SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

PERSPECTIVES OF PEOPLE LIVING WITH SICKLE CELL PAIN IN THE
ACCRA METROPOLIS

BY
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DECLARATION

This is to certify that this thesis is a handiwork of a study undertaken by David Tenkorang-Twum under supervision towards the award of Master of Philosophy Degree in Nursing by University of Ghana-Legon. Authors of all authorized materials used for this work have duly been acknowledged in the text and the list of reference.

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DEDICATION

This work is dedicated to my adorable family, my virtuous elegant wife Mrs. Margaret Tenkorang-Twum, and my God given angels, Maame Dedaa Tenkorang-Twum, Nana Pokua Tekorang-Twum and Papa Twum-Barimah Tenkorang Twum for their unflinching and unmatched genuine support and prayers throughout this convoluted journey.
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<tr>
<td>BPS</td>
<td>Biopsychosocial</td>
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<tr>
<td>GHS</td>
<td>Ghana Health Service</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
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<td>PiSCES</td>
<td>Pain in Sickle Cell Epidemiology study</td>
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<td>SCD</td>
<td>Sickle cell disease</td>
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<td>TENS</td>
<td>Transcutaneous Electrical Nerve Stimulation</td>
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ABSTRACT

Pain associated with sickle cell disease can be very severe with debilitating effect on the sufferer. This study sought to gain an in-depth understanding of the experiences of individuals who suffer sickle cell pain. The study employed qualitative methodology using exploratory descriptive design to achieve the purpose of the study. Participants were purposively recruited from the Accra Metropolis. Data saturation was achieved with fifteen (15) participants. One-on-one interviews were conducted and audiotaped. The interviews were transcribed verbatim and analyzed concurrently using thematic content analysis. This study was guided by the Siddall, Lovell & MacLeod, (2015) conceptual framework which is a Biopsychosocial-Spiritual model. Findings indicated five main themes: physical experiences of sickle cell pain, psychological experiences of sickle cell pain, social experiences of sickle cell pain, spiritual experiences of sickle cell pain and the pain management experiences of sickle cell. Participants were unable to do anything for themselves, had support from others, had fear of death, worry and insomnia, were stigmatized by school mates and working colleagues and felt depressed, isolated and rejected and some lost their job. They coped with sickle cell pain through belief in God and use of multimodal pain management strategies. Participants experienced poor attitude of caregivers and lacked access to health and specialist care when in pain. In conclusion, it was recommended that effective pain management should be provided for individuals with sickle cell disease. The care should be integrated in the national health insurance scheme.
CHAPTER ONE

INTRODUCTION

1.1 Background

This chapter covers the background of the study, problem statement, purpose and objectives of the study. Research questions aimed at answering the objectives of the study are also captured as well as the significance of the study and operational definitions.

Sickle cell disease is an autosomal haemoglobinopathic disorder typified by a structural anomaly in the chain of the haemoglobin molecule within the red blood cells (RBCs). The sickle mutation is a single base change in the sixth codon of exon-1 of the beta- globins’ gene on chromosome 11. This change leads to the synthesis of beta-globin polypeptide of the haemoglobin molecule (Ndefo, 2008). This genetic transformation causes the replacement of the normal amino acid glutamine with valine, consequently leading to the formation of sickle cell haemoglobin (Akinlade et al., 2014). The haemoglobin then assumes a rigid and sickle shape when exposed to an environment deficient of oxygen (Brousseau, Panepinto, Nimmer & Hoffmann, 2010). The syndrome causes normal, oval-shaped red blood cells to lose oxygen and collapse into a sickle shape, precipitating vaso-clusive crises. Globally sickle cell account for 7% of the world’s population accounting approximately 80,000 among African Americans (World Health Organization (WHO), 2008).

