3). Focus Group B consisted of five participants: Comfort [42 years, female, Christian, Secretary], Damilola [29 years, female, Christian, Seamstress], Gbenga [21 years, male, Christian, Student], Hannah [27 years, female, Christian, Petty trader], and Joke [39 years, female, Christian, Caterer] and met three times (FGB1, FGB2 and FGB3).
Each focus group identified the most important issues related to their challenges and how social structures could change to accommodate them in a positive, supportive way. In the focus group discussions, in addition to an initial reiteration of themes covered in individual interviews, ten primary thematic categories related to living with SCD and depression emerged. These themes (and sub-themes) identified are:

1. survival and success reaffirming positive identity of SCD [survival reaffirms positive identity of SCD, pain experiences reaffirms positive SCD identity in comparison with others, and pain as a catalyst for positive relationships],
2. being in group opens opportunities for self-disclosure and encouragement [illness sometimes unpredictable, not alone in the family, and living with SCD as it is in you],
3. group interaction reinforces the belief that the problem lies in others rather than in themselves as someone with SCD [the problems lie in the society, and the problems lie in the family],
4. sharing information that is of possible use to one another [sharing information about a clinic with better treatment for SCD, sharing information about a sickle cell club with helpful tips on SCD management, sharing information about genuine centers for genotype tests, and sharing information on self-management of pain with social interaction],
5. Discussion of possible mutual support group [look after others with SCD who lack family support, look after others with SCD so they do not stress/kill themselves with overly heroic individual efforts, providing information to guide parents and protect the next generation with SCD, support for parents of young ones with SCD, and support for young ones with SCD]
6. Challenging counterproductive strategies [debating stress management with house help, debating the management of pain episodes, challenging counterproductive strategies of survival in the society, and debating the merit of a relationship with AS or SS persons]
7. Challenging negative attitudes/reactions/labels [challenging the attitude of others who feel they have the right to pass opinions on those living with SCD, developing the resilience to challenge negative labels, negative attitude/reaction of others as a form of violence against the person with SCD, and challenge to a nurse who projected a negative image of people with SCD by use of negative labels]

8. Getting ready to address social barriers [they are prepared to talk themselves about sickle cell in public, sharing benefits of standing up for SCD and the idea that persons with SCD should represent themselves]

9. Canvassing for support from significant others [strategy to have buy-in of NGOs to support them, educating significant others to be better advocates for SCD, and educating other regular community leaders about SCD]

10. Areas of interest to the group [campaign for genotype test, people with SCD could be trained to be peer counsellors, accessing/using the media for campaigns, the importance of getting many stories of SCD into the public domain because not all are the same, reporting mechanism for those who abuse people with SCD and support mechanisms for people with SCD, possible strategies to achieve reasonable adjustments in schools/employment, strategies for reasonable adjustment in the hospitals, and debates around microfinance and cooperative approaches to finance]

The following discussion summarizes the themes that emerged in the six focus group meetings. Samples of participants’ comments on the above themes with the author’s interpretation of their meanings are provided below.

**Theme I: Survival and success reaffirming positive identity of SCD**

Members of both groups related individual experiences that showed survival as reaffirming positive identity of SCD, how pain experiences reaffirmed positive SCD identity in comparison with others, and even how pain might be conceived as a catalyst for positive relationships. This theme emerged gradually as members of the groups began to know each other during the first and subsequent focus groups.
Sub-themes

1. Survival as reaffirming positive identity of SCD

Early on in both focus groups, the participants shared experiences that reaffirmed their positive identity as persons living with SCD. They recalled certain experiences that illustrated their survival to date and/or their success in life as a reflection of their positive identity. Members of both groups further reflected on their lived experience and recounted how living with SCD has made a positive impact on their confidence in facing challenges in life. The following discussion highlights their shared experiences:

“Aderonke [43 years, female, Christian, Widow]: We are talking about relationships and having good time. As I said before, I was like a tomboy and I go out a lot. I joined dancing club and I was one of the best dancers in school (secondary) then. I have also realized that SS persons are very intelligent. No matter how playful we are when we sit down to read our books, we are the best.

Eniola: Yes we are intelligent!

Niniola: Very sure…

Odekunle: That is true” [FGA1: 6]

Aderonke noted that she realized that persons with SCD were very intelligent when they sit down to read their books. In response to her assertion, some of the participants affirmed it (Eniola), some said it was certainly the case (Niniola) and that this was true account (Odekunle). It seemed these participants resonate with Aderonke’s impression about the intelligence of persons with SCD. It is apt to note that there were few of these positive comments affirmatory of the abilities of SCD in individual interviews but there were more such comments in these focus groups. They also identified positive characteristics that would help them as a group to face social challenges. They had the following conversational exchange:

“Joke [39 years, female, Christian, Caterer]: Living with sickle cell has made me to be bold and to face reality. There is nothing now that I cannot face. Maybe because I have gone through a lot, and because my friends have deserted me, I have learnt to do things on my own. Even if the pains got me
so badly, I can still get up and do some things for myself. I will cook the food I want to eat or boil the water I want to use for myself. So sickle cell has made me strong and to rely on myself. I can do anything, there is no challenge that I cannot face now. It has made me much stronger and much closer to God.

Comfort [42 years, female, Christian, Secretary]: It has even made me strong like she said, you don’t have anybody around you. You learn to do what you have to do. I am also very strong being a ‘sickler’. I don’t really feel too bad about it because I know there is a reason for it and God knows it. I have been living with it successfully and I am okay by the grace of God. At work I am also strong because of what they do for me. You cannot let them know you cannot do this and that. When you see that telling them make you to lose some things like money and respect, you learn to do things yourself. By then you make yourself strong and act as if whatever they ask you to do you can do it. You also learn to do these things with little or no stress. When you avoid stress as much as you can, you pace yourself at work and plan far ahead. Nobody will say you are not meeting your target. You know what you have to do and you do it on time.

Gbenga [21 years, male, Christian, Student]: My grand-mother, my mother and my auntie they always encourage me and I appreciate their support. They all have sickle cell and they know how to guide me too. So I don’t see having sickle cell as the end of life. I have ways of coping with life and I can even do better in life than those who do not even have sickle cell. I am strong and belief in myself. Sickle cell is not a negative in my life.

Damilola [29 years, female, Christian, Seamstress]: Well it has made me a strong person.”

In this exchange, they all identified in themselves positive qualities of self-independence and self-reliance that emerged, sometimes in opposition to lack of social support, and even when they were in pain. In addition, Comfort shared the perspective of focusing more on strength and less on weakness, and the act of learning to be resilient and meeting goals when there is no support. Gbenga contributed his view that when there was support from others, the negative view of SCD did not arise. As Aderonke mentioned in the beginning, this was the first time they were meeting as a group, following the in-depth interviews, and they focused on more positive experiences in their lives. In this instance they were in a group comprised exclusively of people with SCD, and so they did not have the negative community commentators present. There is the possibility that it is the group situation that permits them to propose the positive characteristics of people with SCD and to be affirmed.
in that view by others. This possibility could happen as they convince themselves that they have vested interests in common of shared negative experiences).

2. *Pain experiences reaffirm positive identity in comparison to others*

The participants also had the opportunity to reflect with others on their past experiences of pain. However, in contrast to the exposition of pain in the individual interviews, in the focus groups they also noted the positive aspects of pain from their past experiences. They compared themselves with others and discussed the positive consequences of living with pain:

“Aderonke: But with sickle cell, you can cope with all kinds of pain. Any pain that comes your way, you can cope better than someone that is not an SS patient. Each time I remember this, it makes me get stronger and stronger. Each time I see this, I get stronger and stronger. It makes me feel that my blood is a wonderful blood. Although, there may be a problem, there may be something inside that blood, but I believe there is a purpose why God created that blood into me. It is a wonderful blood. I may not be able to jump around the way some people jump, and come back and take their bath and go to sleep when I would feel that I went through a stressful job today, I did a stressful thing today and it would show in my body, but then, I know that the blood is the best of all blood for me. The pain that SS patients go through and they survive if other people go through it they will die. An SS patient when he goes through pain, he would get up and move around, but some others when they go through that pain, that’s the last of them. They will not make it, the next thing is they are in the mortuary. So that keeps me going.

Odekunle: Yes that is true.

Niniola: They cannot bear pains like us

Eniola: Yes, you are right. ” [FGA1: 18]

Aderonke saw the advantage of being a person with SCD as it relates to the capacity to cope with all kinds of pain. She emphasized all kinds of pain. She then went further to review the blood of a person with SCD and called it a ‘wonderful blood’ and saw it as the best fit of blood for her. Other participants could identify with all that Aderonke said. It is noteworthy that this kind of positive framing and sense of achievement did not emerge in the individual interviews.
Such comparisons of oneself to others did not occur in the in-depth interviews. Coming together might be having the effect of drawing out the positive identity of life as persons with SCD. The participants also shared among themselves experiences that illustrated how pain reaffirms positive identity in persons with SCD.

“Damilola: It was a motor vehicle accident and I was in a bush in pains. I had a broken leg, and though I was really in pains, I was like the crisis pain was more than this and I don’t need to shout like others who had fractures in the accident. In fact one guy had died already and I looked at him and said to myself if I had died, I would even be free of these pains. I wasn’t afraid. I was having pains like mad but I was saying to myself that it wasn’t up to the pains of crisis. When they now took me to the hospital and the doctors saw me, they said I did not behave as a person who had accident and got a fracture. They asked if I was among the accident victims and I said yes. They said “you look stronger than these other people then.” I was stronger than people with AA and this gives me strength and courage that if anything happens to me, I would overcome it. So I don’t believe that there is anything that will make me weak. I have given myself that courage and that confidence to meet with life on its terms”

Odekunle: This sickle cell of a thing has heightened my pain threshold. I can take a lot of pain, I can take a lot of stress and I keep going.” [FGA1: 22]

The two participants here mentioned how they saw living with SCD as being responsible for having heightened pain threshold compared to others, and the ability to take a lot of stress and keep going. They showed by example that they can counter the negative stereotype that people with SCD have lower pain thresholds (see above, page 6; Chapter 5, page 19-23).

3. Pain as a catalyst for positive relationships

In FGA1, participants looked at the impact of pain on their social relationships. Odekunle noted that, with hindsight, his previous experiences of painful crises had a positive meaning. It cemented his relationship with his mother. He saw his mother as his doctor possibly playing the role of making diagnosis and initiating treatment plan, as his nurse, who possibly continued cares for him and as a friend, who shared his pains and joys with him.
“Odekunle: And ehm... those years of childhood and teenage, I was having crisis, she was always the one, she was my doctor, she was my nurse, she was my friend. And there was even an occasion when she got so fed up, so fed up that she started to cry. And out of sympathy for that, I cried too. So we both cried together, but today I see it as a positive experience. At that time I didn’t like the fact that my illness was making her to cry but the illness sort of cemented our relationship and we shared a lot together.

Eniola: So it was comforting to know

Niniola: True

Aderonke: Exactly that is it.” [FGA1: 3]

Others participants in this group validated the experiences of Odekunle, along with the meanings he attributed to them. They all affirmed what he said. It was comforting to know that he had such stories to share. SCD pain is held to teach others something about life. It could be one of the opportunities to develop empathy for the pain of others.

In the first series of focus groups, the participants described experiences where positive aspects of their identities such as self-independence, self-reliance, in short a positive view of SCD, were foregrounded. They listened to each other’s narratives and validated the positive messages in these narratives. They saw their survival and success in life as reaffirming their sense of identity, pride and strength. They come to a collective realization that sympathy and support from others, especially from significant others, and support that is sustained over a long time, can be very beneficial to the experience of living with SCD.

Theme II: Being in a group provides opportunity for self-disclosure and encouragement

In the focus groups, participants shared their views about aspects of living with SCD. They sought clarification from others about the unpredictability of SCD illness; they shared experiences that showed they were not alone in their family, and they also talked about how they saw themselves as living with SCD. As others made their contributions, they confirmed one another’s’ experiences.
Sub-themes

1. Illness is sometimes unpredictable

Joke [39 years, female, Christian, Caterer] sought to clarify whether or not others experienced their illness as unpredictable. She started the discussion thus:

“Joke: You all know that sometimes this our illness does not show. Many at times, you will wake up in the morning feeling well, there is nothing wrong with you; you look agile and ready to face the day. There was a day I went out. There was nothing wrong with me that morning. I had crisis at Ketu (name changed). But that day if I had had some symptoms, I would not have gone out. I would not have left the house. I don’t know if it is like that for everybody.

Gbenga: Yes it happens.

Hannah: It is like that. It will just happen suddenly. You could have just finished washing or cleaning and you felt okay before you started to do this, but you will suddenly fall into crisis.

Gbenga: There was a day I was cutting onions and I started to have pains all of a sudden. People around would not understand and would say but you woke up healthy this morning. I just went downstairs and sat down to rest. If they see me and complained I was not working, I would not answer them because they would not understand. They will even make the matters worse for you by saying but you are well this morning, what kind of illness is this and so on.” [FGB1: 4]

Joke found out that her experiences with regards to the onset of crisis were not unique but shared. The participants living with SCD brought to the fore how their onset of illness could be understood as different from how other illnesses could start. They highlighted that others would not understand this. In their view, others probably had a fixed concept that illness was reliable in terms of time of its onset. Gbenga mentioned how this lack of understanding shown in the reactions of others could impact negatively on his lived experience. By implication the suggestion is that empathy from others who share the experience would impact positively.
2. Not alone in the family

Participants in both groups related experiences of when they realized they were not alone in their family. Odekunle narrated how he realized that he was not alone and that he was not an Ogbanje (malevolent spirit) as previously thought by members of his family. He led this strand of discussion when he said:

“Odekunle: exactly, it was a comfort to hear and know that I am not an Ogbanje. Okay so they were carriers which they didn’t know. Today I have nephews with sickle cell. I do my best to encourage them and this is positive for me too.

Aderonke: Let us continue, you have really encouraged us with all that you have said… I have a sister abroad who has a son with SS. She now understands me better. It is comforting to know and it gives you the experience that wow, I am not alone. It brings some people closer to you.” [FGA1: 4]

Aderonke could connect with Odekunle. In this shared narrative, Odekunle reflected on how he used to think about his life as a cursed existence, and how this view changed with the births of nephews and nieces with SCD. He expressed the comfort and relief he had to know he was not alone in the family as someone with SCD. He was also able to use this experience to reject the label of Ogbanje. Aderonke expressed that his narrative was encouraging to them. It reaffirms in them that they are not Ogbanje and that there is another, different, and positive aspect to being a person with SCD in that it brings people closer to you. This self-disclosure and reflection could be a source of encouragement to others to adopt and maintain a positive attitude to themselves.

The participants had greater opportunity to express and disclose more of themselves than in the in-depth interviews. They provided a sounding board for others with their experiences. They also appeared to derive encouragements from such interactions.

3. Living with SCD ‘as it is in you’
Participants discussed what living with SCD meant for them. They encouraged themselves to accept a practical point of view. In the following discussion, it is interesting that they expressed the illness as being embodied.

“Damilola: It is not that I don’t know I have it inside me, but I have decided to live with it and enjoy my life as much as possible.

Joke: But when you have something in you, you just have to maintain your life and cope with it. It will not go, but you can live with it.

Hannah: God bless you, that is the key, living with it as it is in you. Coping with it and getting what you want in life.” [FGB1: 5]

When Hannah said ‘God bless you’ to Joke and Damilola, she meant that they expressed her view about SCD correctly. They all shared: I have it inside me (Damilola), you have something in you (Joke) and living with it as it is in you (Hannah).

They also showed in their individual expressions decisions to ‘live with it’, you just have to ‘maintain your life and cope with it’ and coping with it and ‘getting what you want in life’.

Being in the group allowed them to disclose safely, and use others’ experiences to validate themselves. It is important to note that this did not happen in the interviews. They learnt that their illnesses are unpredictable, and not unique to one person, and they also confirmed how it was comforting to know that they are not alone in the family when they had relatives with SCD. In addition, they shared the view that the illness is embodied and they needed to cope with it in order to get what they want in life. Being in the group appears to be a sounding board for them to reaffirm that their experiences are not unique and are held in common with persons who have SCD; that they are not alone in the family and could get close to others in the family; to reinforce the view that it is possible to successfully manage living with SCD, and to orientate themselves to obtaining what they want in life.

Theme III: Group interaction reinforces the view that the problem lies in others

During discussions, members of both groups noted that the problem lies in others rather than themselves. Instead the problem could be located in the family or in the society at
large. In FGA1 and FGA2, members noted that the problem resided in the society while in FGB1, they talked about the problem being in the family.

Sub-themes

1. Problem lies in the society too

In FGA1, others in the community were reported to have ascribed the negative label of Ogbanje to persons with SCD, and persons with SCD apparently accepted this view of society and thought they were accursed and responsible for their problems. A different emphasis emerged later in the focus group, and the new positive view was reinforced by reference to the role model represented by others, such as a person with SCD who wrote a book. Eniola said this:

“Eniola: Before I used to think being an SS patient I am accursed like people used to tell me then that I am an “Ogbanje”. They used to tell me in my family that I am the cause of their poverty; I caused this negative thing or that. I used to accept that blame and believed it was true. But later when it got dawn on me that these things are not true, I started to develop this kind of strength, I wouldn’t call it strength, it is courage, I developed this courage because I have been reading lots of books such as the “I Am Still Standing” [a book written by someone living with SCD] and even I have met her in person. She had encouraged me and helped me a lot.

Aderonke: I realized that after some time and after reading this book. The society does not see the good things in us.” [FGA1: 17]

Aderonke supported this view, and noted the negative view of the society towards persons with SCD. The positive view of SCD by the participants emerges out of interactions with others living with SCD. The interaction with others was expressed by Ifeoluwa as giving her courage. This has implications, since meeting as a group could be a platform where encouragement could emanate from others and persons with SCD could support themselves to maintain their stance that they should be valued members of society.
In the FGA2, the following conversation took place:

“Eniola: I used to tell them that whatever black magic you can use against me will not work. I have not offended you; you are the ones who offended me by talking to me in a hurting manner, and looking down on me.

Ifeoluwa: I used to tell them too that whatever black magic you can use against me will not work. I would also say I have not offended you, you are the ones who offended me by talking to me in a hurting manner, and looking down on me.

Odekunle: Yes they are the ones who look down on us. They cause more problems for us because they do not understand us.

Aderonke: This is just not fair. Leaders in the society who should know and give us support are also against us.” [FGA2: 16]

They were discussing how they saw others in the society who looked down on them, and talked to them in a hurtful manner. They also mentioned that these negative attitudes and acts were seen in leaders in the society. Odekunle saw such leaders as lacking in understanding and a cause of more problems for persons with SCD. It seems that being in the group tends to facilitate greater identification of problems facing people with SCD as lying in the wider society than was the case during the in-depth interviews.

2. **Problem lies in the family**

Members of the group talked about family as the source of their problem. Joke in the group was able to air her view and had the opportunity to hear the views of others that it was not her fault. Gbenga pointed out that what she experienced was the kind of negative attitude most families have against persons with SCD. She was able to talk and be listened to. She knew she was not the problem from her experience but this feeling was reinforced by others in the group. She started:

“Joke: They are the source of this problem and they do not want to take care of me.

Hannah: It is not your fault now…

Joke: I know that I am not the problem, but I want my family to calm down.
Gbenga: That is a kind of negative attitude that most families have towards sickle cell persons. It is not good at all.

Joke: Yes they do not know. It is when I have started coming out and meeting with groups of persons with sickle cell that I myself knew that I do not have problems and they are the cause of my problems. I know that I am just as normal as others only that I need to take special care of myself. That’s all.” [FGB1: 1]

Joke was able to articulate herself the view that she was just as normal as others and what she needed was special care. Previous attendance of group meetings gave her this insight, and this insight was shared by others in Focus Group A. In other words, the coming together of persons with SCD could lead to the realization, or reinforce an existing belief, that the problem lies in others rather than in themselves.

In FGB1, they shared experiences that could show how the family contributes to the problems of persons with SCD because of their negative view.

“Comfort: They are ignorant about the disease and they need enlightenment. We need to campaign for the recognition and awareness of sickle cell for every family member of those with sickle cell for a start before we take it to everyone. They have a belief that sickle cell is spiritual and needs spiritual attention.

Joke: The reason is that of education. The reason why I am facing all these challenges is that my daddy is not alive. He is more educated than my mum and would have taught her not to say such things that she keeps saying up till now.

Comfort: They get aggressive against the child with sickle cell. So they need enlightenment programmes and also support from us who have gone through life with sickle cell. We can tell them how to make life easier for their children from our own experience.

Gbenga: When I cannot do something, I say I cannot do it and they don’t force me to do what I cannot do. This is what most parents should know. They should know the dos and don’ts of persons with sickle cell and strictly abide by them. It saves them a lot of harm and problems. They won’t have to pay extra in the hospital because the frequency of crisis will reduce and they will all be happy.” [FGB1: 9]

It is also interesting to observe that Comfort hints at a political strategy for sickle cell that recognizes the need to have allies. She suggested a campaign for recognition and awareness
of SCD for family members as a starting point before taking the campaigns to others in the society.

She also raised a possible benefit of such program for younger people with SCD. Gbenga corroborated what Comfort suggested, and also mentioned some advantages of this social re-arrangement such as cost savings in health bills, and a reduction in harm and problems for persons with SCD.

The participants in both groups had the opportunity to share their experiences. Their interactions highlighted past instances to illustrate how the family and the society could, via negative views, contribute to the problems of persons with SCD. But the forum of a group discussion also provided the opportunity for some participants to think of ways to address this issue as well as the possible gains of such approach.

**Theme IV: Sharing information that is of possible use to one another**

In both groups, members interacted with one another and shared information that could be of possible use to themselves. This created the opportunity for some participants to have access to a clinic with better treatment for SCD, to have access to a sickle cell club to learn more tips about self-management, to have information on reliable centers for genotype tests, and to have information on possible use of social interaction to reduce pain.

*Sub-themes*

1. *Sharing information about a clinic with better treatment for SCD*

Some participants offered information of where others could gain better access to care. In the following discussion, Joke expressed her experience of psychological distress which derived partly, at least, from the blame laid on her by others. Gbenga offered information that could begin to address her distress:

“Joke: I went there for a healing programme. There was this guy that conducted an interview with me there. This guy after some time told me that “you have sacrificed your leg inside your group’s darkness power. He said I contributed my leg as a sacrifice to the group.” He said that others of my age
have been contributing to the society via having marriages and children but I am contributing leg ulcer that is financial drain to the society. In fact that night, I could not sleep. I was crying and had psychological aches.

Gbenga: However, do you attend hematology clinic here and tell them about the leg ulcer?

Joke: I do attend here and I have complained about the leg ulcer. But they have not addressed the issue well. It keeps healing and coming back.

Gbenga: Can you attend the sickle cell clinic at Bayley [name changed]? I believe that where you are attending now, they have so many things in their plate and may not really have the time for you. But in this center I would like you to attend; their only focus is for persons with sickle cell every day of the week.” [FGB1: 1]

In this discussion, Joke’s desire was to have healing. She had been attending an orthodox clinic but the leg ulcer kept recurring. She wanted a permanent cure. However she described, in this spiritual place of healing she visited, how the blame was put on her for the leg ulcer she had. She was seen as a drain to the society in terms of finance and reproduction. She was blamed, and she cried and exhibited psychological distress. Gbenga provided peer support in terms of sharing information that could be of possible use to Joke. He emphasized that the clinic he would like her to attend was solely focused on persons with SCD. By sharing knowledge in this way another group member was able to point to a practical source of help. It is possible that this help would be of psychological as well as physical benefit.

2. *Sharing information about sickle cell club with helpful tips on SCD management*

In FGB1, they also shared information on where self-management tips could be accessed:

“Gbenga: If you have leg pains if you put a pillow under the leg and raise it, drink a lot of water and take some analgesics, under one hour it would subside.

Joke: I used to do that but it does not always work for me.

Gbenga: Well you need to attend our sickle cell club, there is a professor that comes to teach us how to manage ourselves and help ourselves with the crisis before we get to the hospital if it gets to that extent.” [FGB1: 4]
Joke had reached a point where her coping mechanism was no longer working. Gbenga offered her another opportunity to increase her fund of self-management strategies, thereby providing peer support to another person with SCD. Members of the group appear to be learning to support others with SCD with valuable information including possibly social information (i.e. rights and policies) to help them cope with lived experiences of SCD.

