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Anxious Lives: Exploring Lived Experience of Nigerian Sickle Cell Patients

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Author's contribution

The sole author designed, analyzed and interpreted and prepared the manuscript.

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ABSTRACT

This paper discusses the illness narratives of undergraduate students suffering from sickle cell anaemia. The study explores participants' concept of the self in relation to the disease on the one hand, and on the other, the construction of their identity in relation to significant others, friends and the wider community in order to gain a deeper understanding of their symbolic and interactional meanings. Data was generated from six undergraduate students in a private university in south western Nigeria. The qualitative data collection techniques used included in-depth interviews, unobtrusive observation and informal group discussion. The study was conducted over a period of two years and the data were content analysed. The study found that sickle cell patients defined the disease as "natural" due to its hereditary nature. Participants' experiences with the disease in relation to others were described as "frightening", "stressful" and "delimiting" within a broad socio-cultural framework that is characterized by empathy and endurance. The findings suggest a more focused awareness campaign that stresses cooperation and understanding of the disease and interactions with sickle cell patients.

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1. INTRODUCTION

Sickle cell anaemia, also known as sickle cell disease (SCD), is a genetic condition caused by a haemoglobin disorder, characterized by red blood cells becoming sickle shaped, leading to anaemia, functional asplenia, recurrent and unpredictable painful crises (painful swelling of joints), bone or joint necrosis, priapism, organ damage and renal failure [1]. Over 300 million people have sickle cell traits world-wide with three-quarters of that population concentrated in Africa, Asia and the Mediterranean and one-quarterin sub-Saharan Africa [2]. Due to the increase in international human migration in the past century, the disease is now prevalent in other parts of the world. In the United States, for example, the sickle cell disease affects approximately 100,000 citizens. Furthermore, 1 in every 500 African American and 1 in every 36, 000 Latinos is afflicted with the sickle cell disease; while 1 in every 12 Blacks or African American is a carrier of the sickle cell trait [3,4]. These figures translate to a hospitalization rate of about 40% costing an average of US $475 million yearly [4]. Current World Health Organization statistics indicate that 5% of the world's population are carriers of the disease while about 300,000 children are born each year with the disease, with over three-quarter of these cases in low and middle income countries [5]. Out of this number about a million deaths occur yearly from sickle complications with the highest burden in sub-Saharan Africa [6]. Although up-to-date data and figures for sickle cell disease in this region are limited, it is estimated that Nigeria has the highest sickle cell cases with approximately 40 million carriers of the trait and mortality due to the disease estimated at 125,000 yearly [7]. Sickle cell disease is therefore a major public health concern and particularly in holondemic countries where public healthcare services are inadequate. The relational and psychosocial challenges of sufferers as well as the difficulties of treating the disease, call for a better understanding of patients' experience in terms of how they define (and simultaneously construct) the self, informed by their constant interaction with significant others, friends and the society in general.

SCD is an inherited blood disorder that affects red blood cells. The biological explanation for the behaviour of the disease is that sickle-shaped cells obstruct small blood vessels such that less blood reaches some parts of the body thereby causing serious painful crisis [8]. Haemoglobin is the main substance of the red blood cell, which helps red blood cells carry oxygen from the lungs to all parts of the body. Normal red blood cells contain Haemoglobin A, while Haemoglobin S and C, are abnormal types [9]. The normal red blood cells are soft and round and because of their texture and shape, can squeeze through tiny blood tubes (vessels) and live for about 120 days before they are replaced. People with sickle cell condition, on the other hand, make a different type of Haemoglobin A called Haemoglobin S, which, due to their distorted shape, have difficulties passing through the body's small blood vessels with a shorter life span of about 16 days [8]. Carriers of the sickle cell with a higher amount of Haemoglobin A than S function normally and the few sickle cells in the body seem to act as immunity against the *Plasmodium* that causes malaria [9,10]. However, patients with a relatively higher percentage of sickle cell are prone to general body weakness due to low blood level, as well as frequent blockage of blood vessels by the distorted cells causing severe pain to the patient (crisis) and leading to the inability of the individual to perform certain tasks such as strenuous activities that excessively task the body and drains their energy [2,11,12,]. In addition, sickle cell patients are characteristically prone to cold, which compromises their ability to resist other health challenges, thus placing them at greater risks of infection and further incapacitation. Due to their poor health they are usually excused from manual work and are encouraged to avoid cold conditions including the consumption of cold food and drinks.