Sickle cell disease still afflicts millions of people throughout the world and is particularly common among people whose ancestors come from sub-Saharan Africa (Adewoyin, 2015; Creary, 2007). Sickle cell disease, account for one of the most common inherited blood disorders, mostly found in people of African, Hispanic,
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Mediterranean and Middle Eastern descent and affecting close to 100,000 Americans mostly of African descent (Hambleton, 2014). It is estimated that in Africa 50 to 90% of childhood mortality may be associated with sickle cell disease but there is lack of data to support this assertion (Grosse et al., 2011). The only readily available intensive study on sickle cell disease in Africa often cited is the study in the Garski district in Northern Nigeria during the 1970’s (Grosse et al., 2011b). The carrier prevalence rate (sickle cell trait) falls between 10% and 40% across equatorial Africa and down to the ranges of 1% and 2% in Northern Africa and less than 1% in Southern Africa. In West African countries such as Ghana and Nigeria, the carrier rate is 15% to 30%, Uganda and Tanzania which are East African countries shows wide variations of up to 45% in some areas of Africa where malaria is endemic (W.H.O, 2011). It is therefore of public health importance in Ghana. Recent studies indicate that 2% of Ghanaian newborns are affected by SCD; one in three Ghanaians have the haemoglobin S and/or C gene (Kyerewaa, Edwin & Etwire, 2011).

Sickle cell disease imposes immense debilitating consequences on the individual (Haywood, 2013b). Notable among such complaint that normally send patients to medical emergency units and frequent hospitalization is pain (Ballas & Lusardi, 2005; Kanter & Kruse-Jarres, 2013) which comes about as a result of the vaso-occlusive crisis. It may be precipitated by extremes of weather conditions, infection, dehydration, exertion and ischemia (Montalembert, 2008). Notwithstanding the above stated consequences, the disease imposes on it sufferers, myriad biopsychosocial-spiritual concerns that impacts negatively on the individual.

The cost of hospitalization and treatment of sickle cell crisis put tremendous socioeconomic burden on patients and their families (Dennis-Antwi, Culley, Hiles & Dyson, 2011). In a retrospective study done in United Kingdom between 2010-2011
placed the cost at Eighteen million seven hundred and ninety eight thousand two hundred and fifty five pounds (£18 798 255) (Pizzo, 2014). The cost of admissions increases with age (children admissions costs 50% less than adults). Patients between ten and nineteen years old are more likely to stay longer in hospital compared with others (Pizzo, 2014). Vaso-occlusive crisis accounts for frequent hospitalization and reutilization of services among young adults with sickle cell disease (Brousseau, Owens, Mosso, Panepinto & Steiner, 2010).

Sickle cell pain can be due to nociceptive, neuropathic, or inflammatory mechanisms (Adewoyin, 2015; Ameringer, Elswick & Smith, 2014). Nociceptive pain (e.g., acute or recurrent vaso-occlusive episodes), pain associated with leg ulcers (Ballas, 2005; LeKisha, 2010), can be somatic or visceral. This type of pain occurs when peripheral nociceptors are activated as a result of damage to the vascular surrounding endothelium and tissues as a result of deoxygenated hemoglobin, which distorts the shape of and damages red blood cells (RBCs). Whereas, nociceptive SCD pain is as a result of actual tissue damage, neuropathic SCD pain is caused by abnormal somatosensory processing in the peripheral or central nervous system and may occur in the presence of vaso-occlusive episodes (Adewoyin, 2015; Ballas, 2005) or absence for instance, hyperalgesia secondary to opioid withdrawal (Compton, Canamar, Hillhouse & Ling, 2012) sickle cell pain may occur as a result of secondary inflammatory reactions caused by a vicious cycle of repeated destruction of healthy tissues.