3. Sharing information about genuine centers for genotype tests

In the FGB1, members talked about inaccuracies in the results of genotype tests, and the tendency of some laboratories to manipulate results to establish an alleged miraculous change in genotype (from SS to AA) for some persons with SCD after some religious intervention. The following discussion ensued:

“Gbenga: Well concerning the belief that one can change your genotype, I guess the only way is through bone marrow transplant. And it is expensive. Concerning miracle, I don’t believe in it. I am a catholic, I have faith in God. I don’t believe in the miracle of changing blood genotype.

Joke: Haven’t you heard that it has happened before?

Gbenga: All those things are not true.

Joke: I have been in a church where someone gave a testimony that her genotype was changed. I have been to churches where they say they have changed people’s genotype. But my own did not change. I think they are all lying.

Gbenga: There was a woman who did her genotype in 3 different hospitals in three different states in Nigeria. In one, they gave her AS, in the next one, they gave her AC in two other places, and it was when she came to Lagos that she had the proper diagnosis of SS. She said she went for miracle and she said her genotype was changed to AA. But in a proper laboratory, she still had the test come out as SS. Some of these labs manipulate results for these churches. It is only through stem cell or bone marrow transplant that the genotype can be changed. People need to know this basic fact though in the church they will say if you don’t have faith, you will not believe in the power of God. Most people do not go to the appropriate lab. The machine for genotype is very costly and many of these fake labs cannot afford to buy the machine. And in most of these labs, they put several samples not properly labelled on their machine and work table and things get mixed up a lot. So their tests are not genuine, results gets mixed up and one cannot rely
on their results. And again, most of these private labs outside do not have people with experience and many of the ones who do the tests are young people without experience. People should have information on appropriate places where genotype tests can be done with certainty.

Joke: In the last sickle cell meeting that I attended, we discussed about this sickle cell test.” [FGB1: 7]

Joke related her experience of claims that a person’s genotype could be changed, but she realized through her interaction in a sickle cell support group that such claims are false. Gbenga supported her realization, and suggested the need to have information for persons with SCD and reliable services for those who wanted to know their status. It seems that in groups, participants were able to develop the confidence to reflect on their experiences and challenge certain practices as false and unhelpful. This, in contrast to interviews, also opened up the opportunity to think about what could be the problem and how to address this problem.

4. Sharing information on self-management of pain with social interaction

Participants talked about self-management of less severe pain through interaction with others. Aderonke shared this insight from her experience.

“Aderonke: When the pain is not all over me, I would move out and I’m off the house. I go to play, and hang out with friends. I am an extrovert. That has been helping me till now and that was why I mentioned that even when you are in pains and it is not too severe, try and move out. You will find out that you won’t remember you have pains after some time. I believe by the time you move out, you move around, and you talk with people, the pain would reduce,

Odekunle: It works.

Eniola: Even me, I do that and it works for the pains.” [FGA1: 5]

For Aderonke, being out in the world and talking to people is a good recipe for pain reduction, at least when the pain is moderate and not too severe. This is the same for Odekunle and for Eniola as well. It is notable that it is a social initiative (being focused outwards to others, engaging in social interaction) that is identified by Aderonke as one strategy to reduce pain. Furthermore, this social initiative is endorsed by two other
members of the group. In both focus discussion groups, participants were able to share information that could be useful to other members of the group. There is a process emerging of peer support in providing reliable and relevant information about access to dedicated clinics, health clubs and laboratories that could impact positively on the quality of life of persons with SCD. Part of the useful information also entailed the benefit of being in the world and talking with people in relation to mild to moderate pain for persons with sickle cell. This unfolding process, of sharing supportive information and practical social strategies in the focus groups, has the potential to be extended to wider peer support group for other persons with SCD.

**Theme V: Discussion of possible mutual support groups**

As the focus groups continued to meet, the participants started to contemplate the possibilities of mutual support groups for persons with SCD. They mentioned starting such groups to look after other SCD persons who lack family support, to look after persons with SCD who might stress/kill themselves with overly individual heroic efforts, to support the parents of younger people living with SCD and to provide information to guide parents in other to protect the next generation of persons with SCD.

1. **Looking after others with SCD who lack family support**

   In FGB1, they realized that Joke had little or no support from her family and others deliberated on what could possibly help her. Gbenga considered a company with mission to help persons such as Joke, but Damilola suggested establishing a support group and that would possibly take care of persons such as Joke.

   “Joke: I don’t even want to remember some days of interaction with my family. Even some days I don’t even know what went wrong with me. Since November last year, I have been up and down, up and down with one sickness or the other. For years I have not been admitted but since last year, I was admitted in December and January I was admitted. None of my family members showed up in the hospital during my admission and when I was being discharged.

   Gbenga: There is a company (name withheld) that gives a drug and it is blood supplement. They also give other medications to us free. I think you
need to register there. We need to share information on things and places where we can all benefit. This will help those who do not have access to information and we will be better for it.

Damilola: I think having a support group outside the family would help having listened to Joke. This group will give persons whose families are not supportive social support.” [FGB1: 7]

It could be argued that the process of being in a group, and discussing issues of mutual concern, was instrumental in opening up thoughts of setting up mutual groups to support persons with SCD.

Participants began to think about the relevance of a group to campaign for support for persons with SCD and for challenging negative labels put on persons with SCD. They started to suggest the formation of a group that would advocate for persons with SCD in various institutions including schools and government.

“Odekunle: We can then go on as a group to tell people about how to support us and not to exclude us from the society by giving us names that are not our parents’ names. So we need to work as a group to learn effective ways of responding individually to such persons and then learn how to address it as a group up to schools, and government levels. If we do it alone on the individual level I know it is not as effective as when it is done on the group level but I think the group can teach individuals to be confident and be strong and then the group can also create awareness on a broad basis so that most people will know and support the individuals. [FGA3: 6]

Odekunle pointed out that addressing the social problems facing persons with SCD individually would be problematic, but advised that the most effective means of addressing them would be in a group. He mentioned advantages of such group membership, such as teaching confidence, and strength to members and creating awareness among others in the society.

2. Look after others with SCD so they do not stress/kill themselves with overly heroic individual efforts

The participants raised the issue of a person with SCD who was working herself to death in other to gain social acceptance. Damilola confirmed that such people with SCD, who wish
to show that they could meet their social responsibilities, and that they could satisfy others, exist. Comfort thought of the means of addressing this situation which could otherwise lead to the death of those persons. She said they needed to be their ‘brother’s keeper’ and save them as a group.

“Joke: I know of a sickle cell woman that pounds yam for seven people in the household to make them happy.

Gbenga: Ha! She wants to kill herself.

Damilola: There are some people who would like to show that they can meet up with responsibilities and would want to satisfy others to the disadvantage of themselves. I cannot do that.

Comfort: This is what I have been saying. We need to be our brother’s keeper. I could imagine many persons with sickle cell trying to prove that they are strong and they kill themselves. We can save these persons as a group. When we talk on radio and television and any other means so that people know and understand what we can do and cannot do. When people know you have hypertension, they do not stress you. And the person with hypertension tells them and will not stress himself. Why can’t they do same thing for people with sickle cell?

Gbenga: It is the person with sickle cell who is trying to prove what is not there. It is the person with sickle cell that needs to be taught on what to do and what not to do and to have our backing as a group. She is killing herself under pretense.” [FGB1: 13]

They identified that persons with SCD negotiating possible social acceptance in such manner is problematic and that these people needed their support as a group. They needed to teach such class of persons with SCD what to do, and what not to do. They also realized that others whom this class of persons would like to satisfy needed to be reached through the media, possibly implying the need for a broader campaign of some sort.

3. Providing information to guide parents and protect next generation with SCD

There arose the issue of parents of persons with SCD who try to self-medicate their children in other to treat their SCD, and that this might be harming those young people with SCD.
“Damilola: When I was small they would give me all sorts of concoctions and herbal preparations. But now, you have to drag me before I would take all such. They are not healthy and they could complicate your issue. There is no standard measurement. I think the government should control the sales of such things or give more information to people about the harms of these combinations. Many persons with sickle cell are being harmed with these preparations from their parents who want to cure the sickle cell for them. When I was small, they gave me kerosene with some herbs to drink. They said it was supposed to cure the sickle cell in me. They also gave me chicken egg and lime.

Gbenga: They also give quail eggs and lime. They say it is good for all kinds of diseases. Some even will add Moringa seeds.

Joke: Cocoa too is involved in the preparation and pawpaw.

Damilola: When my mother-in-law came in one day, she said these yellow eyes can be removed with pawpaw and lime drink. She said it will clear the yellowness in the eyes. I did not drink it.

Joke: It is said to clear it. But I don’t know. It may not be true. You will be shocked at what people drink to boost their blood. I think people really want to have solution to this problem. The parents are trying but they need to be properly guided. They need information. Otherwise they will listen to this and that and will try all sorts of things that might injure the innocent kid.”

The participants mentioned that the parents wanted to treat things such as their yellow eyes, and their low blood level. Some wanted to cure the SCD completely. The parents would use herbal preparations that had no quality control, different fruit combinations, and other harmful substances such as kerosene. They suggested that there was need for parents to be properly guided and that the government needed to be play an active role in this endeavour. The members were beginning to identify issues that could be taken up by a group instead of by individuals. The participants thus touched upon a possible social re-arrangement that could improve the quality of life of persons with SCD.

4. Support for parents of younger ones with SCD

In FGA1, their discussion centered at some point on how to help parents of young people with SCD face those young persons later in life. These parents recognized that they took a
conscious decision to marry and have children despite their sickle cell carrier status. Odekunle illustrated how he was able to be of help with a particular case. He said:

“Odekunle: Some years ago before we started *Immaculate* sickle cell club [name changed], or by the time we just started, a woman came to me and said, “Look at this child that I’m carrying.” I said I have looked at him. She now asked, “Will this child not blame me when he is fifteen or sixteen years old?” I asked why. She said you see, I knew I was with the sickle cell carrier state, and my husband too knew. We were both AS. And now this child is SS, and later in life when his eyes are opened, when he is of age, 15 or 16 years old, he would now come back and ask me, “Why did you do this to me?”

Eniola: I have asked my mum such questions [laughing].

Odekunle: She even prefaced the question with another question. She asked, “please sir, have you ever blamed your parents for having this condition?” and then she also asked, “please how old are you?” I said well, this child, yes, the child would ask questions definitely. That was the first born, at that time she did not have another child. The boy was just about 15 months old. Later on he is going to ask, and this is the information age. He would go to the internet and search and know that it is only carriers who can have a child with SS. So definitely, prepare your mind he is going to ask. She now asked what she should tell him. I told her you need to tell her the truth. I told her tell him you knew of it. She even told me that as a child she lived in a medical compound and that she knew her genotype and the implications. But she said this one [male] would come and she would ask for genotype and it would be AS. She was sending them away. She said she lost five men like that. Then the sixth one came and he was AS again, so do I expect her to keep sending men away in these days that men are not serious to marry. So she decided that it is just a risk, it is one out of four. And she may just be lucky and not have a child with sickle cell. But the first child happened to be SS and that was why she came to me. I said well, you would be prepared and that there is something that children need to know. If they don’t need that experience, they would never have that condition. Since it is chance, if it is SS and SS now we know that definitely all the children would be SS, but if it is AS and AS, it is one out of four and if the one out of four happens to be this child, he can’t blame you now, he could have been something else. He could have been AS, he could have been AA but he wants this experience, he wants to go through life as SS and that is why he is SS. It is not because you took a risk, forget about taking risk, you are not the creator of SS. You are not the creator of genotype. God created him as SS for a purpose. If he had been AS maybe he would have died, if he had been AA maybe he would have died too, remember he was just 15 months. I said he could even have died before this age.” [FGA1: 26]
Eniola could identify with such instances that Odekunle painted. She said she had asked her parents such questions. But it seemed she had received no satisfying answers. Odekunle showed that it was more helpful to tell the truth about the social/family context of decision to have a child when both parents are carriers. In his narrative Odekunle was sharing this experience to illustrate the usefulness of having a sickle cell group, which could address the needs of parents of persons with SCD.

5. Support for the younger ones with SCD

In FGB1, the members started to share insights into strategies that could help younger generations of persons with SCD for example, Joke proffered that:

“I think if we talk to people and share our experiences with the young ones and correct their negative beliefs, life would be better for the young ones coming behind us.” [FGB1: 3]

Members of the group talked about being a career counselling group. Their goal would be to support persons with SCD at work and advocate for their rights. They would also counsel the younger ones about challenges they could face in the future. They considered helping them too with jobs that would suit the lifestyle of persons with SCD.

“Odekunle: And we could also be a career counselling group that supports persons with sickle cell at work and advocate for the right of the person. We can even counsel people about jobs that suit our lifestyle. We can also do this in schools so as to inform the young ones of certain challenges that lie ahead and ways of avoiding them or overcoming them.” [FGA3: 8]

The groups in their meetings highlighted the following issues: lack of family support in certain persons with SCD, ‘working to death’ to satisfy others and gain acceptance, unapproved self-medication of young people with SCD by parents, concern of sickle cell carriers who have kids with SCD, and job challenges of upcoming youths with SCD. Within these groups, members shared experiences to illuminate possible strategies to address the identified issues. Such strategies involved having sickle cell group that would provide support for: those without family support, those who might kill themselves to gain social acceptance, parents of those with SCD to guide in proper medications, sickle cell carriers who have SS children, students with SCD and employees with SCD. Their
deliberations in the groups underscored the possible crucial need to change social arrangements in order to improve the living conditions of persons with SCD.

**Theme VI: Challenging negative attitudes/reactions/labels**

In the focus groups they began to challenge the negative attitudes of others, their own negative reactions, and they also challenged the negative labels placed on persons with SCD.

*Sub-themes*

1. *Challenging the attitude of others who feel they have the right to pass opinions on those living with SCD*

In the FGB1, they talked about some aspects of the discrimination people with SCD seem to face. One is that others feel that they can go beyond the usual boundaries of social interactions and moralize, advise, chide people with respect to one aspect of their SCD. Damilola recalled:

“Like yesterday I want to buy diapers for my son and a woman told me that my eyes are yellow and I need to do something about it. She was like you are not well and you should go and take herbal preparations. She even asked are you really well? I don’t know her from Adam and she just invaded my space like that. It is not proper and that’s the way many of us are being treated without respect. If you tell them, they would also pity you and tell you sorry, oh, it is a pity as if you will die the next day and you are a walking corpse.” [FGB1: 3]

In her account, she identified two types of negative reaction, one of which is verbal abuse, and the other of which is sentimentality: a pitying of the person as if they are a helpless tragic victim. The fact that Damilola was able to raise this issue in the group, and not in the interviews, suggests that there is thus something significant about group membership/discussion in enabling this kind of reflection. Furthermore, Gbenga joined in the discussion to validate this common experience and the need to challenge it. He added,
“That is what I hate, the word pity and the demonstration that you are being pitied. For what reason should anyone pity me.” [FGB1: 3]

Gbenga did not like the word pity. He described the act that brings his feelings of hate as “the demonstration that you are being pitied”. In his description it seems he saw the person who demonstrated pity as pretending to be a “good” person who at the same time manages to position the person with SCD as a morally “bad” person. In other words, it is as if the person with SCD does not deserve pity, but others display pity to show others that “I am such a good person that I even pity those who do not deserve that pity”. Gbenga did not like such patronizing attitudes. This illustrates the possibility of others in the society positioning people with SCD as receiving, but not being deserving of, pity.

2. Developing the resilience to challenge negative labels:

In the FGB1, the participants also discussed how others used negative terms to refer to them. They said:

“Damilola: I don’t even feel comfortable saying the word ‘sickler’. It means I am known with sickness.

Hannah: yes. That word should not even be used for us. It is not a good word.”

Joke: It is not a good word…

Damilola: I think people should know and respect us and give us the space and what we need. It is our nature and that is it.

Gbenga: Once people cannot come to meet me and tell me the rubbish, I am okay. If there is a law that prohibits them from saying that and it is enforced, I am happy. They can have it in their minds but they don’t express it. That is okay.” [FGB1: 11]

It is interesting that the participants talked about the need to challenge others to change their attitude to them as persons with SCD. They said they deserved respect and their space. Gbenga was even of the opinion that there should be a law against putting negative labels on persons with SCD.
3. Negative attitude/reaction of others as a form of symbolic violence against the person with SCD

Participants described their experiences. There appears to be elements of validating one another’s experiences and exhorting another to challenge their circumstances.

“Niniola: Most times she tells me, most especially when I’m ill, she tells me that I’m the cause of my problem, that I am the one causing my sickness. That is what she tells me to the extent that I will start crying and I will be depressed.

Aderonke: Oh, no that cannot continue. You should have told her out rightly.

Eniola: Exactly the same thing that my brother says. He says who are you really? You are the emere in this house. You are the cause of our poverty as in we don’t have money and whenever we have money that is when you fall sick.

Aderonke: What I am telling you to do is that you [Niniola] should have claimed your right from your elder sister or Eniola from your brother. I had to fight for my right and my happiness. Fight for your freedom. Break free. I mean it.” [FGA1: 8]

It is also interesting that Aderonke talked of rights. They seem to see the negative attitude/reaction of others as a form of symbolic violence that needed to be challenged. In addition, it is noteworthy that the discriminatory social relationship is named as causing the depression rather than the SCD illness directly.

4. Challenge to a nurse who projected a negative image of people with SCD by use of negative labels

The participants talked about how others made reference to persons with SCD as ‘sicklers’ and raised the issue of a nurse who used such labels to project a negative image of people with SCD. Aderonke described how she rose to challenge such negative behavior of the nurse.

“Eniola: Well they used to say that the sickle cell stuff always means you are falling sick. But when I did my research, sickle cell does not mean you will fall sick all the time. Sickle cell is just about the blood and it doesn’t mean you will fall sick all the time. But when you tell them [people] that you have
sickle cell, they will say oh you are a sickler, which means you fall sick all the time.

Niniola: That’s the lay man’s understanding of sickle cell. Sickle cell, sickler means you are always falling ill.

Eniola: But if I try to explain to them, they don’t want to agree.

Aderonke: Well sickle cell people are always ill is what they say every time, but I could remember, maybe you would also remember, Odekunle, the event that happened to me in a teaching hospital. Maybe you would remember the way I gave it out to them. The workers there said “awon omo SS yi tun ti de,” [these people with sickle cell have come again] but they did not know I overheard them. I went to them and asked them if they were really sensible at all, I said “se ori yin pe rara,” [are you sound upstairs at all?].

Eniola: We went to confront her and we fought her.

Aderonke: I was the one who first gave it back to her. You were all silent until I gave it back to her. When I said oh what kind of rubbish did this nurse just say and I stood up to go and meet her. She heard me and ran into an office and locked herself in there. I went there and knocked at the door and asked her to open the door and face me. One of us said “ha auntie Aderonke, I trust you, you will fight her.” She did not come out. I asked her who were the “emere” children? Come out and tell me. But she did not talk inside and she didn’t open the door. The second day when she saw me, she was afraid…

Eniola: That second day was her birthday and she was asking her to wish her happy birthday and we told her that oh so you want emere and Ogbanje children to wish you happy birthday, you want bad children to wish you happy birthday. So you think we are friends with all you said yesterday, you say negative things about us, you prophesize negative things on us and you want us to wish you well. That is not the way the world goes round. Then she said she was sorry.” [FGA1: 16]

Their interaction thus illustrates an example of how group solidarity and action could have significant effect on the life-world of the participants or others with SCD. The exchange between Eniola and Aderonke is interesting, as Aderonke rebuked Eniola a little for claiming partial responsibility for confronting the nurse by saying “you were all silent until I gave it back to her”. Eniola then later reinforces her original assertion “we told her
that…” Their interaction illustrates how the participants are orientating and presenting themselves to the world in a group situation.

It is interesting to note how the group oriented themselves to one another and how they tried to make sense of their experience and address challenges. They were able to develop insights into negative reactions of others as a form of symbolic violence that needed to be challenged, even by means of legal redress, to challenge the negative attitudes of others, and to develop the resilience to challenge negative labels.

**Theme VII: Challenging counterproductive strategies**

The group provided the members with opportunities to debate animatedly during the sessions. They discussed among themselves about individual strategies that might make life easier for themselves. It was interesting to note how they debated and challenged what they felt could be counterproductive strategies. This section consists of their debates around issues such as management of stress with household help, management of pain, how to negotiate survival in the society and having a relationship with an AS or SS person.

*Sub-themes*

1. **Debating stress management with house help**

In FGB1, members talked around the issue of working with support. Joke saw herself as the strongest person in her family and mentioned that she could still manage to do her house chores during those periods of time that she had relief from crises. Other members thought that she needed to have support, because if she continued in such manner she would put herself at more risk of having crises frequently. They debated the idea of having a household help and the cost implications.

   “Joke: I am the strongest person in my family despite my ailment. I am the strongest among them. The work I can do, most of them cannot do it. If I have crisis and my clothes are dirty, once I have a small bit of relief, I will go and wash them. I will wash, I will spread and I will rest.

   Gbenga: But ma, I think you could pay for house-help. We sometimes need to have this kind of support in order not to go into crisis or stress frequently.
Damilola: Do you know what it costs to have a house-help? When you do not even have enough money to survive, the little you have you want to waste it on house-help.

Hannah: House-help may not be a bad idea. It is the money we are looking at. What about the relief from ailments and the rest it will afford you. You are not looking at the cost of that. I think we need support for some things so that we don’t expose ourselves to too much stress.” [FGB1: 15]

It is interesting to note that Hannah differentiated the cost of relief from stress and crisis from the cost of getting a house help. In her analysis, she pointed out that saving on the costs of house help could be counterproductive. The extract suggests the emergence of a problem-solving approach to issues within the group.

2. *Debating the management of pain episodes*

In FGB1, members also raised issues of strategies to manage their painful episodes. Members talked about pain that would not subside with some medications and how they tackled such problems. Joke started the discussion thus:

“Joke: I have pains now that only subside with diclofenac.

Gbenga: I have learnt that diclofenac causes stomach ulcer and I will suggest you replace it with tramadol.

Comfort: Doctors are very reluctant to write such drugs for you. They think we will get addicted to the drugs. Well but I know how to get the drug without doctor’s prescription. That is what can kill my pain and I do not abuse it. I only use it when I have the terrible pain I cannot manage with rest and paracetamol.

Gbenga: If you are good with injection, if you know how to give yourself injection, you can use Fortwin (pentazocine).

Joke: I want to learn how to give myself injection.

Gbenga: The only problem is if you can get addicted to the Fortwin. My auntie is now addicted to it, immediately she has a little pain she asks me to bring the drug for her and she takes it.

Hannah: I don’t know but it may not be that she is addicted. She may not want to experience that pain again. If I have the opportunity to have such drug, I will not allow any pain to worry me. I am looking for a drug that will remove this crisis and pains forever in my life.
Joke: That would be good” [FGB1:16]

They talked about the reluctance of medical doctors to prescribe pain medications because of the belief they could get addicted to the drugs. Comfort mentioned that she could get some pain medications without a doctor’s prescription, but she exercised caution with such medication. She would take such medication only when she had terrible pain. They came to the issue of drug addiction. Gbenga talked about the possibility of being addicted to Fortwin (an injectable opioid analgesic). He gave the example of his auntie who would use such medication to avoid even minimal pain. Hannah then mentioned that it would be desirable to have a drug that would remove crisis and pains in her life. Here she highlighted that what should be salient is the removal of pain and crisis and not the issue of drug addiction. The discussion provided an opportunity to consider strategies and look at the respective advantages and disadvantages. Being part of focus groups appeared to be giving members the opportunity to suggest, amend and debate strategies for pain relief within their own frame of reference.