2. THEORETICAL FRAMEWORK

Sickle cell patients' experience in relation to the disease and their social interactions requires an interpretative framework that explores the construction of self in relation to SCD and how that construction influences behaviour and/or affect social interactions. Such framework prescribes an interactionist perspective that captures and analyses the experiences of sickle cell patients and the social context in which they relate and interact, enabling the voices of SCD sufferers to be heard and their experiences appreciated.

Social actions relating to external stimuli are mediated by the meanings assigned to social behaviours, which serve as cues in initiating and sustaining social relations. People's perceptions that they are poorly judged or are assessed negatively based on various factors such as disability, may predispose them to become reserved and cause them to resist further interaction. At the extreme, they may withdraw from that social space. Thus, perceptions and assigning of meanings to symbols are important factors in negotiating social interactions. Perceptions and experiences are therefore key determinants of how individuals may construct their social realities. The relationship between the self and the society is thus mutually reinforcing with the former being influenced by the dynamic process of social interaction characterized by verbal and non-verbal cues. Deriving from this social process, the individual and the society co-create meanings that define social experience and regulate human behaviour. Thus, the definition of self is not constructed in isolation; but rather involves a process of intense negotiation between the objective evaluations of themselves on the one hand and through the lens of the society on the other [13]. Within this context, in defining themselves as delicate or different from others, SCD patients appropriate the symbols provided for them by their immediate environment in constructing the self in relation to others. Thus, people's actions and reactions to external stimuli are largely determined by their definition of the self and their perception of the social context in which they function. From the above we can deduce that the discomfort and pains associated with SCD and the deformities that sometimes accompany the disease can be framed as a dynamic process that affects patients' mood, social interaction and participation.

Attempts at understanding and explaining pain have been of interest to health care givers, sociologists and psychologists [14-17]. Jongudomkarn and colleagues [15], have noted that theories about pain are complex and tend to centre on how individuals approach life in relation to their psychological and physical functioning. In a study of the biopsychosocial aspects of chronic pain, Goubert [18] found that sufferers experienced various forms of anxiety, frustration, helplessness and depression. SCD patients tend to deal with pain at two levels. The physical pain arising from the crisis they experience due to the obstruction of blood vessels by sickled cells and the emotional pain they contend with as they observe the trouble and worry parents and siblings go through for their sake. These layers of painexert significant pressure on patients in multifaceted ways.

In addition to the pain associated with SCD is the stigma attached to the disease. Goffman [19,20] noted that undesired differences in people are a major source for stigmatization, in that others regard them as "tainted and discounted". While this form of stigma is associated with physical disability, whenever there is a significant difference between a person's virtual identity and their actual identity, negative consequences are likely to follow. The distinction between discrediting stigma and discreditable stigma is instructive as they portray a negotiating process between the stigmatized person and the social context that sustains the emotional stress. This is important for sickle cell patients as they continue to deal with their potential difficult day-to-day interaction with others through "impression management" [20], lowering the chances of humiliation or other negative outcomes. The technique of "covering" in dealing with such cases as espoused by Goffman is salient in that affected persons will attempt to engage in normal activities to minimize the impact of their stigma. Such conformity even though may be detrimental to their health is deemed necessary by the stigmatized that is under pressure to meet the expected normative behaviour. Consequently, people with discreditable attributes attempt to hide their negative attributes to avoid being stigmatized, or undertake "information management" strategies by controlling what they do or tell others. Goffman says that a person trying to give the impression that they are "normal" may face considerable problems in managing information, as they will always live in fear of being exposed. The two main attributes for the patient with discreditable attributes are "passing" and "withdrawal", whereby the formeris an attempt to disguise the discreditable attribute from others and the latter refers to the reaction of the victim shielding themselves from social contacts wherever possible.

In their contribution to the theory of stigma, Scrambler and Hopkins [21] recognized its processual nature as both a given state and a reactionary one. While the "enacted stigma" is the instance of being discriminated against, "felt stigma" is a reaction by the victim towards being labelled as inferior and/or abnormal. For example, sickle cell patients who are largely discriminated against due to their inability to participate in

regular sports and other social recreational activities react to being labelled “spoilt sports” or “wet blankets” by concealing their health challenges or becoming withdrawn. They may participate in social activities only when they perceive themselves as normal (that is, when they are crisis-free or not drained physically) and withdraw from friends when their health condition prevents them from participating in social activities.