3. Challenging counterproductive strategies of survival in society

Two members debated how to interact with others in the society. For Damilola it was better to ignore others and she mentioned that she herself had learned to adopt this strategy. However, Gbenga pointed out to her that if persons with SCD continued to ignore others then they would threaten their own survival in the society. They debated thus:

“Damilola: You learn to ignore people now. I have learnt to ignore people…

Gbenga: We cannot ignore people if we need to survive in the society. We need their understanding.” [FGB1: 8]

Unlike the in-depth interviews, focus groups provide the opportunity for disagreement. What is noteworthy about this disagreement above is that Gbenga encourages Damilola to consider the consequences for people with SCD as a class of persons. This might be considered a small step towards an understanding of having social interests as a collective. Members also talked about how to approach negative reactions of employers to persons
with SCD. Joke narrated how she was fired from her job because they identified her as a person with SCD.

“Joke: I have worked in places where they sent me packing immediately they heard I had sickle cell.

Gbenga: They fired you?

Joke: Yes.

Gbenga: You can sue them. This is true. How can they send me off my job because I have sickle cell? I will fight it.

Comfort: You will worsen the case like that. If you even succeed, it will put other employers on their toes. They will be asking you to do genotype and will not give you work if they know you have sickle cell. They may even use style to send you off to avoid legal case. We need the government to tell all employers that sickle cell is not a basis for rejection or being fired at work. [FGB1: 12]

It is interesting to observe the unfolding of issues as the discussion went on. Gbenga suggested the approach of using a lawsuit, but Comfort introduced an element of caution, having mentioned that, even if one case of lawsuit succeeded, there might be dire implications for others because employers would have invented possibly more difficult procedures (such as genotype screening) that would put persons with SCD at more disadvantage. She rather suggested an approach that would involve the government that would lead to a policy that protects persons with SCD.

1. Debating the merit of a relationship with AS or SS persons

Participants also debated the merits and demerits of entering a relationship with an SS or AS person. Eniola felt love that was more important, but others felt that love would not withstand the demands that would come later.

“Aderonke: If you want to get married don’t settle for any less than AA patient.

Odekunle: What if love comes in.

Aderonke: Well if you know you can allow your child to go through the pain you have gone through, then you can marry SS or AS.
Eniola: Love is strong and it can overcome. I have gone through a lot. It is what you have said. I am thinking of getting married to an AS guy. At most we won’t get children or we try just once.

Odekunle: Love will fly away.

Aderonke: Yes, love will disappear. How many kids can you deliver? Don’t say love. The man does not deliver and he would go to another woman. He is not ready to bear the burden like you. So love will change to hate and suffering.

Eniola: Thank you, I have learnt a lot today.” [FGA1: 14]

Eniola, it may be recalled, had gone through rejections from significant others and a rape experience from others and probably felt insecure with those with AA genotype and rather more secure with persons with sickle cell genotype. It is possible she felt such a person would develop empathy and understanding towards her and she would thus be acceptable. However, other participants seemed to act in a way they felt would be protective of a member of their class. In this discussion other members pointed out that most likely a woman with SCD would come out worse if she ever went into a relationship with an AS or SS man. They pointed out that it would be better for Eniola as a woman not to be fooled by love which would turn into hate and suffering when the man could not face the demands of such union and flee from her. They looked beyond the impulsive decision based on love and on the long term outcome. Eniola said she gained from their insight into the issue.

The participants have the opportunity to debate problems and come up with possible solutions within their own frame of reference, not frames of reference set by others. They also show signs of becoming aware that they have social interests in common as a class of persons. These participants in both groups had the opportunity of gaining insights into benefits of having support even when it could be at first financially costly. They also debated around what should be the priority in pain management – avoiding medication addiction or relief from pain and crisis. The counterproductive strategy of ‘ignoring people’ was debated and substituted with ‘gaining others acceptance with understanding’. The members also considered the involvement of government in making policy that could protect persons with SCD in obtaining employment and in remaining employed. The
members had the opportunity to debate problems and come up with possible solutions within their own frame of reference, and not frames of reference set by others. In addition, they showed signs of becoming aware that they have social interests in common as a class of persons.

Theme VIII: Standing up for SCD

In the group, members began to think about addressing the social hurdles themselves. The members noted that they should be the first to stand up to help one another. While they discussed among themselves about getting prepared to educate the public about sickle cell, they identified the benefits of standing up for SCD. There are two sub-themes under this theme.

Sub-themes

1. They are prepared to talk themselves about sickle cell in public

Members showed that they were not ready to hide their identity. They said they were proud to be persons with SCD and could stand up and speak for themselves anywhere. This is the momentum that they began their group session with. The discussion went thus:

“Hannah: I can say my own name…
Joke: I am not afraid to say my own too.
Comfort: there is nothing to be afraid of. I will say my name.
Gbenga: We are not afraid of anything and we are going to use our real names. Sickle cell is not a secret and not a shameful thing for us. We are proud people and not ashamed of ourselves. We can stand up and speak for ourselves anywhere.” [FGB1:2]

It seems that such qualities of confidence, boldness and positive self-esteem are necessary ingredients to be able to stand up and challenge the barriers limiting persons with SCD in the society.

In sustaining the momentum created above, the participants in FGB2 went further in sharing the benefits of standing up for SCD:
“Hannah: people have to know about this illness in the right and acceptable way so that all these negative attitudes will subside. If we do not talk about it, how will the negative view and bad treatment we get go away. We cannot wish them away but we need to face them and tell them with our mouths what sickle cell is and what it is not. If it comes from us directly and they see we can do well, they will change. But most of us hide and do not want people to know and so the society is not aware and treats us badly.

Joke: yes they have to know. This illness is becoming rampant and we that we have it are not getting good treatment. We need to protect the young ones that are coming up so that they don’t go through hell like I did. They small children with sickle cells are not treated well, some of them might have been killed even.”

Damilola: they have to know.”[FGB2:3]

Hannah was of the opinion that hiding away might reinforce the negative reactions of others. In addition, it is helpful when people’s attitude is challenged by speech. It is notable that the participants seek to demonstrate that people with SCD can do what others presuppose that they cannot, such as living into adulthood - “people wonder that I am fifty years old” (Odekunle); having a family of their own – “I have two children” (Aderonke); go to university – “I am a graduate (Damilola); having a career job – “I am a journalist” (Odekunle) and being a carer for others – “patients like the way I attend to them” (Niniola).

Joke also talked about the need to protect the young ones so that they would not go through their ordeals. These ideas came up in the FGB1 but they articulated them more in the later sessions. Members of the group might be developing a sense of collective responsibility for people with SCD (in this case, young people with SCD as the next generation).

2. **Persons with SCD should represent themselves**

In the FGA2, the members discussed awareness campaigns, and who should lead such campaigns. Eniola believed that the campaigns for SCD awareness have not been effective possibly because it was not conducted house to house (face-to-face) but Aderonke attributed the possible cause of ineffectiveness to the drivers of the campaigns. They deliberated as follows:
“Eniola: I believe there should be house to house awareness or community one. I believe that people are creating awareness about SS but it is not just effective since it is not house to house.

Aderonke: Who are the people creating awareness?

Eniola: We have NGOs now doing it.

Aderonke: How many times have you seen them on air or on the radio? See and I thank God that this thing is being recorded. You see, the NGOs, they are using us to enrich themselves. How will their programs be effective?

Eniola: A non-SS should not speak for us…

Odekunle: That is how we want it now

Ifeoluwa: Yes, we don’t want a non-SS to represent us, we don’t want them to speak for us. We can do it and we will do it.

Eniola: SS is not a thing of shame. We should be able to stand together and solve our common problems with the society. No outsider can do it for us, though we need their support and consideration. Let me just say this. I think what is really happening is that those people are not feeling our pains. They cannot feel the pains we go through. When I fall sick and I am in pains, I always say it is a person with sickle cell that can only know how I am feeling. I think we should do the awareness ourselves since a non-SS does not really know where it hurts us.

Unidentified: Yes.”[FGA2:8]

They eventually agreed that things should move from a situation where others (NGOs) were advocating on their behalf, to one where persons with SCD were advocating for themselves. They exhorted themselves to stand together as a group and address their social problems on their own terms. Eniola noted that nobody except a person with SCD could feel the pains of SCD and could represent them better than they would do. According to her, and with others agreeing to this, NGOs are not fully representing the interests of those with SCD. This discussion reflects a development of rationale for persons with SCD representing themselves.

Theme IX: Canvassing for support from significant others

The participants realized that they could not engage in any social campaign alone and they needed support from others. They discussed strategies to gain support from others. This
involved a strategy of enrolling NGOs to better represent the interests of those living with SCD, educating significant others to be better advocates for SCD, and educating other regular community leaders about SCD.

Sub-themes

1. Strategy to have NGOs to support them

Aderonke spoke to explain their agitation about the issue of representing themselves and others seemed to express agreement. They had observed that others had not fully represented them and this had not been to their advantage. They had been at a cross-road about whom to complain to concerning this difficult issue.

“Aderonke: That is why we would like to do the campaign for ourselves. Doctor, you ask us to talk one by one. Why we are all talking like this is because we have been harboring this anger in our mind for a long time. That center is the only recognized center and for God’s sake it is not meeting up with its supposed goals. Most people would wonder why you are not even going to get treatment there. The doctors would want to refer you to the place, others would ask you why are you not going there? And you cannot really explain that they are not helping us now. Who do you complain to?

Niniola: We need their support.

Eniola: We can speak for ourselves, I can talk on air, I can talk on the TV, I can talk anywhere, and it is just that we need support so that we can be heard. The stations will want to take money before they air us. And because people are calling us names, you are Emere, you are Ogbanje, we tend to hide ourselves and hide our pains, and a lot of us are dying in silence. People are dying secretly. We need support to come out and tell people what our problems are and for them to support us more.

Aderonke: we are saying we have people to support us, who should first be our support if not the NGOs? I think the [NGO people] are not aware that they are not helping us. We can invite them for a discussion and see how we can join hands with them and make things right. That is if they will agree. Most people think we would get better treatments there but they don’t know what we are facing there.

Ifeoluwa: my doctor wrote a letter for me to take to the center. He was telling me that I should be going to the center and would benefit more there.
They have doctors there but if you go there and you ask to see their doctors, they would tell you the doctors are not around.” [FGA2: 9]

Aderonke suggested one way forward and that would be to invite the NGOs for a meeting to discuss and agree on the modalities of help and how to achieve the goals of those with SCD.

2. Educating significant others to be better advocates for SCD

In the FGA3, the participants deliberated on the usefulness of educating significant others to be better advocates for persons with SCD. They came to the view that they would need to negotiate support from important personalities who have blood ties with persons with SCD. They attempted to identify people with political power who have personal connections to SCD. They looked to the prospect of engaging such group of personalities in Nigerian politics and using this leverage to negotiate an improved social situation for people with SCD. Aderonke captured it thus:

“There are important persons in the government who have children with sickle cell. For example, late Chief Hayes [name changed] decided to help people with sickle cell when he lost one of his children who had sickle cell. These people if they have one like us they would know the meaning. They would understand. Yes, Binta [name changed], his daughter was an SS patient and she died during childbirth. So what will Binta tell us? Will he tell us he doesn’t know about SS? Look at Anthony [name changed], a former governor, he lost one of his children to sickle cell. He lost his daughter to sickle cell. His wife wanted to support sickle cell because of that.” [FGA3:6]

It is interesting that they have a political strategy for sickle cell that recognizes the need to have allies. It is also important to note that they are aware of some of the complications in such attempts to negotiate better life. With regards to influential personalities with personal connections to SCD, Odekunle cautioned,

“One other thing is that we have talked about prominent people who have a connection with sickle cell one way or the other, they can be used as our advocates. It is not always like that because some of them are not always interested in things like this. I know the son of a former head of State. He is about 48 years old now. He has sickle cell but he does not want to identify with anything that has to do with sickle cell. He does not identify with the
condition anyway; he does not even want to hear about it. He considers it a personal problem. If you tell him it is not like that he would tell you to forget about it. However it is not all of them that would behave like him.” [FGA3:11]

It is important for them to realize that not every important figure with ties to SCD would be amenable to supporting their cause. Odekunle noted that some of these personalities considered SCD a personal problem. He also noted that some would be of help to their cause and these are the ones they needed to target. Niniola suggested a way counteract this challenge if they encounter it. She shared her suggestion,

“I think getting prominent personalities to support us and who can talk to those who think it is personal problem to change their mind is another way to solve the problem.” [FGA3:11]

Niniola did not want to even lose the potential support of those who might think SCD is a personal problem. From her perspective, it seemed these persons might not realize that the problems faced by persons with SCD could be due to the social arrangements and could be approached by initiating and negotiating adjustments to those social arrangements.

3. Educating other regular community leaders (teachers, religious leaders etc.) about SCD

In the FGA3, participants discussed about educating regular community leaders about SCD. Odekunle premised his expression of the need for this line of action on his experiences concerning parents of children with SCD. He therefore mentioned that teachers needed more education on SCD, what disabling barriers pupils with SCD faced, and what enabling environments they needed. The discussion went thus:

“Odekunle: So teachers today should be well informed about certain conditions that could make a pupil not to be in class. We can educate teachers as a group. We can take our campaign to schools and give talks to teachers about our conditions and what they can do to help us. The principals and other staff members in the school too but more particularly the teachers because they interact more with the students and parents. I know that till today there are many teachers who don’t know much about
sickle cell. I receive a lot of complaints from parents of persons with sickle cell and persons with sickle cell at our club meetings concerning the lack of awareness among teachers in schools. Not only the teachers but the society lack credible information and knowledge of sickle cell.

Aderonke: Yes, churches, mosques, religious congregations and create the awareness about sickle cell. That way we can make them appreciate us and give us support even if it is just understanding. It would go a long way.

Odekunle: This is the core of the advocacy. We take our message to the religious institutions.

Aderonke: Yes, we would write to them and we will go and give our message to them.

Odekunle: Maybe we can take it from the region. If we talk to the head pastor and call a meeting of pastors and tell them that it is not that we don’t need prayers but we also need to recognize that we cannot change the genotype except through bone marrow transplant, we cannot fight it but need to accommodate this condition as long as it exists. They cannot kill us but need to understand our plight and sufferings and support us in the time of need. So if we go through that route, pastors who work for small parishes would get the message and it would be less difficult for you to now speak in the church.” [FGA3: 7]

They agreed that enrolling key community leaders to their cause was core to their advocacy strategy for SCD. Such efforts to bring regular community leaders into the fold, in terms of understanding what social conditions enabled people with SCD to flourish, would bring about support and positive change for persons with SCD. Aderonke suggested that “if they train us, we can be better counsellors for others”

Theme X: Areas of interest to the group

The participants in their discussions identified certain areas that are of priority to them. They realized that they would need to create awareness for genotype test/screening. In addition, they would want to be peer counsellors and would require technical assistance with training. They also highlighted possible strategies to gain access to the media. Other areas that would be expedient are simple but effective approaches to financial buoyancy, strategies to achieve reasonable adjustments at school, workplace and in the hospital, effective mechanisms to report those who abuse persons with SCD as well as mechanisms
to support people with SCD who are victims of abuse, and creation of medley of stories that encompass many facets of SCD reality.

Sub-themes

1. Campaign for Genotype test

Members talked about the need to create awareness about genotype test. They discussed the need for people to know their genotype status and be ready for the responsibility of rearing children with SCD if it happens. They deliberated thus:

“Niniola: What I feel is number one is creating awareness. Let people know what sickle cell anemia is all about. What brings sickle cell anaemia to life, to counsel people to go for genotype test.

Ifeoluwa: people should know what it is all about

Aderonke: People should take precautions…

Odekunle: People need to know what to do before marriage…

Eniola: Yes it is important.

Niniola: The lady and the guy should know their genotypes before getting married. People should be made aware that if two people with AS genotype come together, there is a big possibility that they might have a child with SS. Then if something like that happens, they would know that it is their responsibility because they should have taken precautions. It is not that the man would backslide and say that it is the woman that caused it. No, they caused it together.” [FGA2: 7]

The members in this discussion wanted to create awareness of SCD through a campaign for genotype testing. This would give people the opportunity to know their status and to have information with which to make decisions. The members mentioned this approach in the spirit of preventing other generations from going through physical and social pains, should society continue to remain as it is. If the society continues to ignore persons with SCD, then it would probably seem logical to prevent coming generations of such ignored persons from coming into such society. Here, the members were themselves advocating the need to avoid further births of people with SCD so that such new SCD people do not have to endure the current discriminatory societal arrangements. Such orientation seems to accept that the
social arrangements could not change. They think that there is no alternative way to end discrimination other than by preventing further births of persons with SCD. In other words, they could not, at least in this moment, see the possibility of creating a society where people with SCD can flourish, and where there is not an implicit pressure to reduce the number of SCD births. There are a number of possibilities as to what this orientation might mean. On one hand, it is possible that the members might still internalize the dominant scripts of what others think they should be advocating. On another hand, the members might not have yet fully developed their own anti-discriminatory thinking and are still stuck in less progressive modes of thinking. It could also be that they have found a way to hold, at the same time, views that appear contradictory (i.e. support people with SCD but prevent too many new births of people with SCD).

2. Accessing/using the media for campaigns

In the FGA3, they debated about how to have access to the media and what media to use for campaigns to support SCD. They went on to consider other options of negotiating better existence with others in the society. They said:

“Eniola: Apart from that [inviting parents to meetings and educating them with the goal of making them understand what you go through and giving them the chance of making adjustments in how to relate to you and as such make your environment more comfortable for you], we might even bring out a programme, we might not call it sickle cell…

Odekunle: Let’s present it on your radio station.

Ifeoluwa: We can even turn it into a magazine.

Gbenga: The newspaper has to be the core newspaper that people read. It won’t be our own newspaper.

Eniola: The idea of the magazine is good but most of our people don’t read at all. However we can air the programme for an hour or even 30 minutes.

Aderonke: Yes, thirty minutes, forty minutes is okay.

Eniola: When we air the programme, we would bring up issues that of concerns to us and people would call in and ask questions and we would share our experiences with them and from there I think we can get
somewhere with making non-SS people appreciate us and provide support for us.

Odekunle: What she is saying is that there should be media interest in sickle cell and we could use the opportunity provided by the media to reach out to many people and increase the awareness of sickle cell.”

Aderonke: The only thing is if you have a website and you don’t include the social media, you will be alone. You will not be heard. You need to include the bloggers, the afro-entertainment, and so on. If you don’t involve these social media, you will be alone and most people will not click to your site talkless of knowing anything about it. If you include the bloggers who always go their site to find out what is new, then you have made your situation known. So one thing I know is that the media can help us and we need the media. We need the newspapers and not this alone because most people don’t read them, so you will lose a lot of people if you restrict yourself to newspapers alone. Some will read but they won’t show interest in that part of the sickle cell. But if they see news or information about sickle cell on YouTube, on social media, radio, television and then newspapers, they will stop to find out what this thing is all about. The television and the radio are important and we need to find out if they have something like corporate social responsibility where they can allow us to air our awareness programmes free of charge.

Eniola: My radio station will ask for money.

Aderonke: Not all of them will ask for money. We need to find out those that have health sections and are willing to support us. We can liaise with some people who have sickle cell and work in some stations. I know some people.”[FGA3:4]

It is important to note that the participants noted that it was necessary to include people with SCD in the mainstream and their issues should not be dealt with in a special, separate, part of the media. They also considered ways of minimizing costs such as going through the corporate social responsibility policies of companies.

3. Putting many stories of SCD into the public domain because not all are the same

Odekunle suggested that placing many stories into the public domain would address the many facets of SCD and enhance better understanding of persons with SCD. Odekunle said:

“If we present our stories to many societies, institutions, and also via news media, I think they would change their attitude. We can start bit by bit and
Odekunle advised that the stories about the life worlds of persons with SCD should be put in the public domain as these would be read by many and they would possibly change their negative attitudes. He was of the opinion that these stories would be introduced in the media bit by bit, and the awareness would grow within the minds of others and with many aspects of SCD being presented, they would likely begin to change or adjust their attitudes, and then persons with SCD would begin to have more positive experiences. He says “our” suggesting that people with SCD have concerns in common with one another, but “stories” with the plural suggesting the importance of recognizing diversity within the class of people with SCD.

4. Reporting mechanism for those who abuse people with SCD and support mechanism for people with SCD

In the FGA3, participants talked about addressing the abuse of persons with SCD and support for the victims of abuse. Odekunle, in reaction to Eniola’s experience of a man who hated persons with SCD with a passion, suggested that:

“In a case like this where the guy said he hates people with SS with a passion. We may have a registry where such abuse can be reported or we may as a group support you in mediating with such a person if need be.”[FGA3:3]

He also talked about having a complaint procedure for churches in the FGA3, he said:

“For instance we may send a request to talk in his church or where he worships and talk about how people react to us and the consequent psychological problems we have and how we need people’s understanding.” [FGA3:3]

With regards to the complaint procedure for health institutions in FGA3, Odekunle said:

“Just like in the campuses now, they say if any lecturer makes any advances to you as a female, you can report and they will take it up. It can even be an anonymous report. So on most campuses now, there is reduction in the reports of harassment of ladies. So we can advocate for that kind of
mechanism in the hospitals management board, we can also provide supportive counselling as a group for those SS persons who are victims of verbal and emotional abuses from people in the society.” [FGA3: 3]

In the focus groups, they considered the relevance of reporting mechanisms in various institutions such as churches and hospitals, and also mechanisms for providing support for the victims of abuse from others in the society. The members also seem to touch on the importance of policy, where addressing social arrangements through policy is apt rather than reliance on educating individual people. They also hinted at a policy that is strongly and consistently enforced.

5. Possible Strategies to achieve reasonable adjustments in schools/employment

In discussing the reasonable adjustments that the participants mentioned it is necessary to note that they identified education through schools as key to better quality of life for persons with SCD. Some of the participants reflected on the problems they faced because they did not get the opportunity of going to school. Joke mentioned this limitation as a barrier to earning a better living for herself.

“Joke: Like me, if not that I was discouraged from going to school; right now I would have been holding a certificate. I would have been able to work and earn a living. But I tried to develop myself. I attended one vocational catering school. I learnt how to bake cake there. If I see people doing things that I like, I join them to learn them too.

Gbenga: When parents have children with sickle cell the best thing they can do for the child is to give him or her good education. This is because we cannot do strenuous work like others. Education will afford us the privilege of working but choosing what we can do without so much stress. So I advice parents to give their children with sickle cell education, see them through to university level. Once you have a university degree, you can move on by yourself.

Damilola: Well if the government would listen and people can talk to them, it should be written thing that anybody with sickle cell disease have these rights and they can only be allowed to do this and that. Once it is in the school laws, I don’t think each person will be fighting to let people know and protect them.
Gbenga elaborated on the need for parents to ensure that their children with SCD go to school. He mentioned that education gives persons with SCD the opportunity to choose the job that would suit his life, rather than people with SCD forcing themselves to suit the job. Joke and Damilola both identified the need to have enabling laws in schools. This could be something to campaign for by the group.

In developing ideas about addressing the barriers in education, Comfort said:

“If people realize that we have certain challenges they could accommodate us by giving us some other opportunities when we cannot meet up. Even if it is exams, they could arrange our exams again if they know we were ill. Nobody wants to be ill during exams. So if we are given another opportunity to take our exams and we don’t repeat the class and we are able to move with our classmates that will reduce a lot of worries that we have. We need this kind of support…So we need to create awareness for the lecturers and even teachers at the primary level. This awareness will encourage them to make rules that will encourage us to succeed in school. We won’t be frustrated out of school and our parents won’t be afraid for us.”

Gbenga suggested the need to have a school policy. The policy would address the use of posters (with pictures) to create awareness on SCD and the need for respect of their rights. Other aspects to be addressed by such a policy would include the physical and verbal abuse, and options for those who missed examinations. Gbenga and Hannah led the discussion thus,

“Gbenga: We can use posters with pictures of persons with sickle cell and say their body shapes are characteristic of persons with sickle cell and they should not use these to abuse them. They should rather show us more respect and I think there should be school policy where those who use body to abuse sickle cell person will be punished… And once it is enforced in schools, it will send messages to the society and they will start to be careful with persons who have such body parts.

Hannah: I think we can make posters and place them in classes. There can be words like person with sickle cell is your friend. They should be respected. They need your support. It is normal for a person with sickle cell to have yellow eyes. Their eyes can be different from yours but it is okay.
Such posters can be used by teachers to teach and tell others that we need to be respected and not abused. So if some parents abuse them outside, their children can caution them that they had been taught in school not to abuse them and that those things are parts of being a sickle cell and they need to be respected and supported.

Odekunle: Yes, that is it. It will even encourage parents of kids with sickle cell to talk more and bring forth their children.

Damilola: I think we can ask that candidates can indicate their genotype in the form for the exams.

Gbenga: And they can arrange a period where those who missed various papers can come together and sit again for the papers. That would help.

Comfort: If the exams hold once in a year, people with sickle cell can have their own two times in a year and so you have the opportunity to be present for some papers in one and be able to do the rest another time in the same year. That will be a privilege and a lot of us will benefit from that arrangement.

Gbenga: We have a lot of persons with sickle cell in Nigeria and there will be quite a number that will benefit.

Comfort: Even in schools when we miss classes and exams, there could be catch up lessons for us and this will assist us in being supported. I think there should be a law to back this up in schools.

Damilola: Well if the government would listen and people can talk to them, it should be a written thing that anybody with sickle cell disease have these rights and they can only be allowed to do this and that. Once it is in the school laws, I don’t think each person will be fighting to let people know and protect them.” [FGB3:16]

It is noteworthy that the participants seemed to consider using multiple approaches including enlightenment campaigns, as well as discussing the possibility of developing and enforcing a policy.

In the FGB3, as regards to employment, and the related challenge of seeking and getting employment, they were of the opinion that,

“We could address your case or similar cases by advocating for policies that allow us to rest at work. And we could also be a career counselling group that supports persons with sickle cell at work and advocate for the right of the person. We can even counsel people about jobs that suit our lifestyle. We can also do this in schools so as to inform the young ones of certain challenges that lie ahead and ways of avoiding them or overcoming them.” [FGA3:8]
Odekunle reflected on certain problems that put persons with SCD at risk in the workplace because of poor social relationships and faulted the assumptions of other social actors. He said,

“Yes a lot of people with SS have lost their jobs on account of going to attend their clinics. I know so many and it is because the employers do not understand. If we attend clinic and we are okay we will be able to work better but if we don’t attend clinic we would fall sick more. Attending clinic and staying healthy saves a lot of cost from not coming to work because of illness. But then they will sack people. Where do they want us to feed from or get our source of livelihood?” [FGA3:9]

Odekunle also pointed to the need for employment among persons with SCD. He revealed that,

“Many people will not employ you if they know you have sickle cell? It is a big issue. And I think there should be quota for people with sickle cell. As long as you have the qualifications and it is not a stressful job, then we should have certain percentage in intake into that institution. If you don’t have money, you cannot live long, you cannot feed yourself and buy drugs for yourself. We need to have education and employment so that we can take care of ourselves and do well.” [FGA3:10]

Odekunle seems to show that if the social structures could change to accommodate persons with SCD, persons with SCD would enjoy life better. With regards to employment, he mentioned policies can be put in place to support people with SCD. He said,

“That’s the kind of support we need. So if there are policies to support us and not just one person being supportive and another person with a different attitude. If it is a policy for us it will be referred to and it will be done… we can lobby as a group to have some consideration in job interviews and job placements and welfare in our places of work… I know that in the UK they are talking about rights of sickle cell and the same could be done in Nigeria. We would also need to form networks with other sickle cell groups in the UK and America to have more ideas and support.” [FGA3:18]

There is the need for an official policy to be in place rather than the individual good deeds of a sympathetic boss. The policy would empower persons with SCD individually and as a group. The official policy would be a reference point from which to seek redress. It is also important to seek support and ideas from others living with SCD outside Nigeria.
These discussions set the tone for the need to involve the government, who will empower persons with SCD through policies that will make adjustments to the inflexible social structures in work and employment,

“So if the government can help us to some extent and employ some of us; some of us can do some work on our own, we can be self-employed. The employers can be made to understand up to a certain level that at least they can give a lee way; they can indulge or give some allowance a little okay that from time to time they might be ill. But, you know, what people tell me is that we people with sickle cell are usually very good at work. It is only that we may have to keep from work because of ill health. And there are medications that are available now that can reduce the number of crises. The government can also subsidize these drugs and make them available and accessible to those who need it. This will go a long way in helping us succeed at work and compete with others.” [FGA3: 9]

The participants seem to have enumerated some strategies to engage and negotiate with stakeholders in schools/employment agencies as well as the involvement of the government. They recognized that the government as key to better quality of life in terms of enacting supportive policies and laws.

6. Strategies for reasonable adjustment in the hospitals

Later in the same focus group Aderonke also raised an important issue of lack of knowledge of SCD among general health care providers. She said,

“Most doctors don’t know about us except those who take care of us…And in some hospitals when they rush you there when you have crisis, they will tell you they don’t know about sickle cell and you should be taken elsewhere.” [FGA3:16]

Others could relate with her narrative and shared their own experiences thus,

“Eniola: I have had crisis before and I was taken to a private hospital. The doctor there said they should take me to the hospital that I used routinely that there is nothing he can do for me.

Ifeoluwa: Yes it has happened to me. They told me I should go to my hospital where they are familiar with me. And I had even paid some amount of money for treatment there. They told me I should not come there again since they don’t understand my condition. It was because I was having
regular crisis and they have used this and that but I was not getting better. They said I should not come there again.

Eniola: I am wondering if there is something we can do to that. If we can as a group call our doctors to do a seminar for most of these private doctors and teach them how to respond to our emergencies. Some people with SS have died in private clinics because the doctors didn’t know what to do. We can request the help of our doctors to teach these doctors about sickle cell and how to handle our cases.

Niniola: Even if it is to give first aid and save a life before referring to the teaching hospitals.

Ifeoluwa: When I am taken to a private hospital, the doctors there will pick up phone and call my doctors in the teaching hospital that what else can we do for your patient. They ask them what to do one by one.

Aderonke: Even in specialist hospitals, for instance when I went to orthopedic hospital for my hip replacement, they don’t know much about sickle cell. They had to speak to doctor A from here. I support it that we should call for them to be educated and taught about us. That will save many persons who might have died if they don’t know what to do for them.”

Comfort: The mobile teams need to know much about sickle cell emergencies. And I also know that if others in the private and other primary health care centers know much about sickle cell we would not be many using the teaching hospital. I think we need to tell the experts to help teach others on how to treat us. Many hospitals you go, they will tell you they cannot treat sickle cell, and where else will you go?” [FGA3:16]

Their deliberations reveal they are becoming aware of how they could approach issues that are germane to them. They would want refresher courses for health care workers in order to receive better health care, and live a more rewarding life as a result. They identified that it is not inconceivable that social arrangements are contributory correlates of their problems, and therefore that changing such arrangements could help in making things better.

They also realized in their discussions that some health workers, especially nurses, would require more attention. They had a rationale, and some ideas on what to do to address this cogent issue.

“Odekunle: Nurses deal more with our group and our families than even the doctors. The doctors will just write their prescription and medical jargon and the nurses will carry it out. I remember one time at a hospital where I had crisis, the nurse was shouting at me that I was making noise and said, can’t you shut up!? Can’t you bear it!?

Comfort: Nurses are terrible!
Gbenga: Some nurses are terrible.

Odekunle: Nurses should be our focus. I have had a lot of relationship with nurses and most of them are very bad. Their attitude to you is poor and negative. Their body language and the way they look at you even when you are okay and you just come for an appointment. This is especially true in public hospitals and they are very nasty and aggressive. Abroad you can complain about such behavior and the management will deal with that. But here [in Nigeria], we don’t have the support of the management. We can meet with management and present our plight and then maybe they can put in place a mechanism of complaint and they will act on such issue. When they act on such, I think they will sit tight.

Damilola: I think we may need to talk with the nurses as a body and enlighten them on how we have interacted with them and how we have been treated. We can appeal to them and then we can have a meeting with the management. If we talk with the management alone, the nurse may or may not become cold towards us even though they do their work. We still need their support… I used to hear a radio programme where people call in to talk about the condition of their roads, light, water and all sort of welfare issues and I think it helps. We can also as a group call in to stations and bear out our grievances in the hospital if they don’t listen to us. We can write to the management what we go through and ask for a discussion with them since we represent a part of the user of the hospital.

Gbenga: in visa application centers, and banks I have seen that people behave well to their customers. I have a friend who works in the bank and when I asked him if they were specially trained to be respectful, he said yes but it is the cameras around that enforce such acts. I am thinking of hospital receptions have such CCTVs, such bad behaviours will reduce. This is in addition to all that has been said.

Odekunle: If we have all these approaches, if one does not work, the other will work. Or they will even work together and make people act on it quickly.”[FGB2:19]

The participants seem to have enumerated some strategies to engage and negotiate with nurses who have been identified as being key to a better quality of life for people with SCD in the hospital experience. There has to be meetings with hospital management in order to initiate complaint procedures, meetings with association of nurses, and policy/law that is enforced and that prescribes mechanisms to monitor the quality of care, such as the use of CCTVs.
Participants raised the issue of finance for health care and some ways to approach this issue. The following discussion took place:

“Gbenga: I also think there should be a facility in the hospital that gives credit to persons with sickle cell who do not have money at that point in time and give them a time period to pay back. It may be a microfinance bank in the hospital that can lend you money. They would have your details and everything, and you can pay back in instalments.

Joke: apart from that, like they do in the private hospital that I sometimes use, money or no money if it is an emergency, they will treat you. They will attend to you and you will later pay in instalments.

Comfort: if we also form a small group that can lend people money such as co-operative society.

Gbenga: cooperative society run by us will be a good idea but some people will borrow money and not pay back. There may be a way around that. Well I think if we are all committed it will work. But I think microfinance is better, since they are into lending people money and they have a way of getting the money back.

Joke: such microfinance can also help us in setting up business for those who do not have government jobs. So it will help us that way. If the cooperative will work, people will not be allowed to borrow more than thirty or fifty thousand naira at a time (120 or 200 pounds sterling) and then pay back before you can borrow again. This is to prevent some people to take undue advantage of such good thing and then kill it.”

Gbenga: I think family members can also be sureties so that nobody breaks the contract. And when one also earns salary, this will contribute. Then the microfinance or even the cooperative will work.

Comfort: this is most likely to work. If there is a surety and the person does not pay back, the surety will be held responsible. The surety details are with the cooperative or the microfinance bank and there will have been a background check on the person. A group of family members can come together to stand as sureties. The workplace or the organization where the person works can also be used. At least the sickler will be covered one way or the other and the burden will not be on one person. A problem shared is half solved then.”[FGB3:10]

The group has identified setting up microfinance as a possible way to change the social structure to improve their lived experience with SCD.
Conclusion

Participants in this study seemed to have the opportunity to reflect on their individual experiences in their groups, and were beginning to note how their actualities contradict the views of others in the society. These actualities demonstrated that they could do/achieve what others pre-supposed that they could not do/achieve. Their experiences could also be framed as opportunities to teach others certain values, such as empathy, that could be instrumental in social re-arrangements to make life better for persons with SCD. Participants in their groups seem to develop more confidence, in contrast to the interviews, to reflect on their experiences and challenge certain practices as false and unhelpful. Their interactions thus illustrate various examples of how group solidarity and action could have a significant effect on the life-world of the participants or others with SCD. It is interesting to note how they oriented themselves to one another and how they tried to make sense of their experience and address challenges. In some respects, the members of the groups might be developing a sense of collective responsibility for people with SCD.

The forum of a group discussion provided the opportunity for some participants to think of ways to address this issue as well as the possible gains of such approach. The members began to identify issues that could be taken up by a group, instead of by individuals, and touched upon a possible social re-arrangement that could improve the quality of life of persons with SCD. They shared knowledge, and pointed to practical sources of help for one another as well as next generations of persons with SCD. In other words, the developing process, of sharing supportive information and practical social strategies in the focus groups, could potentially to be extended to wider peer support group for other persons with SCD such as those without family support, those who might kill themselves to gain social acceptance, parents of those with SCD to guide in proper medications, sickle cell carriers who have SS children, students with SCD and employees with SCD.

By becoming aware of their common social interests, they animatedly debated problems and came up with possible solutions within their own frame of reference, not frames of reference set by others. For instance, they had the opportunity in the group to suggest,
amend and debate strategies for pain relief within their own frame of reference. One social initiative - of being focused outwards to others and engaging in social interaction - was suggested as one strategy to reduce pain. They came up with ideas for a campaign strategy, considered that NGOs are not fully representing their interests and developed the rationale for persons with SCD to represent themselves, albeit with the support of NGOs, and of key personalities in Nigerian politics. They considered their engagement with these significant others as possible leverage to negotiate an improved social situation for people with SCD. They had the opportunity to deliberate on the potential for strong and consistently enforced policies to achieve reasonable adjustments in various sites of their social world including schools, hospitals, and workplace.

Thus far the thesis has reported on a disease-focused questionnaire identifying those with SCD who exhibit a significant level of depression, conducted depth interviews with 15 such people to ascertain the illness experience of living with SCD in Nigeria, and undertaken six focus groups in which those living with SCD began to explore the societal sickness that is the discrimination in society that they face. In the next chapter we compare these issues to the existing literature.
CHAPTER 7: DISCUSSION

Introduction:

The previous chapter presented the findings of the focus groups that illustrated how discriminatory social structures might contribute to the problems faced by participants and how these could be challenged. This chapter presents the discussion of the findings of chapters 4, 5 and 6 in the context of past literature. The discussion is embedded within the threefold framework of Kleinman that suggests how SCD might be conceived as, in turn, a disease, illness and societal sickness. Although methods of data collection were broadly conceived as reflecting this framework (questionnaires eliciting information about SCD as a disease, interviews generating responses about individual illness experience, and focus groups about the societal sickness of discrimination against SCD) in practice, as we shall see, each entity overlaps with the other. Furthermore, where appropriate, the chapter also harnesses the relevant theories of Goffman, Link and Phelan on stigma and Oliver on theories of disablement. Within this framework, the chapter has been laid out in three sections namely i) disease context of SCD ii) illness experience of SCD and iii) societal sickness of SCD. These levels of Kleinman’s framework represent a unified whole and the understanding of it is cumulative as one cannot develop full understanding of SCD on one level without an understanding of the others. In other words, the framework is a cumulative, coherent whole where there is no full account of the impact of one level
without the others. Therefore it should be noted that the levels of the framework are separated primarily for reasons of clarity of presentation.

**Disease Context of SCD**

In identifying the sample of people living with SCD who were depressed, a validated psychiatric scale was used. The study participants were all recruited from Lagos, in the western part of Nigeria and they appeared to be from a range of backgrounds, providing a good basis for evaluating sickle cell disease and depression. Demographic characteristics were comparable to Adegoke and Kuteyi (2012) who studied a sample of persons with SCD in another western part of Nigeria.

The majority of respondents had genotype SS, which is consistent with reports from authors such as Benton, Ifeagwu and Smith-Whitley (2007) who found SS in 65% of sickle cell patients, Rosana et al. (2012) who found predominance of SS genotype among 85% of their sample in Brazil and Adegoke and Kuteyi (2012) who found that 87.1% of their sample had SS genotype in a Western part of Nigeria.

The rate of depression in the cohort was 71.8% which was higher than the rate of 50% reported by Edwards et al. (2009) in their US review. This rate might be higher because of the different context in US where, through Medicaid, there is at least limited free biomedical treatment options and some health insurance opportunities. These social arrangements suggest a contrast to the levels of pain and stigma that exist in Lagos among the participants in this study. Another possibility could be a difference in the instruments, and cut-off points of the instruments used. A difference in cut-off point might cause variance in the estimate. The rate in this study was also higher than rates reported in other developing countries. For example Rosana et al (2012) reported a much lower rate for depression of 40% among their Brazilian sample. The different economic situation and available biomedical options might also be responsible for this difference in addition to the different instruments, and cut-offs to assess depression, among the samples. In comparison to other studies in Nigeria, it was higher than the rate reported by Ohaeri et al (1995) who found depressive thoughts in 55% of their sample. Similarly a study by Anie et al. (2010) in
Lagos reported a lower rate of 50% among their sample population with age range 14-56 years. The downturn in the economic situation in Nigeria within the last five years could be responsible, as well as the different assessment instruments that were used in these studies.

This rate is higher than the range of prevalence of depression among those with SCD in the developed countries. This was 18 to 44%. (Wallen et al., 2014; Grant et al 2000; Hasan et al 2003; Laurence et al 2006; Levenson et al 2008). The high rate that was reported by some authors (Schaeffer et al., 1999; Hassan et al. 2003; Jenerette et al. 2005) was more of depressive symptoms and not of depression as a disorder. In reference to the Schaeffer's study, the rate fell from 43% to 18% when stringent criteria were used. This was comparable to the range of rates of 22-28% for depression by some authors (Jenerette et al. 2005; Asnani et al. 2010; Levenson et al 2008). The higher rate in this study could reflect high false positive rates of screening instruments which has been reported in literature due to the issue of appropriate cut-off (Schaeffer et al., 1999), and the overlap of physical symptoms of depression and SCD (Alao and Cooley, 2001; Yang et al., 1994; Anie et al., 2010). However, to avoid the problem of overlap, the mental health scale used in this study was cross-culturally validated in line with argument of Grant and colleagues (2000). Another possible explanation could be the transitory association between depressive symptoms and acute episodic complications of SCD (Atkin and Ahmad, 2001). The cohort in this study might have had acute episodes of SCD complications before the interview (plausible, since they were recruited when in attendance at a medical SCD clinic). The finding might be valid with regards to its convergence with findings of the in-depth interviews where participants expressed varying symptoms of depression at various times. This supports the need to also consider the aspect of illness experience apart from disease experience to have a complete picture of what goes on with a group.

In this study, those who had depression were older, had higher rates of admission in the past year, more blood transfusion episodes and lifetime history of leg ulcer. Adams et al (2009) found that those with SCD who had depression were older, similar to the finding in this study. Anie and colleagues (2010) found that depression was associated with frequent hospitalization as in this study. Consistent with the finding in this study, several authors
found association between depression and leg ulcer (i.e. Molock and Belgrave, 1994; Asnani et al., 2010). Hassan et al (2003) found that depression was associated with higher rate of blood transfusion and severe forms of SCD such as leg ulcer and these findings are consistent with those of this study.

This study is significant in that while it has identified persons with SCD and depression, and possible factors associated with the disease such as leg ulcer or frequent blood transfusions, and other associations, such as older age, it recognizes that the problems of these persons go beyond associations. Although other studies showed comparable findings with those of this study, the studies located depression inside the persons with SCD, and associated depression and other co-varying factors such as key symptoms as consequences of being persons with SCD. However, such descriptions reflect what SCD currently “is” and not what the SCD experience “could be” in changed social circumstances. Moreover, it uses the perspective of the researcher (third person account) and does not give voice to the participants. This view is shared by many researchers who would recommend that the solution to the challenges of persons with SCD lay in them such as gene therapy and bone marrow transplants (Whitten, 1992); or that the family must “learn to cope” with insecurities, aggression, antagonism and other prejudices the misconception about SCD creates (France-Dawson, 1986). This reflects the inertia of traditional research that is content to identify ‘associations’ rather than challenge the social conditions that might give rise to such factors.

A further consequence of inertia of correlational research is that the researcher potentially derives credit from the research while the researched are alienated. There still remains unanswered what social factors trigger pain or depression in persons with SCD. A review of literature that used social perspectives to study persons with SCD has underlined that social contexts are taken for granted issues that might more appropriately be used to explain the experience of these persons. For instance, Lemanek and colleagues (1986) pointed out that social class rather than SCD explained many of the behavioural problems of persons with SCD.
Additionally, it should be noted that many authors who relied solely on a biomedical perspective not only wrongfully ascribe depression to the 'condition' of SCD, but also imply that the depression derives from something maladjusted about the behaviour or psychology of the person themselves that it is to blame for their woes. They locate the problems in persons with SCD without taking cognizance of the social context and relations. So on this problematic premise, these authors would recommend that people with SCD must 'learn to cope' (France-Dawson, 1986: 735), have pain that is not adequately controlled (Oheari et al., 1995); or need 'positive self-presentation' (Malat et al, 2006: 2481). In a sense such authors are blaming the victim, taking what are social problems and reconstituting them as problems lying within or generated within the person themselves.

**Illness Experience of SCD**

This strength of this study is reflected in the use of (1) the phenomenological influence of Husserl in highlighting the lived experience of depression and stigma among persons with SCD and (2) the symbolic interactionism of Goffman to highlight the invocation of social norms that are oppressive in the life-world of persons with SCD. Link and Phelan’s conceptualization of stigma was also used to highlight the components of stigma and the link of power structure in the society to push stigmatized persons down the social hierarchy and discriminate against them. The portrayal of the nature and extent of stigma, including the power component and the ‘disciplinary gaze’ of the society, overlapped into consideration of the need to renegotiate social identity of stigmatized persons with SCD.

In this study people with SCD who have depression were asked to describe their life world and their perceptions of life and lived experiences with stigma and depression were explored. This approach gave voice to the researched and highlighted factors outside persons with SCD that were challenging as well as set the tone for the need to challenge such factors. In this study, the analysis of the interviews revealed seven themes that illustrated the social factors that could be oppressive in their life-world.

The participants described the experience of disapproval in various contexts. Experiencing disapproval was particularly poignant as participants identified parents, siblings, relatives,
friends, peers, neighbours and others in the society as social forces that were oppressive to them. They noted that others in their lived world avoided, excluded, disliked, limited and cast aspersions at them. Feeling judged this way led participants to feel both morally bad and emotionally sad. They also described experiences of various negative emotions from anxiety, loneliness, and depression to thoughts of suicide. Their feelings are similar to those with other chronic illnesses who felt exiled from others and felt disgraced due to encounters and lack of support by providers, friends, family, the community, and the workplace (Sartorius, 2006; Slade, Molloy and Keating, 2009; Halding, Heggdal and Wahl, 2011). This illustrates that their emotional disturbances of persons with SCD could not be solely located within them but were also sourced from without. This study however differs from the perspectives of these authors (Sartorius, 2006; Slade, Molloy and Keating, 2009) who located stigma and negative emotions in the medical condition. For instance Sartorius (2006: 1) reported that “mental illness stigmatizes those who have it”, and Slade and colleagues (2009) slipped into writing that persons with chronic pains were stigmatized because of their pains and not as a result of their breaking societal norms/expectations. This study is more aligned to Halding and colleagues (2011) who suggested stigma experienced by persons with a chronic disease was consequent upon breaking societal norms. This study highlighted the stigma arising from the social relations surrounding SCD, a chronic illness, and further pinpointed the consequent emotional disturbances as following the oppressive social relations. In contrast to the authors discussed here, this study did not alienate the participants after highlighting the social productions of stigma and depression but also went further to initiate processes to challenge such within the frame of the participants’ reference, as will be seen in the section on societal sickness below.

Another significant theme from the interviews was the ‘experience of disbelief about pain from significant others’. The context of this experience ranged from family and hospital settings to various other settings in the society. In Schreiber’s article (2000), a person with SCD recounted: “It’s devastating for a person to be in pain but not to be believed. It makes you feel less than human. The trust is broken when the person you come to for help reacts negatively.” Many participants in this study described such experiences and feelings. They
themselves highlighted possible social expectations/norms they broke in these contexts as responsible for these disparaging acts. For instance, in the family and wider society, certain fathers, mothers occasionally, siblings, relatives, neighbours and others shared negative attitudes, such that persons with SCD were pretending and were breaking the social expectation that a child or sibling should be considered a source of joy. In the hospital setting people with SCD were held to have broken an expectation of bearing what was termed “little” pain by health care workers. Persons with SCD had recounted that health workers were at times insensitive and often did not understand or believe their self-reports of pain (Pack-Mabien and Haynes, 2009). This study differs from Pack-Mabien and Haynes’s as well as Screiber’s by adding, first, that the emotional disturbances are consequences of the oppressive social relations, and secondly, that persons with SCD could be involved in making efforts at changing these social arrangements.

Consistent with this study, Maxwell and colleagues (1999) illustrated in their qualitative study of persons with SCD in hospitals that some common themes are mistrust of patients with sickle cell disease, stigmatization, and neglect. It is important to note here that biomedical approaches to pain framed the experiences of pain as fundamentally individual and purely biological (Good et al., 1992). However, this study drew on the social perspective that broader social relations could also account for the perception, response to, and communication of pain (Helman, 1994). Similarly, the decision to seek treatment, avoid treatment, or conceal pain is a social action influenced by social context and individual meanings and experience, and not just a straightforward individual response to the experience of physiological symptoms (Maxwell, Streetly and Bevan, 1999).