This study explored the world of young adults suffering from the sickle cell disease with the aim of examining their perception of the disease in relation to self and how the disease affects their social lives. The key objectives of the study were: (1) to examine how sickle patients perceived and defined the sickle cell disease; (2) how they constructed their identity in relation to others and (3) how this construction influenced their social interactions. For this reason, an in-depth, qualitative method was adopted based on a framework that uses symbolic interactionism to understand the meanings that are associated with sickle cell patients’ social interactions.

3. METHODS

3.1 Participants

People who suffer from sickle cell anaemia constituted the study population for this study with a specific target of undergraduate students in a private university in south western Nigeria. The number of students who suffer from the disease could not be ascertained due to the private nature of the illness. For the purpose of the study however, six undergraduate students were purposively selected. Three of the respondents were selected by the researcher based on his prior knowledge of the students’ health condition, while the remaining three participants were recruited based on referrals from the previously selected participants (the snowball method). The main criterion for participants’ selection was their health condition, that is, as sickle cell patients. They were made up of two men and four women with an average age of 19.5 years. One of the participants was in her fifth year of study; three in their fourth year of study and two in their third year of study. The ethnic/geographical background of the participants was as follow: one of each came from the middle belt, the Niger Delta and the mid-western part of the country and the remaining three were from the south-western part of the country. All participants were from educated homes with their parents having a minimum of a university degree. All participants were from high income background with an average family income of fifteen million naira per annum (US $1=N160). All participants were familiar with their health conditions and were knowledgeable about their restrictions in order to stay healthy. However, when in crisis they seek professional medical service from the university health centre and in severe cases they travel home for more intensive care.

All participants were purposively recruited during formal and informal interactions. Formal interaction involved counselling of the students by virtue of the researcher’s position in the university as unit coordinator for students, while informal interaction involved casual meetings informed by the application of the snowball technique. All participants were recruited at various times as the research progressed. As each recruitment exercise was initiated, the prospective respondent was intimated with the aim of the study. Consent was sought from participants after the author had explained the nature of the study, its aims and objectives and the intention of publishing the findings of the study. For their personal reasons as well as for professional ethics they were all assured of their anonymity and confidentiality. In the process of collecting the research data, the researcher did not obtain any official records from the university health centre butrelied only on participants’ self-narratives of their understanding of SCD; their health condition and their personal social experiences in relation to others.

3.2 Data Collection

The complex nature of SCD and its manifestations in patients necessitated the triangulation of data collection methods, which involved in-depth interviews, unobtrusive observations during social interactions and during crisis regimes and informal discussion with participants. In all, six students participated in in-depth interviews that were semi-structured based on an interview guide. Series of interviews, which were conducted over several months, lasted for an average of ninety minutes per session and were immediately transcribed from an audio-recording device. Unobtrusive observations were conducted during crisis regimes, during care giving by care-givers and during normal social engagements. Observations were focused on the crisis process and how patients managed and endured the pain

associated with the crisis. These observations were crucial in that they placed in context what pain meant to participants and how the management process influenced their construction of the self in relation to others. It would have been impossible to imagine, understand and translate the description of their pain and what they contended with if information was merely elicited from interviews. Observation, especially to the sensitive and trained researcher, is extremely important in qualitative research as the researcher feels what their subjects feel and is able to approximate the extent of participants' suffering and endurance and how they construct and live their lives. This emic approach to qualitative research is the hallmark of behavioural study, which distinguishes it from the etic approach of quantitative study that focuses on the manipulation of statistical data in quantifying human experience.

Informal discussions served as an important method of collecting data from the participants. These discussions were conducted at various times including when participants were just recovering from a crisis; during restrictive periods (especially during cold seasons or rainy periods) and during normal social activities. These discussions were not audio-taped but gave the researcher the opportunity to explore further the world of participants during different periods of their health conditions. Field notes were used to summarize discussions and these summaries served as benchmarks in clarifying data categories and emerging concepts during data analysis. The field work was conducted between May 2010 and February 2012.