In this study participants’ accounts of their treatment in the hands of health workers concord with previous US and UK research (Alleyne and Thomas, 1994; Murray and May, 1988; Black and Laws, 1986) in highlighting issues of mistrust, stigmatization, and undertreatment of pain. This study, though, goes beyond previous studies in suggesting an explanatory model that illustrates broken expectations/norms in the health professional/family-members/others-patient relationships for management of SCD pain. A pervasive mistrust of patients with sickle cell disease results from the stereotype of being
considered a witch, and from breaking the norms of bearing little pain, proper timeline for pain medications, and timeline for pain reaction. These authors (Alleyne and Thomas, 1994; Murray and May, 1988; Black and Laws, 1986) all reported that significant others exerted excessive control over their regimen for management/support of pain, but the authors failed to recognize the link to broken norms/expectations.

Disapproving behaviors and emotional disturbances such as depression have been linked in the literature (Jenerette and Brewer, 2010). Jenerette and Brewer (2010) suggested that the link between SCD and depression could be due to social arrangements and this is consistent with the approach of this study. However, these authors did not take this any further, by not suggesting that such disapproving behaviour could and should be challenged.

There are studies that wrongly imply that persons with SCD are depressed because of the SCD. Ohaeri et al. (1995) reported that depression, together with periods of inadequately controlled pain, may result in feelings of helplessness and even thoughts of suicide in people with SCD. These studies had their perspectives guided by biomedical philosophy which locates depression and poorly managed pain in the person but did not consider that there might be feelings of depression and other negative feelings in persons with SCD due to social arrangements.

Similarly, Anie and Green (2002) reported that low self-esteem and feelings of hopelessness in persons with SCD occurred after incessant pain, hospitalizations, and loss of job. In other words, these authors largely ascribed depression to the 'condition' of SCD and thereby located the problems in persons with SCD without taking cognizance of the social context and relations. These authors’ implicit claim, that all pains are inevitable and given, is problematic.

First, Jenerette and colleagues (2010) showed that some pain in SCD is perhaps inevitable, but some pain is derived from the negative, disapproving behaviours of others. The findings in this study support this claim. Secondly, even though some pain onset may be inevitable, there could be certain social arrangements that could ameliorate such pain. Whether or not that pain is ameliorated or resolved may depend on certain social factors highlighted in this
study. These factors are (a) access to services, which in Nigeria may be a function of availability of money, or willingness of family members to spend that money on behalf of the person with SCD and (b) the attitude of health service providers. Participants in this study reported that providers are unsympathetic in making them walk long distances between departments to fetch their own test results when they presented with painful episodes. Those antecedents of pain that are derived from negative disapproving behaviors of others can be avoided by, for example, stopping the discriminatory attitudes of others or of health care providers.

Thirdly, even pain that cannot be avoided by reconfiguring social arrangements should not necessarily lead to hospitalization and could be ameliorated by social adjustments such as making pain management strategies available in the community to people with SCD. This study argues that the distress experienced by persons with SCD could be caused by social factors surrounding hospitalization. Such factors are the company of unsympathetic healthcare providers, accompanied by a degree of social isolation, and some stress over how the bill might be paid. These factors are likely causes of the pain rather than the SCD per se. Fourthly, even pain that requires hospitalization does not necessarily lead to lack of employment. This situation depends rather on whether the society establishes strong and enforceable disability discrimination laws with regard to employment. Thus the (further) pain may not be due to SCD but due to discriminatory employers and lack of appropriate laws and policies.

Studies that used third person account to reflect this aspect of reality could be limited in reflecting social contexts that are challenging to persons with SCD. In this study, it is argued that from the first person account, social relations are contributory to negative feelings of persons with SCD. In contrast to the work of Edwards and colleagues (2005), who reported that persons with SCD had diminished ability to cope with pain, and that emotional disturbances such as depression and anxiety are associated with negative pain management experiences, this study found out that participants claimed they could better handle pain than others but that the negative reactions of significant others, in the family, and hospital among other settings, contributed to their feelings of depression and anxiety.
In this study, persons with SCD were confused and surprised that such significant others in the health care system would refer to their pain experience, particularly the severity, as illegitimate. This view is in contrast with some view of authors who located the problems with persons with SCD and not others in the society. For example, Jenerette and Brewer (2010) argued that persons with SCD needed to know what information their attending health worker requires and how to provide such information. In addition, Malat and colleagues (2006) argued that African-Americans with SCD need to improve their presentation of themselves in order to get the best medical care. Ballas (2005) also mentioned that the more information a person with SCD provides, the more likely the attending health care worker can devise an appropriate person centered treatment plan in collaboration with the person with SCD and the more likely the health worker will avoid stereotypes of adults with SCD in terms of addiction to opioid analgesics. Other authors posited that positive self-presentation among persons living with SCD should be promoted by increasing their communication skills and this would facilitate their unobstructed access to individualized, proactive pain strategies and consequently improved pain management experience (Malat, van Ryn and Purcell, 2006). Whilst not denying that clear communication by the person with SCD would help health care providers to help that person, it is a short step to blaming the person for their alleged lack of communication skills and/or trust in the provider.

In contrast to the views above that locate the problems in persons with SCD, the accounts of persons with SCD in this study showed that problems derive from significant others who believe (wrongly) that persons with SCD are pretending when experiencing a painful crisis, and are deemed by others to be “lazy”. Receiving support rather than blame alleviates feelings of emotional upheaval and allows possible shift of focus to more positive things for persons with SCD.

In a landmark study, Smith and colleagues (2008) documented that SCD pain is a daily phenomenon in contrast to earlier beliefs that SCD pain only occurred during a sickle cell crisis. This study also highlighted the need to clarify the complex and multi-faceted ways that SCD pain is experienced. This would involve focus on the subjective experiences of
pain (Mitchell and MacDonald, 2009) because a purely biomedical approach, with its focus on pathophysiology, is considered inadequate to study such pain complexities that persistently affect all areas of people’s lives (Thomas, 2000). This qualitative approach, which is essentially the focus of this study, is needed to reveal people’s lived experience and highlight contextual underpinnings for better understanding (Adegbola, 2011b; Greenfield and Jensen, 2010; Thomas, 2000; Thomas and Taylor, 2002). Given that pain is a consistent feature of the SCD experience and that there is a need to clarify the complex and multi-faceted ways that SCD pain is experienced, this study has explored the lived individual illness experience of SCD in highlighting certain contextual factors that could characterize the SCD pain experience.

It is important to have support against significant others who believe (wrongly) that persons with SCD are pretending when experiencing a painful crisis, and are deemed by others to be “lazy”. This support could alleviate feelings of emotional upheaval and allow a possible shift of focus to more positive things. Persons with SCD would be more likely to refuse the support of significant others who doubted their pain experiences. It is interesting that even discrimination about pain experience that happened a long time ago continues to resonate even decades later. The negative effects of discriminatory remarks on mood and possibly on mental health are therefore possibly long-acting. Persons with SCD could consequently conceal their pains in other to avoid the negative reactions and the demonstrable lack of empathy of others.

The participants also identified the experience of stigma. Participants described experiences where people in their social world discriminated against them because they were, in Goffman’s terms, discreditable. The acts of others emanated from persons with SCD breaking others’ expectations in terms of physical appearance, economic independence/provision, or presumed physical capacity/capability.

Participants discussed how others reacted to them negatively because they were smallish, had yellow eyes, leg ulcers and protruding belly. They noted that the more a person has these physical characteristics, the less they would want to deal with him/her. This confirms the statement by Jones and colleagues (1984) that when people with certain illnesses have
tell-tale signs that make them different from others in the normative categories for them, they discount these people. These less tolerable tell-tale attributes bring them in other people's mind from a whole and usual person to a tainted and discounted one. Persons with SCD were smallish and skinny as opposed to tall and well-built respectively. They should have unblemished skin as opposed to skin broken and exuding smells as in leg ulcers; should have white eyes as opposed to yellow eyes. Such are the bodily norms that persons with SCD are held by others to break.

In this study, several participants described how they encountered role limitations because of these attributes such as they could not fulfil their role obligations, for example marriage, because of leg ulcers. They also described the emotional distress that results from this stigma. One of them expressed distress through the phrase “ran mad” and noted that this sort of reaction would not have happened if there was enough money to prevent the leg ulcer via rest and taking cabs instead of walking long distances. Many of the participants recalled that these experiences made them “cry, feel sad, bad and depressed”. The origin of their emotional distress is more social than biological in these instances.

These negative reactions have not been noted in societies where persons with SCD do not have obvious tell-tale signs (Ohene-Frempong and Nkrumah 1994; Atweh and Schechter, 2001). These signs are noticed in societies where optimal biomedical treatment, access to disease-modifying treatments, and access to good food and nutrition are not available from birth for people with SCD (Wessberg et al, 1980; Acquaye et al, 1985; Dick 2008). In other words, if the social situation could change, such discrepancy between virtual and actual social identity would blur out and these reactions would no longer occur. Apart from this social adjustment, if the others in the society would change their expectations of social identity in terms of body features, then the experiences of persons with SCD would in all likelihood become better.

In this study, others also discredited persons with SCD when they broke the norm of economic independence and physical capacity/capability and were denied certain opportunities such as to sit for examinations, proper education, and employment. Several
authors have pointed out that, in many societies, there are idealized versions of people who can undertake certain roles such as education and being fit for employment (Katz, 1981; Jones et al., 1981). These authors referred to such social reactions as stigma where certain attributes of a person (more commonly noted in long-standing disorders) interfere with interpersonal relationships.

In this study, participants described experiences that illustrated how norms of economic independence were broken, and the subsequent negative reactions from significant others. People living with SCD were referred to by others as a financial waste. As children they broke the norm of children considered as a future source of economic provision. Moreover, some of the participants not only broke the social norms and expectations, they were deemed to do so in a manner that contradicted their very names within the naming system of their culture (wherein norms and expectations are built into their names). They expressed the experience of sadness, shock and unhappiness from such reactions. Babalola (whose real name means person who has wealth) expressed his experience of shock and unhappiness when he was referred to as a kind of waste.

Persons with SCD described how others shunned them because they did not have physical capacity or capability. For example, one participant could not join the social network of his peers because of physical capacity (specifically the physical capacity of young men) that he fell short of, to be physical and tough; to socialize without becoming tired; to consume alcohol and not to avoid it for their health and not to curtail their geographical range in order to be close to support if falling ill. This discrimination also occurred in other social contexts such as the workplace and places of worship where others felt they could not cope with the energy-requiring demands in such places.

It is also a characteristic of those stigmatized that they are placed under more extensive moral scrutiny than others. This again is self-fulfilling. If you are a person without SCD and are not under heightened scrutiny, then that scrutiny has less chance of exposing variations in patterns of living one’s life. However, once stigmatized, you are likely to be under greater scrutiny and each and every little variation from norms will be liable to be
picked up. As Damilola recounted, “my mother’s eyes are following me everywhere” and this prevented her from participating in household chores, joining her friends in social activities outside, wearing clothes in fashion with others, and selecting her university of choice among other factors.

The participants also were denied opportunities to engage in work or have insurance cover because they were expected to die young and, as such, were assumed by others not to be able to engage in a long term contract. Participants remarked upon the unfortunate nature of this social behaviour of others. Some authors, within a limited biomedical view, have suggested that SCD imposed limitations such that persons with SCD had disruptive experiences in schooling, employment, and social encounters (Adedoyin, 1992). However, from the findings in this study, it could be that it is the social relations in terms of broken norms rather than SCD per se that is associated with the negative attitudes and behaviours of other constituent members in the society. These reactions of others limit the social encounters, career progression and insurance/employment opportunities of persons living with sickle cell.

Additionally, persons with SCD could be experiencing the stigma dimension of “Threat or Peril”, as discussed by Katz (1981) and Jones et al (1984), which has to do with the perceived danger posed to others (i.e. insurance companies, and employers) by virtue of a person allegedly possessing a social attribute (they die young). A change in this attitude could initiate positive adjustments in the social structures, such that persons with SCD would have opportunities for jobs and insurance and be able to provide for themselves, become economically independent and live in such a way that differs from the present, mistaken, claims by others.

This study illustrates that the social context influences how a group of persons is related to. In the US, persons with SCD were not stigmatized by virtue of being in a different context. Hill (1994) highlighted that persons with SCD were valued among low-income African Americans. Within their circumstances of being torn between adopting elusive decent/hard work or street culture, they adopted street culture because hard work did not pay. They
rather assigned value and status to those who produced babies (Anderson, 1991, cited in Hill, 1994). These babies, whether with SCD or not, were valued and seen as the future of the race. Childbearing and having children were seen as natural and highly desirable phenomenon among the low-income black people (Stack, 1974, cited in Hill, 1994). Having a child was an alternative life-course strategy in many multi-generational black families (Hill, 1994). Motherhood was viewed as a route to adulthood and children were accepted and valued regardless of the circumstances of their birth or genotype (Hill, 1994). Young black women were almost ‘required’ to have children who were regarded (with or without SCD) as precious (Hill, 1994). In that period as well, the civil right movements created a supportive environment for persons with SCD with increased public awareness such that they had policy backing with medical care (Medicaid) and hence could not be seen as drains on the family’s purse (Hill, 1994).

This study may be contrasted to Hill’s exposition to illustrate that people with SCD experience stigma because of different social arrangements (lack of financial support for treatment, absence of historical legacy of slavery that could inculcate a sense of the importance of survival) and not because of their SCD per se. This study also attempts to present a perspective of SCD and stigma being as a result of broken societal expectations and not located in SCD. This approach aligns with Goffman’s original depiction of stigma as based on relationships, specifically relationships to societal norms and expectations, rather than attributes of, say, a chronic illness such as SCD.

The components of stigma were elucidated in the accounts of respondents in this study. The study also highlighted from these accounts how power in the society allowed these components to synchronize such that others applied stigma to persons with SCD (Link and Phelan, 2014). Others in the society made social selection of human differences among persons with SCD that were significant enough to be labelled (Link and Phelan, 2001, 2015). In the context of cultural beliefs, the labels were associated with undesirable characteristics, and this association led to separation. Respondents gave accounts of disapproval from several facets of their society which led to their separation. They lost status and experienced discrimination. The aftermath of these social processes were denial
of education, denial of the chance to marry, unemployment, loss of relevance, loneliness, loss of self-esteem, and depression (Link and Phelan, 2001, 2015). The accounts of participants highlighted the precautionary gaze (Foucault, 1995) of others in the society including family members. They also shared how they internalized this gaze of others and provided instances of the consequences including ‘self-doubt, shame and guilt’ (Scambler and Hopkins, 1986). In line with the research objectives, the reflections on these accounts lead this study to have a very different view of the relationships between SCD, depression and stigma.

This study, true to Goffman’s concept of stigma (1963) and in line with later arguments of Link and Phelan (2001, 2015), revealed that stigma entrenched in "a language of relationships” that is social relationships where some characteristics of persons with SCD that is contrary to a set of norms (body, investment, health) of Lagos culture are defined as discrediting or discreditable. Hence, others in their social world, ranging from family members, and intimate partners to the larger society, acting in ways consistent with one another and thus deriving power, apply undesirable labels on them. The stigma, that persons with SCD experienced, exists in interrelated components. With regards to labelling, others in their lifeworld identified differences between persons with SCD and them, and labelled them (yellow eyes, short life expectancy, weakness, people who pretend, and bad investments to mention a few). The human differences that they identified and distinguished are the ones that are significant for the society. Hence there is social selection of the human difference that is significant for labelling. For instance early death is framed as unhealthy in terms of investment and survival of the society.

There were dominant cultural beliefs, such as *Ogbanje, Sunwonan, Emere* and *Abiku* among others in the Nigerian society, that associate persons with SCD with negative stereotypes such as being sickly, and without physical capacity. These links were established among persons living with SCD in this study who were therefore placed in distinct categories in order to alienate them from others (Devine et al., 1999; Morone, 1997). The respondents at various times were referred to as "sicklers" instead of people living with sickle cell.
In their lived experiences, persons who have SCD lost their status (i.e. could not go to school, could not marry, could not socialize) and faced lots of discrimination (i.e. chorus of disapproval) from others in the society. These actions were with consequences of dissimilar paybacks (no opportunity to re-take examinations in school, losing jobs and lack of support in marriage). It is revealed that when these persons were labelled, isolated and associated with unacceptable attributes (physical, moral and financial), others members of the society had a reason to exclude them and they became disadvantaged in terms of life profiles (no or low income, no or poor level of education, poor physical health and mental health – depression and suicidal thoughts) (Druss et al., 2000; Link, 1987). It is essential to draw attention to the impact that the social processes (labelling, isolation, and linking with unwanted characteristics that lead to loss of status) have on the potential that people with SCD have to carry out tasks for which they are in fact proficient.

The study depicted attitudes and beliefs among relations, health workers and others in the society that led them to acts of discrimination against that persons with SCD, such as refusal to send them to school, to marry them, and to appoint them into jobs. It was obvious from their accounts that stigma thus impacts on social structures and relationships around the persons living with SCD.

The respondents also highlighted in their experiences certain social psychological processes about people with SCD (they are not supposed to live long for example) that they went through early in life as part of socialization into their culture (i.e. Angermeyer and Matschinger, 1996). This conception became a lay theory about what it means to have SCD for some respondents. They related some understanding that people living with SCD would not be acceptable as friends, or employees. Given this world view, some of the people with SCD engaged in risky behaviors, some had negative expectations as well as fears of rejection that led to restricted social networks (Link et al., 1989), depressive symptoms (Link et al., 1997), and unemployment (Link, 1982, 1987).

According to Link and Phelan (2001, 2014), social and political power facilitate the development of the various components of stigma. The society believed persons with SCD
were poor investments and so not needed. There was lack of funding for SCD, compared to funding for persons with HIV or cancer for instance. The number of research studies and interventions on SCD are also fewer compared with those for persons with HIV or cancer.

First, people with SCD in their narratives in this study reported their actual achievements, such as obtaining employment, having babies, and living to old age, that contradict social expectations. These are actualities that challenge the existing norms of the society in which they live. Secondly, persons could do things if disabling barriers were removed. For example Joke said if she had money she would not have leg ulcer because she would take transports instead of walking long distances and then would not have the challenge of losing partners due to the leg ulcer. Social re-arrangements in form of transportation for those with leg ulcers and insurance and microfinance access could challenge and remove such societal norms/expectations. Thirdly, following on from the first two premises, the existing social norms/societal expectations are not beyond criticism. Possibly, the values implicit in those norms are “wrong”. This study therefore highlights from the accounts of participants how some have developed some certain degree of agency in order to challenge enacted stigma and prevent internalized stigma. In other words, by recounting these instances, they made attempts to prevent themselves being categorized into what Goffman (1963) referred to as ‘tainted and discounted’.

We now move from experiences of stigma discussed as product of social relations in line with Goffman’s original idea, and proceed to another theme on how people negotiate their lives despite social neglect or oppression. The theme “I am a different person” highlighted among the participants that they also felt lack of acceptance, quite apart from being disapproved and stigmatized by others. This sense of lack that emerged as being different is arguably connected to the social reactions of others and social norms. Perhaps when they had experienced continuously being put down into such another class by others they accepted it to be their regular position and saw themselves as different from others. In other words, in the interviews, participants conceptualized SCD and stigma in terms of bodily limitations, and did not frame it as resulting from negative social arrangements that could be ameliorated by social re-adjustments. Unlike other studies this study highlights that
“being different” in the experiences of persons with SCD is a social product of lack of acceptance.

This study also identified the theme “thinking and talking about death”. The participants described their challenges in the negative attitude of others which could undermine their will. They identified that the attitude of neglect or emotional coldness in others to persons with SCD could even account for some deaths of people with SCD in their view. They expressed that these negative reactions from others made them feel depressed and made it difficult for some of them to have long term plans. Their lived experiences seemed to underline that the view of significant others, and others in general, that SCD ‘is’ an early death sentence puts persons with SCD at greater risk of thinking more about death or dying. This study therefore suggests that the constant focus on early death predicted by others may itself contribute, in ways that are self-fulfilling, to stigma, low mood and ultimately depression.

In highlighting the theme “we wished we were dead”, this study drew attention to the experiences of lack of social support from relatives and friends, social factors beyond SCD per se, in the genesis of suicidal thoughts, risky behaviours and suicidal attempts. In the presence of widespread discriminatory attitudes and in the absence of social network and support, persons with SCD were prone to suicidal experiences. In addition this study pointed out how negative social arrangements that spread belief of early deaths among SCD people could result in persons with SCD making attempts to gain social support with a trade-off between short-term enjoyable activities and long-term physical harm to health. The problem lies with the broad social relations and not the SCD per se.

In the analysis of the interviews in this study, “Coping with SCD” emerged as a theme. The experiences of participants were about staying within their limits and being frugal with money in order to fit into society. In other words, they seemed to make attempts to renegotiate their social identity by policing themselves in line with the admonishments of others. The participants at this stage of the interview framed SCD as a problem within themselves and thus they accepted the responsibility for adjustments by policing
themselves to stay within their limits of physical and financial capacity rather than the others making necessary social adjustments to accommodate them.

The findings of this study explored the depth of participants’ experiences in highlighting the social interactions and forms of social relations that underscore their experience of SCD in terms of coping. This is in contrast to the quantitative studies that explored SCD using third person account perspective. For example, several authors (Gil et al, 1989; Gil et al, 1992) reported that psychological coping strategies could significantly reduce the frequency and severity of pain experience. McDougald et al. (2009) reported that coping strategies influenced responses to pain.

This study’s findings contrast with structured studies that attempted to quantify subjective states of mind, and found social functioning of persons with SCD to be undermined. For example, Hilton et al. (1997) in a study of Jamaican adults found adults with SCD had fewer social relationships compared to a matched control group of non-SCD adults. Barrett and colleagues (1988) in their quantitative study of 89 adults in the USA also found that employment prospects and opportunities were also negatively affected by SCD. These studies found associations but their perspective is limited, first and foremost in locating the problems in SCD per se. These studies showed that persons with SCD had fewer social relationships and opportunities but did not account for why they are in these situations. It is possible to account for these situations by attending to the illness experiences of persons with SCD. This study illustrates that they have fewer social relationships and opportunities because of the social norms/expectations they break, and subsequently they are socially excluded from relationships and work opportunities or they avoid the chorus of disapproval and labelling by avoiding social relationships. In other words, the issue is why should people with SCD seek additional relationships, when many of those relationships would be with people who disparage them. Their choice is effectively to engage more with people who discriminate against them and insult them or to withdraw from all but a few trusted contacts.
In the interviews, this study illustrates how persons with SCD have associated their negative experiences with lowering their mood in such a way as to suggest that social discrimination might conceivably be implicated in the genesis of depression. The participants had several disapproving encounters in different social contexts that could be analytically conceived of as a “chorus of disapproval”, which places them in a difficult position where they are subject to pervasive negative experiences of sadness, depression and shame. In their experiences of disapproval, disbelief about their painful episodes, and stigma, the social reactions of others were predicated on social norms/expectations that persons with SCD break and not on the SCD per se. The present social arrangements, with pervading discriminating beliefs, also preoccupy the mind of persons with SCD, who then prone to frame events negatively, so that they cannot enjoy life, plan for the future, or keep things in perspective, and such that they become depressed with fears of, and attempts at, suicide. Their thoughts of, or attempts at, suicide are embedded within the social arrangements that deny support for persons with SCD. It is worthy of note that if participants were left in this stage of research, they would continue in this oppressed situation, while the research could potentially have gained the author some status. For these reasons the author engaged in extensive reciprocity with the participants.