The data generated from this triangulation methodology indicated similarities in participants' experiences but with marked differences in conceptualizing the self and in social interactions. Participants struggled with similar issues in different ways depending on family background and orientation, social processes and individual personality and disposition. Nevertheless, the data show some common thread in the construction of the self by participants and also similarities in their perception of self in relation to others. Thus, validity of the study was ensured by adopting Lincoln and Guba's prolonged engagement in the field; unobtrusive observation and data and methodological triangulation [22].

3.3 Data Analysis

Data analysis was based on the collation and transcription of in-depth interviews, participants' self-narratives and the summarization of informal discussions and observations of social processes. Based on the objectives of the study, preliminary coding and classification of emerging themes was initiated after each session, which suggested the direction of the study and the need for appropriate information to be sought in subsequent interviews, observation and discussion. Analysis of the comprehensive data set followed Fielding's [23] method of content analysis involving: (i) the familiarization of the data by constant reading and re-reading of the transcription; (ii) classifying (and reclassifying) of the data set; (iii) establishing themed relationships based on identified central concepts and sub-concepts and (iv) exploring and interpreting symbolic meanings associated with concepts, ideas and definitions in the data. The validity of the study was enhanced by involving the participants during part of the coding and classification process. At each stage of data analysis, the participants were further engaged in examining the emerging concepts and whether data categorization as well as the author's reflection and interpretation of the data matched participants' views and constructs regarding their lived experiences.

3.4 Findings

The data generated emic descriptions of SCD and the pains associated with the disease in relation to the definition of the self and how this construction influences their social interaction. The results also highlight the state of mind (anxiety) of sickle cell patients; their personal capabilities in relation to others and for themselves and their general disposition to family members, friends and classmates (Table 1). In the following section, further details of each concept will be described.

3.5 Defining the Self

Study participants' definition of the self, started with a self-consciousness they were first confronted with, which triggered the awareness of their sickle cell condition. That realization came very early for participants at an average age of 6.5 years. This revelation was the beginning of the assumption that their identity was different and "abnormal" from other children of their age. As one of the participants noted:

> *I first came to the realization that I was different from other children in school when I became very ill at a time and could not attend*

school. My parents took me to the hospital where I remained for a day or two and was finally discharged. I had wanted to go back to school immediately on arrival at home but my mother restrained me telling me how different I was from other children but special to the family. Although I did not understand what she meant at the time, it stuck to me from then on that something wasn't right with me compared to other children.

Another participant also recalled how she first got to know about her health condition:

Mom was a nurse and I was born in England so I got to know about my health condition very early in life…probably at age five or six. Mom always insisted that I dress warmly, stay in doors to play and take only warm foods and drinks. As young as I was then she would always try to explain my health condition to me informing me that I needed to stay warm to avoid crises and not to imitate other children who were healthier than me. Soon afterwards, I realized that I was different from other children and accepted my fate.

Another quote that emphasized the unique difference between a sickle cell child and other children from an early age also came from another participant:

As a child, I have always been ill and I recall that I was always unhappy because I was not allowed to do things children my age did…I could not go out when it was raining, I was forbidden from taking cold drinks and I was always in very thick clothes. My mother said these don'ts must be adhered to if I wanted to live! It was scary but I accepted the conditions even though I didn't have a full realization of them.

For participants, constructing an identity of the self, started early in life, influencing their behaviour as well as their social interactions subsequently. They had come to the realization of difference (not in terms of being unique as an individual but different in terms of health conditions) and were special in a way that may be okay in the family but disturbing in the public space as they related with other healthy children. Unlike other chronic illnesses that manifest at a later stage of the life circle, sickle cell patients do not have a prior (positive) identity to serve as a reference for them to reconstruct a new identity; rather they conform to their health condition as imposed on them from birth. Accepting their fate at this early age has two important implications: First, it developed in them an intense self-awareness of who they are in relation to others and secondly, how that self-awareness would shape their world and define their social relations. One of the participants summarized her experience regarding society's attitude towards her poor health by saying: "I have always wanted to play like other children but my health condition would not allow me and it hurts when you are referred to as 'unusual' or 'wet blanket'".

Table 1. Themes and constructs of participants' narratives

Central concepts	Sub-concepts
Defining self	Acceptance (matter-of-fact, stoicism, or resignation to fate?)
Anxiety (state of worry)	Unease; fear; doubts; uncertainty;
Self-limitation	Helplessness; vulnerability; dependence
Social isolation	Strained relationship with family/friends; physical restriction; exemptions (from physical work).