The illness experience of participants highlighted several emotional states such as anxiety, frustration, depression, and negative thoughts including thoughts of suicide. There was erosion of self-worth and confidence among participants. The participants illuminated through their experiences that the broader social context and the inability of other social actors to accommodate differences might constitute barriers to their positive life experiences. This is in line with several authors who have suggested that the difficulties faced by disabled peoples more generally (Oliver, 1996; Barnes et al, 1999) or persons with SCD in particular (Atkin and Ahmad, 2001) could be the result of negative social relations, insensitivities on the part of others and the resistance of others to accepting human differences.
This study therefore illustrates the extent to which the people with SCD themselves (i) identify that it is the gap between societal expectations/norms, and what it is imputed by others that they can or cannot do, that is the origin of stigma; and (ii) conceive what they have done as achievements but not publicly project them as achievements to others and (iii) point out what they could achieve with support and reasonable adjustments. The participants discussed in the interviews unrecognized achievements that illustrate actualities that contrast with broken norms/expectations of the society. These narratives became sounding boards for further discussions as we would see in the section on societal sickness where they projected these achievements in the group and where participants conceived of projecting these to the public through media and campaigns. Hence, the findings in this study represent a body of knowledge with a potential for providing policy makers with the needed foundation on the social context of SCD and the need to challenge the “societal sickness” of SCD discrimination. They provide a foundation for rethinking through broader social relations, which account, to a substantial degree, for the depression and stigma felt by persons with SCD. The findings in this stage do not map neatly onto the threefold Kleinman framework. The points (i) and (ii) above fit within the illness experience but the point (iii) begins to draw, implicitly, on the types of social model of disability outlined by Oliver (1992) among others. In the individual interviews, despite that the participants recounted many instances of oppressive social relations, some began to make some suggestions about what social arrangements could or should be changed. These instances that drew implicitly from another level of Kleinman framework suggests that these levels are not as rigid as they seem but that each level seems to interpenetrate or overlap one another. Nevertheless such mooted challenges to social relations found oppressive became far more amplified when we look at the results of the focus groups.

**Societal Sickness of SCD**

In framing the negative reactions of others as a “societal sickness” the particular use of focus groups allows for the formation of a critical mass of persons with SCD in developing a sense of common interests and sense of common goals capable of challenges to existing oppressive social relations identified using their frame of reference. This study highlights
findings in focus groups that contrast with findings of some qualitative studies of persons with SCD that used focus group methods. These qualitative studies framed the challenges of SCD as consequent upon having SCD, unlike this study, which underscored the challenges as social creations, consequent upon broken norms/expectations, and the potential tendency of persons with SCD to change such social relations as a group.

This study noted, within the framework of Oliver’s model of disability and Link and Phelan’s (2001, 2015) reconceptualization of stigma, that research could not be limited to the illness experience of persons with SCD and micro-level interactions of such disadvantaged persons. This is also in line with the argument of Whitley and Campbell (2014). These authors contend that while studies that explored lived experiences to comprehend the nature and extent of phenomena including depression and stigma are useful, their descriptions fall short in certain other respects. For instance, such studies could not provide answer to what strategies persons with SCD can engage in to challenge, prevent and/or manage social products such as depression and stigma.

This research addressed this limitation of illness experience by giving consideration (to a greater extent in the groups than in the interviews) to questions that explored what the participants considered were oppressive about their social conditions, and questions that explored what could change in their social relations, how such changes could be negotiated, and how to help others with similar social situations. Within the focus groups, participants were therefore invited to engage with debates about what types of explicit challenges could be initiated. Furthermore, in participating in the focus groups, there was a sense in which the people themselves began to refer to interests in common and even to notions that they themselves constituted a group.

For example, Thomas and Taylor’s (2002) qualitative study of young adults with SCD in London highlighted all domains of problematic experiences as effect of SCD. This study underlined that ‘SCD carries a huge psychosocial burden’ (p. 345) and that it had negative impact on their physical, psychological, social, and occupational well-being as well as on their sense of independence and sense of self. However, this study locates emotional
distress in persons with SCD just like quantitative studies (i.e. Belgrave and Molok, 1991; Edwards et al., 2009; Harris, Parker, and Barker, 1998; Hasan, Hashmi, Alhassen, Lawson, and Castro, 2003; Udofia and Osekihuem, 1996; Wilson Schaeffer et al., 1999) and even when they gave voice to the people with SCD, the framework within which their voices are interpreted continues to locate the problem in the individual body or psyche. Thomas and Taylor (2002: 345) concluded that “SCD undermines quality of life in important ways”. Despite the study adopting qualitative methods of data collection, because of the traditional manner in which data were interpreted in a way that continues to locate problems with SCD itself, the authors still ended up framing the problems as one lying within the person with SCD themselves rather than in the discriminatory structures of wider society. This view perhaps fails to attend to the details of experiences in the data, does not frame the experiences of participants in the phenomenological tradition and nor in the way of disability rights. This study, by contrast, has given individual voice to persons with SCD within an interactionist perspective and provided for the potential for a collective voice with a disability rights perspective.

In the focus group discussions ten primary thematic categories related to living with SCD and depression emerged. The theme “survival and success, reaffirming positive identity of SCD” emerged in the group. Along the line of this theme, participants engaged with one another and reaffirmed their positive identity of SCD in recounting their experiences of survival and comparative pain, as well as the social influence of pain in relationships. It is noteworthy there were fewer positive comments affirmatory of the abilities of SCD in individual interviews compared to the focus groups. This momentum appeared to increase as they had further focus group sessions. A longitudinal study would be interesting to explore the outcome of this formation of ‘groupness’ in relation to explicit challenge of oppressive social relations as participants convince themselves that they have vested interests in common.

It is also important to note how the participants, in focus groups, underscored positive aspects of pain from their past experiences in contrast to the distressed exposition of pain in the individual interviews. As the participants drew out the positive identity of life as
persons with SCD in the sessions of the focus groups one tended to have a glimpse of (1) the beginning of the shape of what might happen in the future (as a critical mass to challenge socially oppressive practices and initiate social changes) if they stay together; and (2) the elements of mutual trust and support that emerge as they meet together. The focus group fostered valuable peer support for participants. This improved their morale and self-esteem. This is in line with other research that shows the importance of group support in recovery (e.g. Verhaeghe et al., 2008; Whitley and Campbell, 2014).

Another theme in the focus groups was “being in group opens opportunity for self-disclosure and encouragement”. Participants shared the view that the illness is embodied and they needed to accept it and move on in life. Being in the group provided the opportunity for them to reaffirm that their experiences, although unique, share commonalities with other persons with SCD, that they are not alone in the family and could get close to others in the family. On one hand they had unique experiences, for example, Joke was disparaged in the neighbourhood by unknown elders, Damilola was disparaged in the school by known friends; while Joke saw her life with SCD as characterized by patterns of blood transfusions and significant others thought she pretended, while Babalola saw his life as pattern of pains and significant others thought he pretended. To borrow from the perspective of Atkinson (2010), their life worlds are unique to one another but their habitus is similar in that people outside the family in public places cast doubt on their legitimacy as acceptable human beings.

Participants found the opportunity to reinforce a positive view that they could successfully manage living with SCD and orientate themselves to obtaining what they want in life. This finding is consistent with what Caird and colleagues (2011) found among UK adults with SCD, whose acceptance of SCD allowed them to enhance their resilience by constructing positive meaning, re-establishing their social identity and purposefully negotiating mutually acceptable conditions. This study, in a sense, provides a useful group strategy for persons with SCD to help them function better in their social world of West Nigeria, a strategy that might conceivably be transferable to other West African contexts where SCD is prevalent.
Another theme that emerged within the group was the reinforcement among participants of the belief that the problem lies in others, rather than in themselves as someone with SCD. The focus group provided an opportunity for the participants to begin to develop a considered degree of agency in order to prevent enacted stigma, and to prevent or avoid the consequences internalized stigma. They began to find ways to avoid or avert their being isolated, in their own eyes at least, among Goffman’s (1963) ‘discredited’. Participants recounted how they used to accept the negative view of family members and others in the society, namely that they were accursed and responsible for their problems. Within the group, members reiterated that their view had changed and some pointed to the role model of others with SCD as responsible for this change in view. The participants, being in the group rather than isolated individuals, had greater opportunity to identify that the problems faced by persons with SCD were more from their family and others in the society rather than in themselves. In addition, the forum of a group discussion also provided the opportunity for some participants to think of ways to address this issue as well as the possible gains of such approach. They considered campaigns for recognition and awareness of SCD for family members as a starting point before taking the campaigns to others in the society. The benefits were discussed not only in terms of cost savings in health bills, and reduction in harms and problems for persons with SCD, but also in terms of gains for the younger generation with SCD.

Another theme was “sharing information that is of possible use to one another”. This study demonstrated an emerging process of peer support in providing reliable and relevant information that could impact positively on the quality of life of persons with SCD. The participants showed the confidence to reflect on their experiences and challenge certain practices as false and unhelpful. Unlike in the interviews, being in a group opened up the opportunity to think about what could be the problem and how to address this problem. This unfolding process could be a helpful strategy to create a wider peer support group for other persons with SCD. Indeed this process was noted by the participants themselves through the related theme “discussion of possible mutual support group”. It could be argued that the process of discussing issues of mutual concern was instrumental in opening up
thoughts of setting up groups to support persons with SCD. They identified the functions of such mutual support groups such as to provide support for: those without family support, those who might kill themselves to gain social acceptance, parents of those with SCD to guide them in proper medications, sickle cell carriers who have SS children, students with SCD and employees with SCD. Their deliberations in the groups highlighted how participants are identifying socially created problems and initiating changes in social arrangements in other to improve the living conditions of persons with SCD.

Within the theme of “challenging negative attitudes/reactions/labels”, this study illustrates how the group orientated themselves to one another and tried to make sense of their experience through the development of insights into negative reactions of others as a form of symbolic violence that needed to be challenged, ultimately through the use of the law. Also considered relevant was the need to develop the resilience to challenge negative labels. The group thus helped in developing a sense of agency to prevent and challenge negative social processes in line with Whitley and Campbell (2014).

The study facilitated the emergence of a theme of members challenging counterproductive strategies. Being part of focus groups appeared to be giving members the opportunity to suggest, amend and debate strategies for challenging negative social relations within their own frame of reference, and not frames of reference set by others. The participants had the opportunity of gaining insights into the cost/benefits of having support, even when it could be at first financially costly. The participants also pinpointed a relevant theme “canvassing for support from significant others”. In so doing, members of the group were developing a sense of collective responsibility for people with SCD including young people with SCD as the next generation. In recognizing the need to have allies, participants captured Goffman’s concepts of the “Own and the Wise” where the Own represents persons with SCD and the Wise represents those significant others who have an insider’s knowledge of what an SCD experience might be like. They identified strategies to gain support from the Wise such as enrolling NGOs to better represent the interests of those living with SCD, educating significant others to be better advocates for SCD, and educating other regular community leaders about SCD. The participants intended not just to gain support from the Wise
(educating significant others to be better advocates for SCD) but also tried to gain support by extending the range of people who might come under the term Wise (enrolling NGOs to better represent the interests of those living with SCD and educating others regular community leaders about SCD). Goffman (1959) distinguished between backstage (private) and frontstage (public) settings. In this study, the focus group offered participants a safe backstage shelter where they had a physical and ontological space for renegotiating their social identity. This refuge also allowed for the development of strategies that could be used to manage depression and stigma through helpful initial internal and later external social support (Whitely and Campbell, 2014). In line with these authors, this suggests that backstage activities (focus group) can positively impact on ‘performance’ on the frontstage space (society).

As discussed above, this study facilitated participants to explore what could change in their social relations. They also had the opportunity as a group to consider how change could be negotiated for their benefits and that of others with SCD. These came up as the theme “areas of interest to the group”. In negotiating change, the group considered accessing/using the media for campaigns, and developing a reporting mechanism for those who abuse people with SCD and a support mechanism for people with SCD. Furthermore, the establishment of policy and enabling laws was considered in schools, hospitals and establishments for employment. Dyson et al. (2010) reported that policy initiatives would be more effective, compared to merely raising awareness, for persons with SCD in schools, and this principle could be extended to other social institutions.

The participants with SCD enumerated strategies to negotiate change in various institutions through negotiations with stakeholders as well as involvement of key persons in government who are sympathetic to their cause. For instance in the hospital setting, they enumerated some strategies to engage and negotiate with nurses who have been identified as key to better quality of life in the hospital experience. These strategies included meetings with hospital management to establish complaint procedures, meetings with the association of nurses, and the introduction of policy/law that is enforced and that prescribes monitoring
mechanisms. They also identified setting up microfinance as a possible way to change social structure to improve their lived experience with SCD.

The findings in this study highlights the important of taking a broader social approach that goes beyond the previous works of SCD which are largely located within the ‘medical model’, and which neglect the social aspects of SCD such as disabling barriers and discriminatory structures, and also goes beyond the illness experience model of SCD that only highlights negative social relations without attempting to bring about a change. This study highlights the social construction of stigma and depression in persons with SCD. It also shows the relevance of persons with SCD in bringing about a change within their own terms of reference. These findings are woven together through Kleinman’s framework, the invaluable insights of disease, the broader reminder that living with SCD occurs within a changing relational space and involves negotiation with other social actors (Blumer, 1986; Goffman, 1986) and possible renegotiation through re-engagement with social structures and social relationships (Oliver, 1992). In other words, this approach necessarily synthesizes a wide range of biosocial literature, including a range of theoretical approaches, under-pinned by very different but useful assumptions.

This study therefore illustrates that people with SCD have themselves been through the process of identifying the gaps between societal expectations/norms and what it is imputed by others that they can or cannot do, which is the origin of stigma they face. Through coming together as a group they have started the process of pointing out (i) what they are achieving and (ii) what they could achieve with social support and reasonable adjustments. It is important that these findings represent both a body of useful knowledge and a potential model (i) for persons with SCD to use to negotiate and bring about positive change for themselves, and (ii) for stakeholders in SCD such as policy makers to consider the relevant social context and relations in creating awareness for SCD and movement for change. This study provides a basis for rethinking through broader social relations that could account for emotional disturbances and other negative experiences that persons with SCD undergo in their life-world.
In reflecting upon what the data in this study have highlighted such as (1) the emerging process of collective realization of unexamined accomplishments with resultant positive self-identities; (2) the unfolding opportunities to challenge discriminatory attitudes and behaviours of others; (3) the evolving strategic approaches to provide mutual support for one another, others in similar situations and posterity, and (4) the developing proposal to engage critical others in supporting them, it is possible that findings in this study have potential positive applications to groups of persons with SCD. Thus others in similar situations of socially constructed stigma and depression might possibly make use of data in this study to renegotiate their positive identity and impact positively on their lifeworld. For example, the data from this study might inform the activities of sickle cell clubs in Lagos by suggesting strategies to build social capital and by encouraging the development of stigma resistance. The way forward using the template of focus groups is the sense of coherence of similar interests that could develop, which could encourage persons with SCD to learn, in Goffman’s terms “backstage” in their sickle cell clubs, that the problems do not necessarily lie in them but in others in the society. Moreover, through such group work in this “backstage” domain, they can learn to look after others with SCD who lack family support, to look out for others with SCD so that they do not stress/kill themselves with overly heroic individual efforts, and they can prepare in safe settings prior to acting out these learnings in the “front stage”, in interactions with others. They could also use the sickle cell clubs as a “backstage” where they can define social relations that are oppressive in different settings and contexts and challenge these in their own term of reference with a view to pursing these interests in the “frontstage” of interactions with other members of the society. In other words, the data in this study might inform activities of sickle cell clubs in Lagos to include (1) mutual support via individual counselling and peer support groups, (2) provision of relevant information to positive life experiences for people with SCD, (3) a means and forms of reaffirming positive identity via sharing of successes, (4) a forum to engage themselves and challenge counterproductive strategies, (5) campaign programmes where they learn to stand up for SCD and represent themselves in addition to canvassing support from significant others. These activities could therefore form the tapestry of social capital development and resilience development to socially oppressive relations.
Having looked at potential applications of data from this study, there is a need for future research that could address the tensions between the medical and social models of disability. The medical model locates the problem in the persons with SCD while the social model views the problems faced by persons with SCD as emanating from social structures. The adherents of each of these perspectives disagree on the needs of persons who are ill (in this case, people with SCD) and how such needs are best addressed. As a result, different attempts at implementing changes for persons with SCD could be out of synchrony. For instance in Nigeria, biomedical researchers dominate the spheres of management of problems of persons with SCD and may not see potential applications of changes from the viewpoints of persons with SCD whom they regard as not sufficiently knowledgeable in any scientific discipline to apply such knowledge to solve their own problems. These tensions could usefully be resolved by the consideration of the ecological model of Bronfenbrenner (1979) and a human rights perspective using United Nations Conventions on Rights of Persons with Disability. First, future research could consider the use of Bronfenbrenner’s ecological model in understanding more the multi-layered relational dimensions of SCD, stigma and depression and thus complementary areas of intervention. Bronfenbrenner’s (1979) theoretical perspective describes an approach to explore a person's social proximity and interaction with environmental influences such as family, friends, and other social networks. Accordingly, this theory portrays that people are embedded in differing levels of expanding environmental settings, which in turn are embedded in even broader and bigger settings (Bronfenbrenner, 1989). Generally, there are varying levels of influences in the environment that can interact with and impact on an individual's view of the world (Okun, 2005). Bronfenbrenner (1979:3) highlighted an individual's environment as "a set of nested structures, each inside the next, like a set of Russian dolls". In this paradigm, emphasis is placed on the relationships and interconnections between each person and his or her even expanding nested structures. In the innermost layer wherein the person is embedded is the microsystem that is comprised of various characteristics of family, home, school, peer group and workplace environment (Bronfenbrenner, 1989). The next layer is constituted by relationships established with and interconnections between home and school, school and workplace etc. (Bronfenbrenner, 1989). And the third facet is
one in which events occur that affect or are affected by, what happens in the nested structures. These may include activities, rules within the power structures or other various indirect structures that potentially influence a person. The most outward layer is the characteristic of a given culture or other broader social context that influences a person embedded within this system.

In line with Bronfenbrenner's (1979) ecological systems theory, the social environment clearly has a crucial impact on individuals. In essence, ecological influences within a network of friends, peers and family (including other social networks, such as professional settings in hospitals and workplaces) could be critical in facilitating or counteracting positive life experiences of individuals who live with SCD. In relation to SCD, very few researchers have acknowledged the potential use of an ecological approach to adequately address socially constructed factors such as depression and stigma. So further information on the role of other systems within the environment is warranted to theoretically understand environmental/social factors implicated in stigma and depression production in persons with SCD. For instance, in this study, some families were supportive of persons with SCD while some did not. Some participants noted both in the interview stage and the focus group stage that if resources (including social capital) were available in sufficient amount for other siblings, negative social interactions might not have been created. There might be other factors in systems beyond the family that could account for depression and stigma. By attending to such environmental factors that could socially produce stigma using such an ecological approach, future studies would supply new information in an effort to provide socially significant points of intervention for persons living with SCD. Thus, the exploration of the ecological nature of depression as well as stigma in persons with SCD is relevant to the process of overcoming barriers to positive life experiences among such persons.

Secondly, and in addition to the ecological approach outlined above, future studies also need to pay attention to a human rights approach to disability. This model of human rights moves beyond the perspective based on the purported “needs” of disabled peoples. A needs-based approach is problematic in that these assessed needs can be construed and
defined by paternalistic others, in which the act of meeting the needs of those who live with SCD becomes a gift of the ‘powerful’. This approach does not derive from the view of the persons (i.e. people with SCD) themselves. For instance, as we have seen, from the perspective of persons with SCD, their lack of representation within the Nigerian Sickle Cell Foundation is an important issue.

If the rights of persons with SCD are established as part of national laws, there would in principle be legal redress to overcoming barriers that restrict access to their full participation in valued social activities such as schooling, paid employment, leisure activities to mention just a few. Much of what the participants said in the focus groups is that they wished to be included in such activities.

However, this notion of human rights approach being led by WHO could be problematic to the extent that the persons concerned might see WHO as imposing its own frame of reference onto their lives. Having said this, rights could be turned against those living with SCD. For example, the United Nations Convention on Rights of People with Disabilities highlighted “rights to health services”. Article 25 of this document states: “a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes” (my emphasis). The right to screening, for example, might be fine with regard to new-born screening, but more contested by people with SCD themselves if this were a population-based prenatal screening public health programme aimed at selective termination, in which case it might be against their interests. Likewise, the “right” to know your genotype (as widely promoted by the churches in Nigeria) might easily become an obligation not to marry a fellow SS or an AS carrier.

With respect to enabling laws and policies, others may still not be held accountable or made to adjust their socially oppressive views. The laws/policies may in addition be weakly enforced or not enforced at all. For instance, saying that schools need to make reasonable adjustments to ensure full participation of young people with SCD still leaves room for a
power struggle over what is reasonable, with the school minimizing what they think they should have to do. Again, a law that said buses should stop to pick up people with SCD might be ignored by the companies or ignored in practice by the drivers.

So to the extent that a law places duties on organizations to ensure rights of people with SCD, this could turn the organizations back to paternalistic “protection” of people with SCD in their best interests. For example, it would not be in the best interests of people with SCD to say they have a right to be protected from harm and should not undertake certain strenuous duties if that person with SCD wishes to engage with such activities. For example, some people with SCD love sports and can take part in activities, knowing their own limits. They might not welcome a school upholding their right to be excused sports.

This study is not without limitations as well. There were limitations in the sampling, and the process of data collection. With regards to the sample, some voices were included while some were eclipsed. In other words, even though the study aimed to sample for diversity, there were voices that were relatively under-represented, such as men, Muslims, and other ethnic groups (i.e. Hausa). Thus within the bounds of this study we have not been able to shed specific light on what Nigerian Muslims, or those of Hausa ethnicity who live with SCD would describe as their lifeworld with depression and stigma.

In terms of the data collection process, certain limitations also need to be acknowledged. First, the use of validated scale for identification of depression could be problematic. One of the participants said that he was not depressed notwithstanding results as suggested through the application of the scale. This could represent an imposition of a Western concept of depression in a non-Western culture and could also indicate an insensitivity to a participant’s viewpoint or account. However, whilst disavowing a specific diagnosis of depression, this participant, in common with all the others, recounted many instances where it was clear he was feeling distressed at the attitudes of others. Secondly, although the study was based on mixed methods, of questionnaires, interviews and focus groups, these methods of data collection share the same methodological limitation in that they are all forms of data based on accounts (what people say, not what they are observed to do).
Documents such as diaries, analysis of secondary, non-reactive data such as social media and direct observations (for example of behaviours and exchanges at SCD clinics) could be useful to address this limitation in future studies.

**Conclusion:**

This chapter has discussed the findings of this study in the context of extant literature. This discussion highlighted similarities, and dissimilarities with extant literature while at the same time going beyond these to point out certain unique perspectives for understanding the lived experiences of persons with SCD. This study is the first in West Africa to highlight the potential of a group situation among persons with SCD: to propose the positive characteristics of people with SCD, and to be affirmed in that view by others. This study utilized an interpenetrating and multi-layered framework of Kleinman, and within this dynamic framework also used the theories of Goffman and Oliver to highlight the oppressive practices in the life-world of persons with SCD and to begin the process of challenging these practices within the terms of reference of persons with SCD themselves. Invaluable insights were garnered to demonstrate that full understanding of SCD and depression requires attention to SCD and depression as not only a biological disease, but also as an individual illness experience and culminating in an appraisal of how such societal sickness could be challenged. This chapter leads us to the final chapter that draws wider inferences from the previous chapters, describes the original contributions made to the existing knowledge on depression/stigma with SCD and argues for further areas of research into these aspects.
CHAPTER EIGHT: CONCLUSION

Introduction

The previous chapter presented the discussion of the findings of chapters 4, 5 and 6 in the context of past literature. It was noted in this chapter that although SCD might be conceived as, in turn, a disease, an illness and a societal sickness within the threefold framework of Kleinman, and that methods of data collection were broadly conceived as reflecting this framework, in practice, each entity overlaps with the other. In other words, the levels of Kleinman’s framework represent a unified interpenetrating whole, where the understanding of it is cumulative, in which one cannot develop a full understanding of SCD on one level without an understanding of the others. The conclusion first describes the significant contributions in this study within the context of Chapters 1-6, describes the original contribution to knowledge from the study overall and proposes areas for future research.

Significant Contributions in This Study

A starting point for this study was that hitherto sickle cell disease (SCD) has been seen primarily from a biophysical perspective as a group of inherited blood disorders that affects many people worldwide and represents a public health challenge. Whilst not discounting
this biomedical perspective, in this study SCD is additionally seen as a life-long illness that influences and is influenced by social relationships. SCD has been associated with depression and stigma, entities of no less public health importance. The understanding of the relationship between these entities requires a framework beyond a biological perspective or a social perspective alone. In other words, the association between SCD and depression/stigma cannot be totally understood in biological terms alone without adequate consideration of important factors that influence the illness experience and the social expressions of the sufferers of such disease as social relations, familial bonds, economic constraints, and survival strategies. This study therefore considered possible different epistemological assumptions to the production of knowledge on the relationship between SCD and depression/stigma, and reflected the mutually influencing perspectives of Kleinman (disease, illness and societal sickness), Brown and Harris’s (1978) delineation of social origins of depression among women, Goffman’s (1963) original concept of stigma associated with chronic illnesses, Link and Phelan’s (2001) reconceptualization of stigma, and Oliver’s model of disability, in order to explore the origins of depression and stigma within the social and cultural circumstances of people with SCD living with depression.

The study also sought to suggest possible ways forward that derived from the perspectives of people living with SCD themselves via their self-reports of depression, their reflections on their lived experiences, and their discussions in groups.

The review of literature explored the biological perspective that considered SCD’s epidemiology as well as its pathophysiology, highlighting that SCD is an important public health issue in Africa, especially in Nigeria. The review also included depression, first as a public health issue worldwide in its own right, and secondly, as worthy of in-depth study in conjunction with SCD. The links between the extant literature on SCD, depression, social science, and chronic illness were examined in order to generate a framework of research questions. Consequently, it was found that many of these extant studies were limited because they assumed that depression is solely an organic disease, or that it is a psychological adaptation to SCD, rather than considering the social context of health and illness.
In essence, biological sciences could provide neither a full understanding of SCD and depression/stigma as an illness, nor adequate principles and criteria for treatment. This study therefore considered a fuller and more robust approach in which the primary focus of inquiry is not only the relation of “personal troubles” to public issues of social structure (Mills, 1959) but, to develop the insights of Brown and Harris (1978) on the social origins of depression, also on the impact of social systems as a whole on individuals with SCD caught up in them. Brown and Harris (1978) reported that the social context that generates depression was the isolation of young mothers. This study, in line with this approach, explored and reported the social context in which depression occurred in persons with SCD.

In order to connect the personal troubles of people living with depression and SCD to public issues of society and attend to any possible origins of depression in the social environment of the person living with SCD, the review of literature established the need to capture the life-world experiences of people with SCD who have depression. This was in order to show the SCD-depression link not only in terms of a biological disease, but as an illness experience, and indeed to explore how broader social relations may result in stigma and depression in people living with SCD. There was also the need for the study to explore what various first-person strategies to legitimate illness experience and to re-negotiate social identity might exist, and the need to facilitate what could be possibly done to change social relations resulting in depression and stigma in the life-world experiences of persons with SCD. In other words, it was the critical (in the sense of critique) review of extant literature, moving beyond merely locating the problem within people with SCD and their condition that provided the basis for key features of the research design: the identification of a sample of people living with SCD who scored as mildly depressed on a validated psychiatric scale in order to explore their lived experiences of stigma and depression; and what they may consider is oppressive about their social conditions, what could change in their social relations, how change could be negotiated, and how to help others with similar social situations.

In capturing a rich and nuanced understanding of the life-world experiences of people with SCD who had depression, interpretative phenomenological analysis (IPA) was used in
conjunction with other perspectives drawing upon the works of Blumer (1986), Goffman (1968), Link and Phelan (2001), who took some influences from phenomenology [especially Schutzian] and other aspects of sociology and psychology; and, with respect to the focus group interactions, the disability rights perspective of Oliver (1999) informed the focus on how negative social relations might be overcome. These overlapping and interpenetrating perspectives revealed the myriad ways in which people with SCD in Lagos dealt with experiences of stigma and depression in the course of their everyday life, what they regarded as oppressive in their social relations, the aspects they desired to change, and how they might go about negotiating these changes in order to make their living conditions, as well as others in similar situations, better.

From the disease perspective, key demographic and disease variables of persons with SCD had significant associations with depression. However, it was noted that association is not causation. It is pertinent to note that, for example, having leg ulcers might lead to depression or that just being depressed might lead to less self-care which ultimately leads to leg ulcers or that a third factor (i.e. relative poverty) might lead both to poorer self-care because of inability to afford treatment and at the same time might also lead to depression. This thesis therefore argues for an inclusive view that suggests that it is not so much that a biomedical perspective is untrue, but that it is limited in what it can tell us, and perhaps just as importantly it does not necessarily tell us where lie the possible points of intervention in the lives of people with SCD are that might make a socially significant difference.

The life-worlds of people with SCD revealed significant accounts of negative social experiences. Persons with SCD recounted that their behaviors were being disapproved of by significant others in the society on different occasions. In particular, there is the possibility that family members, who are a potentially key resource in protecting a family member with SCD from depression, may in fact themselves be implicated in the genesis of distressed feelings. Moreover, significant others who could conceivably be shields of protection are the ones who stigmatize their own who have SCD. In terms of social interactions, people with SCD seem to be confronted with an invidious choice of accepting stigmatizing attitudes from others or not having any friends at all, with the possible
negative consequences for lack of social support that a lack of significant others or friends would entail. Thus a possible point of intervention could be in nurturing a close confiding relationship that could provide a form of insulation against the risk of emotional problems such as depression and stigma.

Persons with SCD could also be seen as lacking social capital necessary to negotiate acceptance in their relationships such that they became discredited and thus isolated. The disparagements from significant others and other community members, which could be perceived as a “chorus of disapproval”, were linked to societal expectations/norms that were broken by persons with SCD. A shift in the paradigm of societal expectations/norms when it concerns persons with SCD could be a possible point of intervention, but would require a societal-level challenge, perhaps through disability rights activism.

The support of significant others who believe, wrongly, that persons with SCD are pretending when experiencing a painful crisis would not only alleviate feelings of emotional upheaval in persons with SCD, but also allow possible shift of focus to more positive things. If the support of significant others is lacking or undermined because of mistaken beliefs about the experience of painful crisis of persons with SCD, they would tend to doubt and refuse the support of significant others with consequent withdrawal from social networks and emotional distress. It is interesting to note that even discrimination concerning experience of pain that happened a long time ago resonates even decades later. The negative effects of discriminatory remarks on mood and possibly on mental health are therefore also possibly long-acting. Within the health system, the hurt generated from the treatment by those charged with the care of those with SCD who render instead a dis-service through disbelief of their pain could create distrust with the health system and reluctance to use such system. Such social reactions tend to isolate persons with SCD who are then prone to further abuse, neglect and a negative spiral of emotional disturbances including thoughts about death.

Persons with SCD described their experiences of negative social reactions in relation to unmet social expectations from others. There were certain expectations of persons with
SCD in terms of body in terms of height, build, smooth skin and clear eyes, in which some somatic aspects of SCD meant that people with SCD were seen to have broken bodily norms. Other social expectations that persons with SCD broke, which possibly led to negative social reactions, were of failing to meet the outward-going, risk-taking, physical culture of young men, if they felt compelled to stay in, avoid beer and eschew travel.

People with SCD also broke expectations of economic independence. In certain instances, some persons with SCD had names than meant “someone with wealth”, and yet they fell sick frequently such that the family became broke. Their frequent illnesses, and consequent financial downturn in the family, transgressed expectations of members of family and others in the society. Persons with SCD are therefore regarded as potential barriers to others’ realization of their potentials (role and status) in the society and as such are discredited and disapproved of. In some instances, the consequences of the negative social reactions have resulted in people with SCD being discouraged from participation in schools or jobs, and being denied health insurance, with grave material and economic consequences.

Within the context of individual interviews, persons with SCD conceptualized their differential relationship to others in terms of their own bodily limitations (frequent sickness/tiredness; endurance in physical activities), tended to conceptualize their experiences in terms imposed by others, and only rarely framed their lives within a perspective that located their challenges in wider social structures and disabling social environments. They also accepted ‘deterministic’ views of significant others, and others in general, that SCD ‘is’ an early death sentence, and this puts them at greater risk of thinking more about death or dying by undermining their will to live. This is even more the case, given that members of the society saw no need to provide necessary funds to assist persons with SCD in times of need because, in their view, the outcome could not change whether or not funds were made available. These experiences suggest that shared beliefs from interactions with others might preoccupy a person’s mind, with a negative framing of events, so that they cannot enjoy life, plan for the future, or keep things in perspective. The
acceptance of such ‘deterministic’ views of others, and negative framing of events, could lead people with SCD to restrict their ambition or curtail the extent to which they focus outwards to others in society. Conceivably, the constant focus on negative outcomes predicted by others may itself contribute to low mood and ultimately depression. However, within the interviews some persons with SCD mentioned that social adjustment via making funds available could have had positive impact.

Lack of support from relatives and friends was prominent in the experiences of persons with SCD who had suicidal thoughts. This underlying social factor goes beyond SCD itself in the genesis of suicidal thoughts. In the absence, or with no expectation, of social support, it was sometimes felt better to die. During individual interviews, people with SCD tended to frame SCD as a problem within themselves, thus implicitly accepting the responsibility for adjustments by policing themselves to stay within their limits of physical, emotional and financial capacity.

By contrast, at the focus group stage, many of the participants with SCD had the opportunity to propose the positive characteristics of people with SCD, and to be affirmed in that view by others. This suggested that they were in the process of being convinced that they had shared negative experiences, and vested interests in common, in challenging those negative experiences. The participants also had the opportunity to reflect with others on their past experiences of pain. For example, in contrast to the exposition of pain in the individual interviews, participants in the focus groups noted the positive aspects of pain from their past experiences. They discussed the positive consequences of living with pain, such as the idea that SCD pain teaches others something about life, reflecting the notion of Ivan Illich (1976) that enduring pain oneself teaches one to develop empathy for the pain of others. In other words, experiencing pain has potential social benefits, since by experiencing pain we learn to better empathize with other human beings and their suffering. Persons with SCD also saw their survival and success in life as reaffirming their sense of identity, pride and strength. They started to develop a collective realization that sympathy and support from others, especially from significant others, and support that is sustained over a long time, can be very beneficial to the experience of living with SCD. In other
words, their coming together underscored the effect of drawing out the positive identity of life as persons with SCD.

They were in the process of realizing that self-disclosure and reflection could be a source of encouragement to others to have and maintain a positive attitude to themselves. Their experiences provided a sounding board for others with their experiences. This process of learning that they could encourage others, and/or derive encouragement from listening to others, could provide the means of breaking their social withdrawal and renegotiating their positive identity with others in the society. In other words, they were learning that it is possible to successfully manage living with SCD and to orientate themselves as a group to obtaining what they want in life.

Being in the group tends to facilitate greater identification of the SCD problems as lying in the society than happened in the in-depth interviews. They mentioned that significant others were one of the sources of their problem. They illustrated how significant others and the society in general could, via negative views, contribute to the problems of persons with SCD. In other words, being in the group tended to encourage the realization, or reinforcement of an existing belief, that the problem could also lie in the society rather than solely in themselves. Additionally, the forum of a group discussion also provided the opportunity for some participants to think of ways to address this issue as well as the possible gains of such an approach.

In the focus groups, a process of peer support began to emerge where persons with SCD had the opportunity and possible realization that providing reliable and relevant information about access to dedicated clinics, health clubs and laboratories or information on other aspects of life of SCD could impact positively on the quality of life of persons with SCD. This unfolding process, of sharing supportive information and practical social strategies in the focus groups, could have positive implications when extended to wider peer support groups for other persons with SCD.

It is arguably the case that the process of being in a group, and discussing issues of reciprocal concern, was itself instrumental in opening up thoughts of setting up mutual
groups to support persons with SCD. The focus group empowered people with SCD to a certain extent to begin to think about the relevance of a group to campaign for support for persons with SCD, and for challenging negative labels placed upon persons with SCD. Indeed, they suggested the formation of a group that would advocate for persons with SCD in various institutions including schools and government. They also pointed out some advantages of such group membership, such as teaching confidence and strength to members, and creating awareness among others in the society.

Among the deliberations in the groups was the crucial need to change social arrangements in order to improve the living conditions of persons with SCD. Within these groups, members suggested possible alternative strategies (debating the pros and cons) to address the identified issues, which included lack of family support for certain persons with SCD, ‘working to death’ to satisfy others and gain acceptance, unapproved self-medication of young people with SCD by parents, concern of sickle cell carriers who have children with SCD, and employment challenges facing the next generation of youths with SCD. Suggested strategies included formation of a sickle cell group with the responsibility to provide support for: those without family support, those who might kill themselves to gain social acceptance, parents of those with SCD to guide in proper medications, sickle cell carriers who have SS children, students with SCD, and employees with SCD.

People with SCD were able to develop insights into negative reactions of others as a form of symbolic violence that needed to be challenged, including legal redress. They also saw the need to challenge the negative attitudes of others, and to develop the resilience to challenge such negative labels. It is important that they themselves articulated the view that the discriminatory social relationships could be responsible for their depression rather than the SCD illness directly.

This study provided the opportunity for the respondents to use their own frame of reference to provide solutions to the challenges they faced in the society. The respondents began to recognize that they shared similar social interests, and shared goals of having social support. They were able to express the need for pain management that could not be
undermined by issues of pretense and addiction. They began to realize the usefulness of gaining the acceptance of others through developing the understanding of others, in contrast to the ineffective method of ignoring others when they discriminated against those with SCD. They also realized the significance of gaining the support of key community leaders and government, and the implication this has in ensuring the implementation and enforcement of SCD policies so that society makes reasonable adjustments for people with SCD.

This study has demonstrated that, like other chronic illnesses, the “meaning and context […] cannot be easily separated”, Bury (1991: 453). The social context of SCD is highlighted as having to do with roles played by significant others, from parents, siblings, relatives, extending to others in schools and churches, health professionals, and other members of the society and government. These represent the social structure that influences the meaning of SCD. This study highlighted that in living with SCD, depression and stigma are outcomes of interpretations of others, and not consequences solely of SCD itself, and that these negative connotations of SCD and the imagery they evoke derive from taken-for-granted norms of the society, norms which they:

1. do not necessarily actually break, for example, people with SCD do well at school, obtain and keep employment, cook a family meal when no-one thinks they were able to become a mother when no-one thought they could, live beyond 20 years when no-one expected that they would. Here it is shown that people with SCD have achieved these accomplishments despite the odds.

2. norms which they need not break were they to be given support, or reasonable adjustments in society made. For instance, if persons with SCD were given extra-time for exams or they had extra-classes when they missed schools, they can show their intellectual ability; when transport is provided, persons with SCD can get to a place of work; when there is some micro-finance facility, persons with SCD who have culinary skills could be helped to establish their own catering company; with some financial support and proper training of health professionals in appropriate supportive attitudes as well as technical nursing/medical knowledge, women with SCD can more safely give birth; with some
financial help and social support from the community (caring for her child when mother with SCD is sick), a woman with SCD is supported to be a mother in bringing up her own child. This highlights what persons with SCD are not currently achieving, but which they could achieve were they to be given adequate support and adjustments from others and the society.

(3) norms whose very legitimacy might be the subject of challenge, where for example, someone with yellow eyes at school is no longer bullied or teased because of the establishment of school policies are rigorously and consistently enforced. This is about changing the societal norms and expectations. This might appear conceivably difficult to achieve but it does not mean that such slow and difficult process cannot be started.

As a consequence of breaking the norms of the social world in which they live in, people with SCD reckoned that their everyday activities were threatened, and they were perpetually at risk of being stigmatized, having symptoms of depression and being vulnerable with regard to suicide. From this study, managing the stigma, depression, and suicide entails working out strategies as a function of social circumstances and situations.

The study has added to the literature that highlights the importance of social identity and belongingness for issues of health including quality of life. It has added to the growing body of research that group memberships can become the basis of a ‘social cure’ (Jetten, Haslam and Haslam, 2012). The benefits of social group membership are not reducible to just the physical opportunities for social interaction they afford, but also derive from the capacity of such membership to provide and nourish members with a more abstract sense of shared identity, shared challenges and opportunities with others including posterity.

**Original Contributions to Knowledge**

In terms of literature, this study is among the first to try to apply a social model of disability to SCD. In other words, this study is unique in that it re-contextualizes the social model of disability as it applies to a new chronic illness, SCD and in a new setting, Lagos in sub-
Saharan Africa. One, this study applied this model to a chronic illness, SCD, rather than a disability. Secondly, this study is unique in applying this model in a developing world rather than in the UK or USA where it had been previously applied.

This work is also among the first to be critical of existing literature on SCD and depression that sees depression as an automatic consequence of more severe forms of SCD and/or that attributes depression to poor psychological adjustment by the individual person to their SCD experience. In other words, this study has identified the following gaps in literature of SCD and depression. First, it highlighted that the biomedical view is limited in understanding fully SCD and depression. It was revealed that depression is not located only in the person with SCD and that depression is not an automatic consequence of complications of SCD. In addressing this gap, this study presented the seminal work of Brown and Harris (1978) where depression was shown to be an outcome of negative social relations and attempted to apply this work to highlight the social origins of depression among persons with SCD.

Furthermore, this study showed a limitation in the literature, in that the experience of depression in people living with SCD is incompletely explained by correlations of depression, pain and SCD. Correlations of such social variables are open to such varying interpretation of meanings that it renders such research problematic if not meaningless. Such statistical manipulation of social processes cannot usefully represent the kind of social phenomena that may influence SCD. Many studies on persons with SCD had found similar findings of associations of SCD with depression and stigma, but these associations had a sense of ‘inertia’ in which findings were not developed, nor acted upon to improve the social situation of those living with SCD. These studies framed depression as a consequence of stigma, without looking at the depth of illness experience that locates depression and stigma in the taken for granted social context. The review of literature showed that existing studies are limited because of the assumptions that depression was solely an organic disease or that it was a psychological maladaptation to SCD. The associations or correlations within the purview of biomedical model lead to the treatment of physical symptoms or implicitly require the adjustments to be made by the persons with
SCD rather than by others in wider society. This perspective, while it is desirable as part of the reality, is not complete in that it only seeks answers inside the body. This study looks outside the body and found that depression also derives from negative attitudes, and verbal expressions of other social actors in the life-world of persons with SCD. In other words, this work addressed this gap by drawing upon the alternate paradigm of phenomenology, enriched with perspectives of Blumer, Goffman, as well as Link and Phelan.

Another contribution of this study is that the exposition that stigma in persons with SCD is not as a consequence of the SCD per se but it is as a result of societal norms that are broken. In applying Goffman’s theory of stigma as well as further insights from Link and Phelan, this work identified that extant literature had not applied this theory in a valid way. This study therefore addressed these limitations by re-contextualizing this theory, remaining true to the perspective of Goffman in exploring stigma as the outcome of broken norms. SCD and stigma were seen as a relationship between persons with SCD and social expectations, a discrepancy between social norms and the identities imputed to people with SCD, as different from the tendency, within medical and psychological literature, to view stigma as a consequence of SCD, located inside the persons with SCD.

A fifth contribution of this study is to remedy the fact that the lay and social meanings of depression, as illness, have rarely been widely explored in sub-Saharan Africa. This gap was addressed through drawing upon key extant literature (Brown and Harris, 1978) in order to set the tone for the exploration of the social meanings of depression as it applies to persons with SCD.

The sixth contribution is to draw attention to the fact that most studies that have identified a relationship between SCD and depression have not gone beyond this identification and subsequently, persons with SCD have been left without a voice. Furthermore, persons with SCD in Africa had not hitherto been allowed to tell their story, talk about their challenges and express their ideas about ways out of these challenges within their own terms of reference. This study addressed these previous limitations by incorporating the social model of disability in such a way as to address these identified gaps.
This study highlighted that coping with SCD requires social resources and strategies (Beresford et al., 1996) and that the ability to cope, is neither entirely located in the individual nor related simply to the severity of the condition as presented in most biopsychological literatures (Priestley, 1999). Within the framework of Goffman, reality is an ongoing achievement, almost like a theatrical performance. In this view, there is no automatic limit put on what is achievable, because a performance is orientated to the future. This study adds to the literature by challenging bio-medical conceptions of SCD as a fixed 'condition' in which people with SCD are then trapped within the label assigned to them.

Because this study looked beyond the notion of SCD as a fixed condition, it was possible to identify how people breaking social expectations could lead to depression and stigma. It is also possible to note in this study that lived experiences of persons with SCD highlighted contradictions to social expectations, in that they achieved despite facing discrimination. In addition this study underscored that even when persons with SCD are breaking the social expectations, there is a possibility to invoke social model of disability in which persons with SCD could identify what social relations are oppressive and could be challenged. This study made credible attempts to locate problems and solutions within a broader social arrangements, rather than within persons with SCD. This work therefore has opened up the possibility of research being about social change, as opposed to being limited to mere description of illness narratives. This perspective is new for SCD, and for Nigeria, because previously little research in SCD had been undertaken that incorporated the idea that research has to do with social change rather than description alone.

Seventhly, this work noted that there was a projected population increase among persons with SCD in Nigeria and highlighted the need to explore the social context in which these persons live their lives. This work identified possible social barriers that, if not addressed, could place a significant hindrance on the quality of life of persons with SCD and therefore limit their contribution to the development of the nation. This research further noted that no study in sub-Saharan Africa has attempted to locate the personal troubles of people living with depression and SCD to public issues of society. This review has huge practical policy implications. In addressing these gaps, this study was driven by existing sociological
framework. It attempted to apply the principles that guided the seminal work of Brown and Harris (1978) to SCD and depression. Furthermore, the research develops a new combination of theoretical frameworks, in that it brings together diverse theories, such as Goffman’s theory of stigma, Blumer’s theory of phenomenology and the traditional approach of phenomenology, in order to explore and understand the phenomenon of SCD, depression and stigma. Thus it creates a synthesis of perspectives, the better to understand how stigma and depression in persons with SCD could be products of social relations. This work is also unique in that it identifies an overarching framework that allows the interpenetration of these perspectives in understanding SCD, depression and stigma.

In another vein, this study sought to remedy a situation where no previous research had been conducted to explore how persons with SCD and depression search for consistency among the three representations of SCD (as disease, illness and societal sickness) and how these people negotiate their acceptable self-identities among other members of their society. This study was driven by the application of different theoretical perspectives that point to the complementary importance of social knowledge in re-organizing the disruptive experiences of persons with SCD. This study is unique in combining social model of disability and theoretical perspectives of Blumer, Goffman as well as Link and Phelan with traditional phenomenology in highlighting the life-world of persons with SCD and depression and pointing out that depression and stigma are also socially created phenomena that could be challenged and overcome.

In terms of methods, this study is unique in using a (modified) theoretical framework derived from the work of Kleinman to underpin the mixed methods strategy that was employed. This framework allowed the investigation and understanding of different but interconnected levels of SCD expression. It used the multi-method approach in a theoretically informed way, using the theoretical framework of Kleinman and the analytical framework of phenomenology influenced by Husserl, Schutz, Blumer, Goffman, Link and Phelan. These different methods lend themselves to amplifying the different aspects of illness experience. The research questions and data collection methods mirror the disease, illness and societal sickness framework of Kleinman. The use of structured scale, although
problematic, permits the reader to situate the sample in terms of how the participants map onto measures which many other studies have used to describe depression. The individual interviews helped in attending to illness narratives, and the focus groups provided the ground for facilitating exchange of views with others and for group formation. This study is also unique in working though the notion of reciprocity in research so fully with a group of people with SCD.

In terms of individual interviews, this study is among the first to give voice to people living with SCD in Nigeria, generating original insights into the lived experiences of people with SCD and depression. Furthermore, the respondents in this study had the opportunity to tell their story, talk about their challenges and express their ideas about ways out of these challenges within their own terms of reference.

In terms of the focus groups, whilst many have applied group work methodology to working with disabled peoples, because SCD is usually framed as a chronic illness rather than a disability, this is among the first to apply this approach specifically to people with SCD, and probably uniquely to people living with SCD in Nigeria. With the use of focus groups in this study, people with SCD were able to make more explicit challenges to certain social arrangements they found oppressive and began to explore possible strategies to challenge such arrangements. Thus this study moved beyond many previous SCD and depression studies in identifying the conditions for change.