The desire to be accepted by and play with other children, coupled with the constant reminder that they may not belong to that world, resulted in behaviour associated with withdrawal syndrome. Participants became aware of their "difference" from others, which reinforced their self-constructed identity as "ill" or "weak vessels". Data analysis revealed an underlying tension for participants to reconcile their poor health condition with society's expectations. In negotiating for a balance, they used such expressions as "accepting my fate", "I have no choice" or "it is the will of God" to describe how they resolved the tension. They were all aware of the hereditary nature of sickle cell anaemia and exonerated themselves from any blame for who, or what they are and how they live their lives. For example, a participant spoke of her circumstance thus, "I had no choice regarding whom my parents would be and I had no power over my health condition, but I have the choice to live, even if not like others, at least by my own terms". Also describing the acceptance of their condition another participant stated that, "It is a natural disease that was inherited from my parents and there was nothing I could do about it…I have conditioned myself to accept my fate."

3.6 Anxiety and Anxious Living

In respect of the state of mind resulting from being a sickle cell patient, data showed that the problem of a chronic disease such as sickle cell anaemia causes great anxiety reaching a climax during times of crisis, followed afterwards by an intense fear of death, uncertainty of the future and anxiety towards life generally. For participants, living is marked by a deep sense of trepidation associated with a resignation to fate, which is anchored in a special relationship with God. The daily anxiety of living is expressed by a participant thus:

> *My life is a constant struggle laced with the uncertainty of whether I am going to witness my next birthday, ever get married or have my own children. Whenever I have a crisis what comes uppermost in my mind is whether I would survive this or die. Sometimes the feeling is so engulfing that I cry and worry a lot…not only because I don't want to die but also because I don't want to disappoint my parents for all the care and support they have given me.*

This state of anxiety permeates every aspect of the data as noted by another participant:

> *Ahh, life is a continuous struggle! Even though I try to live a normal life by having a boyfriend, attending social functions and focusing on my studies, I always have this premonition that I will not celebrate my twenty-first birthday or twenty-eight–maybe this is why, traditionally, some people are referred to as abiku (laughs). It is funny, but I have been told that every seven years is a landmark for a sickler.*

This state of anxiety is a common theme among all participants, with the state of mind having significant control over most aspects of participants' lives and social interactions. Such uncertainty creates restrictions and sometimes prevents patients from living a normal and fulfilled life style. During an interview session for example, a participant was asked when she would likely get married. She paused for a moment and enthused:

> *I have thought about this issue* (getting married) *very seriously. You know, I am mortally afraid of bringing a child into this world to go through what I am going through. And if I decide to marry but not have children, I won't want my husband to be bugged down by my frailty and crisis bouts–I should spare some man the stress and demand of taking care of a sickler.*

The state of mind of participants as derived from the data, shows how the definition of the self, due to their chronic health condition, their perceived notion of life, interact in defining their personality and social interactions.

3.7 Self-limitation

Acceptance of their chronic health condition by participants also comes with the acknowledgement of their limitations in performing certain tasks or engaging in certain sports that other healthy people take for granted. Common and recreational activities such as going swimming, dressing lightly or playing football all seem overwhelming for participants and seldom do they participate in them. Accepting their health condition also involved recognizing their helplessness, vulnerability and dependence on others. Participants used words like "not getting along", "feeling tired" and "reliance on others" to describe their state of helplessness in relation to going out with friends. Dependence on family members or friends to help with house chores such as ironing or assisting with typing assignments at school was also highlighted. As a participant put it:

> *Sometimes I feel very embarrassed when I asked my friends to help me with simple chores like getting my food for me from the cafeteria when I am feeling very weak. But I can't blame them because they have their own lives to live.*

In some instances participants decided to do without some of the things they would have wanted to do simply because they didn't want to be a "pain" to others. One of the participants summed it up thus: "I don't like being tagged a pain by my pals so most of the time I do without asking for assistance." While this summation may be regarded as irrational or arrogant, it points to the helplessness of participants and speaks to the exasperation they sometimes encounter in their daily interaction characterized by the dependence on others due to their weakness as a result of their poor health condition.