In terms of findings, this study has shown that the biomedical involvements could be usefully complemented by a body of knowledge drawn from the biography of individuals living with chronic illnesses that highlighted socially oppressive factors that could be challenged and potentially changed. In terms of its findings, this thesis has illuminated the social origins of depression and stigma in people with SCD through exploration of their social relations. This study thus confirms the applicability of Brown and Harris seminar work on depression and women to understanding persons with SCD and depression. This study also confirms the utility of Goffman’s theory of stigma (as well as reconceptualization of Link and Phelan) and extends it in understanding the relationship of
stigma to persons with SCD. It thus added to the novel social interpretations of depression and stigma among persons with SCD. This study went beyond highlighting the role of social relations in the origin of depression and stigma by showing how these social relations could be changed using the frame of reference of persons with SCD. This study thus confirms and extends the utility of Oliver’s social model of disability to persons with SCD.

This thesis was also driven by the application of disability policy debates that the society disables persons with SCD and that depression and stigma are socially created barriers for their exclusion. In the findings, this study is the first to highlight that for persons with SCDs, the real causes of disability are social barriers and negative attitudes rather than the actual physical impairments that may be associated with SCD. These findings add to the literature in the subject area of SCD, depression and stigma. In addition, the study contributes new insights into possible effective ways of influencing social policy in Nigeria. This study thus confirms and extends the utility of Oliver’s social model of disability to persons with SCD.

A further important contribution is that the participants being researched are not alienated from research, but with the researcher remaining engaged with the research participants in an ongoing way, may derive longer term benefits from the research, such as developing a mutual support SCD group. This work reflects the health promotion metaphor of “doctor upstream and downstream”. This is a situation where a walker strolling along the bank of a river notices a man pulling bodies out of the water and asks tentatively, "what is happening?" The man explained that he was a doctor and he was busy saving lives but so busy pulling bodies out of water that he did not have time to go upstream to see why they were falling in. This metaphor is used to highlight how sole focus on biomedical view would be akin to downstream approach of the doctor waiting for people with SCD to become depressed and be stigmatized through discriminatory societal norms. However, using the integrative Kleinman framework, could be akin to moving upstream, assessing and modifying a wide range of social factors that are known to increase the chances of persons with SCD developing depression and being stigmatized in the first place. In other
words, persons with SCD might still get depressed and stigmatized but not as often and not as severely. A joined-up, integrative approach to SCD, that combines upstream and downstream approaches, would make a powerful and measurable contribution to helping people with SCD remain positive and accepted in society.

**Areas for Future Research**

All data for this current study were based on accounts, what was said by participants. Other data collection methods that are not based on accounts, such as observation (for example at SCD clinics) and documents (for example newspaper coverage of SCD, or social media diaries kept by people with SCD), could be used in future studies.

Looking at accounts of interviews and focus groups there were discrepancies. There were logical gaps between what people said and what they did. For example, one of the respondents listed challenges of life in the interviews when she passed negative comments such as “why didn’t you die before we knew ourselves?” but in the focus group there were positive projections of his wife in terms of support. It is possible that both accounts could be true; they could be generated in different circumstances. However, a new way of interrogating the data in order to pay attention to such discrepancies would be desirable in future research.

The issue of reciprocity is another area that would require further studies. Future studies need to consider how the demands of reciprocity could be better handled humanely without creating dependency.

Some of the participants recounted that they felt lonely and abused by others in their social world, particularly parents, relatives, peers, and neighbours. They also described how they tried to make friends through social network on the internet such as E-mail, Twitter and Facebook. An additional possible subject of future studies could be to explore in what ways people with SCD can derive social support through social media.
Conclusion

People with SCD face considerable challenges and discrimination in Nigerian society. They deserve better than to be treated as subjects of research in which their conditions or their own psychological maladjustments are blamed for their depression. They themselves identify that negative social reactions and lack of social support are partly responsible for their negative experiences and low moods. Gathering together in mutual support groups appears to help those living with SCD by enabling them to reject negative labels, identify disabling barriers and develop skills and confidence to challenge such barrier to their own achievements in life. It is to be hoped that future researchers engage with SCD people within the more collaborative frameworks explored in this study, and that families, society and government can be compelled to create the preconditions for a just society in which people living with SCD can reach their full human potential.
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APPENDIX I

Information Sheet for Questionnaires

Study Title: Living with Depression and Sickle Cell Disease (SCD) in Nigeria

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully. Please feel free to ask your family, friends, doctors, nurses, or the researchers if there is anything that is not clear or if you would like more information.

What is the study about? We wish to find out the best way to support those who have SCD. We would like to assess whether or not you are experiencing any sign or symptom of depression. By taking part you may help doctors, nurses, any other person involved in your care to understand how common depression may be among those living with SCD who attend this clinic in LASUTH, and this may have importance in introducing new levels of care for those living with SCD and depression using LASUTH facilities.

Why have I been approached? It is because you are a young person with a sickle cell disorder. This is a study that is being carried out among the outpatient users of the Sickle Cell Clinic in LASUTH. During the period of the study, 500 young people with SCD that we can contact via their clinic attendance will be asked to complete a questionnaire asking about your demographics and symptoms and signs of depression.

Who is involved in the study? The study is led mainly by, Bola Ola of the Lagos State University College of Medicine, Ikeja, Lagos and is being supervised by senior colleagues, researchers from De Montfort University, Leicester, England to ensure adherence to ethical guidelines.
Do I have to take part? No, the study is entirely voluntary. If you choose not to take part, this will not affect your health care in any way. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw from the study at any time. You do not need to give a reason if you wish to withdraw.

What is involved?

Patient Health Questionnaire We will ask you to complete this questionnaire about your emotional experiences, and to return it to us. We think this will take you about 10-15 minutes. This exercise will be strictly confidential but not anonymous because of the ethical and clinical implications of those whose scores will fall into depression categories that may require medical services.

What happens to the information? All the information is confidential. You will be invited to complete a questionnaire. One of the copies will be for research purposes and the other will be given to your doctor who will file it in your case notes. The answers from the questionnaires will be entered into a computer to be added up and analysed. Those whose scores are in the categories of moderately severe depression or severe depression will, if they wish, be offered direct support at the mental health clinic in LASUTH, Ikeja. Among those whose scores fall within mild to moderate depression, and who agreed to volunteer for further study in the questionnaire, a certain number will be invited for further study. Before all the questionnaires are shredded at the end of the study, they will be put under lock and key in a safe and secure room in LASUTH, Ikeja. At the end of the study the database from the questionnaire will have any feature that could be used to identify an individual removed. All data will be treated in accordance with the best practice as identified by the existing UK Data Protection Act. This is an act designed to safeguard the use of personal information.
What if something goes wrong?

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone’s negligence then you may have grounds for a legal action for compensation against LASUTH (who have indemnity for negligent harm), but you may have to pay your legal costs.

What if I wish to complain? Please raise any difficulties or questions related to the study with Bola Ola on (+234) 705 544 1675 or email p1103747x@email.dmu.ac.uk if you are not satisfied, you can contact Dr. Dosunmu (Head, Department of Haematology, LASUTH) on (+234) 802 336 9785 and Dr. Ajose (Chairman, Medical Ethics Review Committee, LASUTH) on (+234) 803 855 9066.

What will happen to the results of the study? Once the study is completed, the results will be submitted to my senior colleagues in De Montfort University as part of my academic requirements. After my estimated successful completion of the programme in 2014, the results will be made available. We will provide a short summary and you will be able to receive a copy of this if you wish. We will also hold workshops in Lagos to feed back the results and to get your ideas about what policies should be put into place to help young people with SCD and depression.

Are there any benefits to me taking part?

- Providing an assessment of whether or not you are at risk of depression that you and your doctor could refer to in the future.
- Identifying if you are currently suffering moderately severe or severe depression and providing a source of support to help you in this.

Are there any drawbacks to me taking part?
The results of the questionnaire will be placed in your medical notes and made available to you at your next appointment. Your doctor will explain the results to you and ask whether or not you wish the questionnaire to be kept in your medical notes. You will have the right for the questionnaire to be destroyed if you wish.

**Who is organising and funding the study?** The study is organized by Bola Ola of the Lagos State University College of Medicine, Ikeja, Lagos and researchers at De Montfort University, Leicester, England. The study is self-funded. The study has been reviewed and approved by De Montfort University Ethics Committee and Ethics and Research Committee of LASUTH.

**Contact for further information** If you would like any further information about the study please contact Bola Ola (+234) 705 544 1675. Thank you for taking the time to read this information sheet. We are very grateful for your participation in this study.

Dr. Bola Ola, Department of Behavioural Medicine, Faculty of Clinical Sciences, LASUCOM, Ikeja (+234) 705 544 1675 p1103747x@email.dmu.ac.uk

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### Information Sheet for Interviews/Focus Group

**Study Title:** Living with Depression and Sickle Cell Disease (SCD) in Nigeria

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully. Please feel free to ask your family, friends, doctors, nurses, or the researchers if there is anything that is not clear or if you would like more information.

**What is the study about?** We wish to find out the best way to support those who have SCD and depression. We would like to find out about your life experiences, your strategies/challenges in coping in coping with stigma, depression and SCD,
what areas you would like to improve upon, and how you would like these to be achieved. By taking part you may help doctors, nurses, any other person involved in your care to understand more about how best to support someone with living with depression and SCD using your own perspectives. You are also likely to be joining a network of people living with depression and SCD in finding how life could be made improved for yourselves within the society you live in.

**Why have I been approached?** You have been invited to be in the study because you are a person living with SCD and because the questionnaire you completed suggested you may be at risk of suffering depression. We would like to find out about your individual experiences of living with SCD and to provide an opportunity for you to discuss your experiences with others in a similar position.

**Who is involved in the study?** The study is led mainly Bola Ola, a researcher from Lagos State University College of Medicine, Ikeja, Lagos, and is being supervised by senior colleagues, researchers from De Montfort University, Leicester, England to ensure that I adhere to ethical guidelines.

**Do I have to take part?** No, the study is entirely voluntary. Whether you choose to take part or not, this will not affect your health care in any way. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw from the study at any time. You do not need to give a reason if you wish to withdraw.

**What is involved?**

**Interview** If you are willing, we would be asking you to be one of 15 young people asked to take part in further research in which you are interviewed by one of our researchers, Bola Ola, about your life experiences (this interview would be tape-recorded and would take around one hour). We would choose people to try to reflect range of experiences of those with SCD and depression. We would be interviewing you at a quiet room within the premises of LASUTH. If you agree to
take part in interviews, we would, with your permission, inform your doctor. We would also support your transport to LASUTH, Ikeja, for this purpose and there would be light refreshments after the interview.

**Focus Group Discussion** For up to 5 people (who will be chosen to reflect the range of experiences of those with SCD and depression) you may also be asked to take part as follows: to be interviewed two times (each lasting between about an hour to an hour and half) about what your life experiences, what has worked for you, what you think has to change with regards to how the society views and reacts to you and how to negotiate this change.

If you agree to take part in the focus group discussion, we would, with your permission, also seek permission from your doctor. We would also support your transport to LASUTH, Ikeja, for this purpose and there would be light refreshments after the interview.

**What happens to the information?** All the information is confidential. No one will be able to identify you from the study. The interviews and/or focus groups will be tape-recorded. The tapes from interviews will be transcribed (listened to and written down in full). The notes taken by researchers, the tapes and the transcripts will be kept safely in locked offices at the Hospital and only the research team can have access to them. Notes, tapes and transcripts will only have codes and not names in order to safeguard confidentiality. At the end of the research the tapes will be erased. At the end of the study the database of the interview/focus group transcripts will have no feature that could be used to identify an individual removed. All data will be treated in accordance with the best practice as identified by the existing UK Data Protection Act. This is an act designed to safeguard the use of personal information.

**What if something goes wrong?** In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone’s negligence then
you may have grounds for a legal action for compensation against LASUTH (who have indemnity for negligent harm), but you may have to pay your legal costs.

**What if I wish to complain?** Please raise any difficulties or questions related to the study with Bola Ola on (+234) 705 544 1675 or email p1103747x@email.dmu.ac.uk; if you are not satisfied, you can contact Dr. Dosunmu (Head, Department of Haematology, LASUTH) on (+234) 802 336 9785 and Dr. Ajose (Chairman, Medical Ethics Review Committee, LASUTH) on (+234) 803 855 9066.

**What will happen to the results of the study?** Once the study is completed, the results will be submitted to my senior colleagues in De Montfort University as part of my academic requirements. After my estimated successful completion of the programme in 2014, the results will be made available. We will provide a summary and you will be able to receive a copy of this if you wish. We will also hold workshops in Lagos to feed back the results and to get your ideas about what policies should be put into place to help young people with SCD and depression.

**Are there any benefits to me taking part?**

- Talking about experiences may make you feel better.
- Meeting others with SCD and sharing experiences may give you more confidence.

**Are there any drawbacks to me taking part?** You may be upset talking about hurtful experiences but you have the right to withdraw from the study and whether you withdraw or continue you will have access to support for emotional difficulties at LASUTH.

**Who is organising and funding the study?** The study is organised by Bola Ola of the Lagos State University College of Medicine, Ikeja, Lagos and researchers at
De Montfort University, Leicester, England. The study is self-funded. The study has been reviewed and approved by De Montfort University Ethics Committee and Ethics and Research Committee of LASUTH.

**Contact for further information** If you would like any further information about the study please contact Bola Ola (+234) 705 544 1675. Thank you for taking the time to read this information sheet. We are very grateful for your participation in this study.

Dr. Bola Ola, Department of Behavioural Medicine, Faculty of Clinical Sciences, LASUCOM, Ikeja (+234) 705 544 1675 p1103747x@email.dmu.ac.uk
APPENDIX II

CONSENT FORM: QUESTIONNAIRE

Title of Project: Living with depression and Sickle Cell Disease (SCD) in Nigeria

Name of Chief Investigator: Dr. Bola Ola;

Name of Interviewers: Dr. Bola Ola.

Please tick the box

1. I confirm that I have read and understand the information sheet dated ............. (version ............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from LASUTH, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I agree to my doctor, being informed of the results of my questionnaire.

5. I agree to participate in filling in the questionnaire for the above study

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of Person taking consent (if different from researcher)</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

CONSENT FORM: INTERVIEW

319
Title of Project: Living with depression and Sickle Cell Disease (SCD) in Nigeria

Name of Chief Investigator: Dr Bola Ola;

Name of Interviewers: Dr Bola Ola.

Please tick the box

1. I confirm that I have read and understand the information sheet dated ............. (version ............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from LASUTH, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I agree to my doctor being informed of my participation in the study

5. I agree to be interviewed for the above study and for that interview to be audio-taped

------------------------------- ---------------------------- -------------------------------
Name of Participant Date Signature

------------------------------- ---------------------------- -------------------------------
Name of Person taking consent (if different from researcher) Date Signature

------------------------------- ---------------------------- -------------------------------
Researcher Date Signature

CONSENT FORM: FOCUS GROUP DISCUSSION
Title of Project: Living with depression and Sickle Cell Disease (SCD) in Nigeria

Name of Chief Investigator: Dr Bola Ola;

Name of Interviewers: Dr Bola Ola.

Please tick the box

1. I confirm that I have read and understand the information sheet dated ............ (version ............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from LASUTH, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I agree to my doctor being informed of my participation in the study

5. I agree to be interviewed for the above study and for focus group discussion to be audio-taped

Name of Participant: ___________________________ Date: ________________ Signature: ___________________________

Name of Person taking consent (if different from researcher): ___________________________ Date: ________________ Signature: ___________________________

Researcher: ___________________________ Date: ________________ Signature: ___________________________
**APPENDIX III**

Indicative Questionnaire

| Research Serial Number: ___________ Hospital Number: ________________ |
|---|---|
| Age in years: ________________ |
| Gender | Male ☐ | Female ☐ |
| Ethnicity (Tribe): ________________ |
| Family type: | Monogamous ☐ | Polygamous ☐ |
| Religion: ________________ |
| First language: ________________ | Second language: ________________ |
| Father’s occupation: ________________ |
| Mother’s occupation: ________________ |
| Your occupation: ________________ |
| Father’s level of education | Primary (1-6) ☐ | Secondary (JSS1-SSS3) ☐ | Tertiary (College of Education/Polytechnic/University) ☐ | None ☐ |
| Mother’s level of education | Primary (1-6) ☐ | Secondary (JSS1-SSS3) ☐ | Tertiary (College of Education/Polytechnic/University) ☐ | None ☐ |
| Your level of education | Primary (1-6) ☐ | Secondary (JSS1-SSS3) ☐ | Tertiary (College of Education/Polytechnic/University) ☐ | None ☐ |
| Who do you currently live with: please tick one box only |
| Both parents ☐ | Mother only ☐ | Father only ☐ | Uncle or aunt ☐ | Non-relative ☐ | I live on my own ☐ |
| Number of brothers & sisters: ________________ |
| Average household (family) income per month: ________________ |
| Personal income (pocket money etc.) per month: ________________ |
| Average money spent on medications for SCD per month: ________________ |
| How many days have been off work/school due to SCD last year: ________________ |
| Age when diagnosis of sickle cell was made: ________________ |
| Type of sickle cell disease: Please tick one box only |
| SS ☐ | SC ☐ | Other (please write in.................................................) | Don’t know ☐ |

*About Your Sickle Cell Disease*

The numbers of days you had pains in an average week: ________________

The number of hospital admissions due to SCD in the past 12 months: ________________

Have you had leg ulcers before or at the moment? Yes ☐ No ☐

Have you had blood transfusion as part of emergency treatment before? Yes ☐ No ☐

Any history of mental health illness in the family: Yes ☐ No ☐

If yes, please describe the situation: .................................................................
Patient Health Questionnaire-9

Over the last two weeks, how often have you been bothered by any of the following problems?

(Use “×” to indicate your answer)

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed or hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep or sleeping too much</td>
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<td></td>
<td></td>
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<td>4. Feeling tired or having little energy</td>
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<td>5. Poor appetite or overeating</td>
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<tr>
<td>6. Feeling bad about yourself or that you are a failure or have let yourself down or your family down</td>
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<td></td>
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<tr>
<td>7. Trouble concentrating on things such as reading the newspaper or watching television</td>
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<tr>
<td>8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Thoughts that you would better be off dead or of hurting yourself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Add columns:

Total score:

Would you like to volunteer for further study: Yes ☐ No ☐

If yes to above, would you please provide the following details:

Name: 
Contact phone: ________________________
APPENDIX IV
TOPICAL GUIDE - INTERVIEW

First conduct the informed consent process.

I. Introduction (10 minutes)

- Welcome participant and introduce yourself.
- Explain the general purpose of the discussion and why the participant was chosen.
- Discuss the purpose and process of interview
- Explain the presence and purpose of recording equipment
- Address the issue of confidentiality.
- Inform the participant that information discussed is going to be analyzed as a whole and that participant's name will not be used in any analysis of the discussion.
- Read a protocol summary to the participant:

This study is intended to explore your experiences with living with SCD and depression, how you have coped with it, and what you think are the challenges with living with this in your community.

Discussion Guidelines:

We would like the discussion to be informal. If you don’t understand a question, please let me know. I am here to ask questions, and listen.

We hope you’ll feel free to speak openly and honestly.

As discussed, we will be tape recording the discussion, because we don’t want to miss any of your comments. No one outside of this room will have access to these tapes and they will be destroyed after our report is written.

I will be also taking notes to assist me.

Let’s begin. Let’s find out some more about each other. Tell us your first name and your job or school, and the community where you serve. I’ll start.

II. Topic Guide (40-70 minutes)
Knowledge of SCD
1. For how long have you been suffering with sickle cell?
2. Please tell me all that you know about SCD?
3. Can you please tell me what to do when crises arises?
4. Do you know what to do to improve the outcome of SCD?

Perception of SCD

1. What was your first reaction when you learnt about your diagnosis?
2. What does having SCD mean to you?
3. Please describe your experiences of living with SCD.
   • Please include anything that you think would help us understand what it is like to be a person living with SCD
4. Please describe a typical day in your life when things were good
5. Please describe a typical day in your life when things were bad

SCD in relation to others:

1. How do other people (father/mother/siblings/neighbours/friends/school/hospital) treat you as someone living with SCD?
2. Please describe a typical day when you were treated well
3. Please describe a typical day when you were not treated well
4. How are people with SCD regarded generally in this society?

Living with depression:

1. Please describe what it means to be sad or heart is sinking low in emotion*
2. Please tell me about a typical week when your heart is sinking low in emotion
3. Please describe your experiences at work when you are low in emotion on a typical day
4. Please describe your experiences at home with family and friends when you are low in emotion on a typical day
5. Can you please tell me any other approaches to help your low mood in addition to those provided by hospital services?
6. Do you think that any life experiences led to the onset of feeling low in emotion? If so, please describe what you think these are and how to have caused your depression?
7. In what ways has this low mood affected your everyday life (such as schooling, employment and making relationships) and the lives of those close to you?
III. Closing (10 minutes)

- Closing remarks
- Thank the participant

* The term “sad or heart is sinking low in emotion” is the lay expression for the term “depression” among Nigerians
Before the group begins, conduct the informed consent process.

I. Introduction (10 minutes)

- Welcome participants and introduce yourself.
- Explain the general purpose of the discussion and why the participants were chosen.
- Discuss the purpose and process of interview
- Explain the presence and purpose of recording equipment
- Address the issue of confidentiality.
- Inform the participants that information discussed is going to be analyzed as a whole and that participant's name will not be used in any analysis of the discussion.
- Read a protocol summary to the participants:

This study is intended to explore your experiences with living with SCD and depression, how you have coped with it, and what you think are the challenges with living with this in your community.

Discussion Guidelines:

We would like the discussion to be informal. In fact, we encourage you to respond directly to the comments other people make. If you don’t understand a question, please let me know. I am here to ask questions, and listen.

We hope you’ll feel free to speak openly and honestly.

As discussed, we will be tape recording the discussion, because we don’t want to miss any of your comments. No one outside of this room will have access to these tapes and they will be destroyed after our report is written.

I will be also taking notes to assist me.

Let’s begin. Let’s find out some more about each other. Tell us your first name and your job or school, and the community where you serve. I’ll start.
II. Topic Guide (40-70 minutes)

Perception of SCD

1. What was your first reaction when you learnt about your diagnosis?
2. What does having SCD mean to you?
3. Please describe your experiences of living with SCD.
   - Please include anything that you think would help us understand what it is like to be a person living with SCD
4. Please describe a typical day in your life when things were good
5. Please describe a typical day in your life when things were bad

SCD in relation to others:

6. How do other people (father/mother/siblings/neighbours/friends/school/hospital) treat someone living with SCD?
7. Please describe a typical day with examples when you were treated well
8. Please describe a typical day with examples when you were not treated well
9. How are people with SCD regarded generally in this society?
10. How do you respond to how people treat you, what strategies do you use?
11. What strategies have worked well in responding to people and what has not worked well to improve your life?
12. How do you think you can help someone living with SCD

Living with depression:

13. In what ways has this low mood affected your everyday life (such as schooling, employment and making relationships) and the lives of those close to you?
14. How have you generally been treated by people when you are in low mood?
   Please include your experiences with family/friends/teachers/health workers
15. How do you respond to how people treat you, which strategies do you use?
16. Please describe any life experiences that you think might have led to the onset of feeling low in emotion? If so, please describe what you think these are and how to have caused your heart sinking low in emotion?
17. What strategies have worked well in responding to people and what has not worked well to improve your life?
18. How do you think you can help someone living with SCD experiencing low mood?

III. Closing (10 minutes)

- Closing remarks
- Thank the participants
APPENDIX VI

The flow chart of Participants through the questionnaire, in-depth and focus groups

103 Participants

Depressed

74

Not Depressed

29

Referral 2 severe depression cases

72 Depressed

15 In-Depth Interviews

Focus Group A: One

5

Focus Group B: One

5

Focus Group A: Two

5

Focus Group B: Two

4 (one did not attend due to rain)

Focus Group A: Three

5

Focus Group B: Three

5

5 did not attend Focus Group