3.8 Social Isolation

Participants exhibited a very strong tendency to withdraw from society especially outside the

home including not wanting to be regarded as a "wet blanket" "a pain" or due to other forms of stigmatization. Social isolation is most apparent among participants that have frequent crisis. Participants that were more prone to crisis attack; with more visible symptoms (such as skinny or "jaundiced" figure, "yellow" eyes) or get exhausted easily, tend to be more vulnerable to social isolation. For example a participant with the above characteristics shared his experience thus:

> *I am constantly conscious of my appearance whenever I am with people generally…even when they want to strike conversations with me I give short answers to minimize the engagement. I guess I developed this attitude from high school when some naughty boys called me names and taunted me…so I guess I am just suspicious when I am around people. To avoid any embarrassment, I tried to keep to myself.*

While this may be the case for some, it was the direct opposite with others. As one participant explained:

> *For me, I want to live my life to the fullest! I know I have just a short time to live so I try to engage each day at a time. I define myself as an extrovert and I like to meet people, attend social events and do all the things I should do as a uni (university) student…you know?*

There is obviously an aspect of personality type in determining how sickle cell patients may respond in their social world, but what is also clear is that their health condition also influences their social outcome, which may be extreme in certain circumstances.

4. DISCUSSION

The data generated from the study indicated a complex interaction of processes that define self as well as the influence of the social interactions of sickle cell patients with others. The process of defining the self, seems to occur in the normal circumstance of being sick to the realization of being different from others and the explanation proffered by knowledgeable others to participants regarding their health conditions. This process occurred in linear progression that peaked with individuals processing their own health condition and coming to a self-resolution of acceptance informed by the hereditary nature of the disease and their inability to change the circumstance but to manage it. The resolution of defining the self, simultaneously initiated a social process of self-evaluation in relation to others, which also prescribed the degree of social interaction with family members, friends and acquaintances.

The process of defining and accepting the self after the recognition of participants' chronic disease included the acceptance of the disease as "natural" and hereditary with very limited scientific advancement for its cure. For this reason, participants resign themselves to their fate anchored in their religious/spiritual conviction and a personal relation with God, as well as with the support of family members through their love and support. A participant expressed her family support by noting that, "I owe my parents an eternal gratitude for their sacrificial support and understanding especially when I am too weak to even have my bath." Although all participants acknowledged the support of family members, it is also a source of worry and a constant reminder of their own limitation and dependence on others. In this context, participants sometimes placed a heavy burden on themselves by refusing to inform parents when they are sick or not expressing the pain they go through in their presence. Thus, it was not unusual for participants to withdraw from family members as they sometimes do with non-family members. The paradox of suffering in silence in the context of love that may be expressed by others has not been extensively explored in the literature. However, one of such few studies conducted by Dar et al. [24] found out that spouses tend to suspect that their suffering partners minimally display the pain they go through to spare spouses of their own pain as caregivers. The withdrawal syndrome is explained in turn by the love sufferers have for family members with the idea of not compounding their personal problems. It is within this context that we can also understand why some people may commit suicide despite the love family members extend to them [25].

If sufferers have a burden to be more expressive with family members, it is even more daunting in their personal relationship with non-family members who may not have the same sympathy or understanding family members have towards them as patients with a chronic disease such as SCD. Issues that border on personality and stigmatization from "ignorant" or "mischievous" members of the public may cause extreme pressure on patient and sensitivity towards others leading to social isolation. Relating with

people at peripheral level may therefore, serve as a defence mechanism in dealing with the challenges of not being like "others" in terms of strength, physical appearance and general health condition. As noted by scholars [26], people with some form of impairment are transformed into socially marginalized group and "one way of describing the attitude towards disabled people is that there is a *social stigma* attached to being 'disabled'". For SCD sufferers, creating and maintaining social relationships is not just an important task, but it is sometimes a difficult and challenging enterprise.

Various studies [27-29] have explored the relationship between chronic diseases, the self and stigma. Study by Fife and Wright [30] reflected similar circumstances that may be helpful in understanding how people with chronic disease relate with the self and others in their social relations. Fife and Wright, in their description and discussion of the dimensionality of stigma, highlighted the impact of stigma on people suffering from chronic diseases and drew our attention to the negative impact it has on self-identity and the social responses the stigmatized person receives. Although their study was primarily on HIV/AIDS and cancer patients, their findings may be applied to the experience of patients with other chronic diseases, such as SCD. Consequently, negotiating the social terrain in creating normal personal relations and being subjected to various social and psychological pressure for acceptance seems overwhelming for SCD patients. This situation leads to constant tension and anxiety, which mounts pressure on their already frail condition and leading to more anxiety about their health and social relations. Galvan and Davis [31] also found in their study that perceived social support among HIV/AIDS patients correlates with perceived HIV stigma and noted that significant others who provide support for HIV/AIDS patients may be a source of stress for the latter. As noted earlier, participants in this study pointed out that even though they were comfortable at home due to the love and support they received, they were sometimes forced to withdraw from parents and siblings because they did not want to be a burden to them. Withdrawing from significant members in the home may be a potential source of stress both for family members and the patient. Thus, SCD patients are constantly anxious in balancing their social relations at home and outside the home.

Studies have shown that anxiety may lead to stress with serious neurotic disorder leading to suicidal thoughts [25]. Although participants in this study were usually stressed and lived a life of anxiety from their own worry about their state of health and in their relationship with others, there was no indication that participants' harboured the idea of committing suicide. All participants were personally attached to God and have a deep sense of spirituality. There have been some inconclusive results regarding the importance of religion and spirituality in coping with chronic diseases [see for example, 32], but other studies have shown that religion/spirituality has been used as a safety net in times of distress [33] and also as an important anchor for many who suffer from chronic diseases [34-36]. Paradoxically, however, even though participants have a personal relationship with God and seem to draw strength from Him, it does not eliminate the anxiety they constantly feel regarding their health and the constant reminder that their lives may be abbreviated abruptly. It is not uncommon to hear participant talk about the faithfulness of God and in the same breath express their concern about death and dying. Marxist's opiate interpretation of religion does have a sound theoretical explanation of its utility in this circumstance, as participants invoke their deep religiosity and spirituality in gaining control of themselves and their social world. Participants acknowledged the pressure their health condition exerted on their faith in God, but they all agreed to its powerful nature from which they draw strength. This orientation gave participants a strong sense of control over their lives as one participant summarized: "God has a purpose for my life that is why I was born and because He is faithful I know it is well with me as I can do all things through Christ who strengthens me." It is also such existential interpretation of their life and health condition that seemed to give participants the will to live and not contemplate committing suicide.

Although participants recognized their physical handicap and self-limitation, they acknowledged the support of family members and friends as well as the psychological and spiritual strength they draw from their personal relationship with God. Participants demonstrated a high degree of balance in their coping strategies in spite of the great challenges they constantly faced with their health condition and in their relationship with others. Overall, the research findings indicate that participants' quality of life was stable but continued to be affected by severe anxiety due to

their self-limitation and occasional social isolation from family members and friends.

There are practical lessons to be learnt from this study. First, is the expediency for the public to have a better understanding of SCD and its effects on sufferers. It is clear from the study that non-sufferers of SCD have limited understanding of the disease, which affects their interactions with SCD patients. Thus, health professionals and non-governmental organisations that are directly involved in the management of SCD patients need to expand their locus of operation to include the public so that explanations are not only provided to patients but also to enlighten members of the public who are constantly interacting with SCD patients [37]. Because the disease is hereditary based on the genotype of parents, the second best plan of action is for would-be couples to be encouraged to undergo genetic testing and counselling to avoid giving birth to SCD babies [38]. Thus, it is of prime importance for government, non-governmental organizations and religious groups to be at the forefront in carrying out appropriate sensitization campaigns and other intervention strategies to discourage sickle patients or carriers from getting married to each other thereby limiting the potential of having sickle cell children.

5. CONCLUSION

In concluding, the findings of this study confirmed that SCD patients live a precarious life characterized by anxiety, self-limitation and social isolation. In accepting the self, reliance on relatives and friends as well as drawing strength from religion and spirituality, participants have managed to cope with the vagaries of their lives as SCD patients. However, despite this extraordinary bravery in living a normal life, there is an underlying anxiety that characterizes participants' life and it is this anxious living that taints the overall quality of their life. The pain SCD patients go through, the constant fear of death they harbour and the various strategies they mobilize to cope with the social stigma, call for an urgent need for appropriate interventions to reduce societal misconception of the disease and to reduce its incidence in the society.

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COMPETING INTERESTS

Author has declared that no competing interests exist.

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