Haemoglobin that has been polymerized, affects the normal shape of red blood cells and causes “sickling” of these red blood cells within capillaries and end-arteriole. This leads to blockage (Taylor, Stotts, Humphreys, Treadwell & Miaskowski (2013) which culminates vaso-occlusive crises which may occur repeatedly in the presence of certain triggers. Clinically, the disease is manifested by chronic hemolytic anemia.
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interspersed with episodes of acute vaso-occlusive sickling crises. In the normal state, most patients with Hb SS have a steady state hemoglobin level of 8g/dl. Hb SC patients tend to have stable hemoglobin level of about 11g/dl but are further predisposed to tissue damage (example, necrosis of the femoral head). Sickle cell crisis results from episodes of increased red blood cell sickling and capillary blockage causing poor organ perfusion (Adewoyin, 2015). Severe intractable pain is the most common manifestation of sickling crisis. Dehydration, infection, exposure to extremes of temperature (heat or cold exposure), and reduced oxygen tension predisposes patients to crisis (Williams & Obaro, 2011; Yawn, Buchanan, Afenyi-Annan et al., 2014). Periodic crises, the direct and indirect costs of frequent hospitalization, the economic burden of SCD, and the early deaths that sometimes occur can lead to poor family relationship (Pizzo, 2014; Wilson et al., 2012).

This is worsened by lack of appropriate and often inaccessible formal and informal social support structures that can prove helpful to the patient and his or her significant others to live positively, with the psychosocial burden of sickle cell pain. The vaso-occlusive crisis frequently causes absenteeism from school and work, consequently leading to school dropouts and job losses (Schwartz, Radcliffe & Barakat, 2009). People with sickle cell disease are often discriminated and stigmatized which further leads to social isolation (Jenerette, Brewer, Edwards, Mishel & Gil, 2014).

Sickle cell patient with intractable pain can experience all three pain mechanisms in-tandem. Physically, sickle cell pain poses serious challenge to the patient, acute recurring vaso-occlusive episodes and mixed pain has a significant negative impact on individuals’ physical and social functioning leading to reduced interest (Ballas, 2005) which can consequently lead to reduced quality of life, including interference with daily activities of life, social seclusion, and decreased well-being (McClish et al., 2005).
Furthermore, psychologically sickle cell pain has a unique dimension from other chronic illnesses that has pain as its cardinal hallmarks because of its unpredictable, reoccurring, unrelenting and excruciating nature (LeKisha, 2010). There is growing body of evidence that psychosocial factors influence clinical disease outcomes (Wonkam et al., 2014).Symptoms such as anxiety, depression, fear of death are but some of the few major issues that confront the sickle cell patient on daily basis. Depression in SCD is associated with immense daily painful episodes, reduced quality of life which affects daily activity of healthy living, and likely poor adherence to treatment regimen and health maintenance practices (Wallen et al., 2014).

Biological factors such as age, gender, race and co-morbid conditions has the tendency of aggravating the painful experiences from sickle cell pain, the individuals genotype and race are all factors that has direct bearing on the disease (Dyson, Berghs & Atkin, 2015; Smith & Aguirre, 2012). Spiritually, individuals are able to commune with their supreme being as a way of ameliorating their pain (Adegbola, 2011). Spirituality is a pursuit of personal beliefs about the essence of being, that enhances and connects other dimensions and domain of human traits and health (Bediako et al., 2011; Harrison, VanDenKerkhof, Hopman & Carley, 2013). Vaso-occlusive crisis management has being the focus of most sickle cell centers, despite the multidimensional approach available in the management of this condition. The use of analgesics especially opioids such as pethidine and morphine and non-steroidal anti-inflammatory drugs appears to be the gold standard in sickle cell pain management (Adewoyin, 2015; Serjeant, 2013). Multidisciplinary approach is the way forward if substantive progress can be made especially in the management of pregnant women who have this condition (Andemariam & Browning, 2013). Bone marrow transplant and the use of hydroxyurea appear to be
gaining grounds but simply out of reach of patients in the South Saharan Africa because of cost implications.

1.2 Problem Statement

Sickle cell disease is widely seen in Sub-Saharan Africa, Mediterranean, South America and Asia where the black race is mostly found and malaria is also endemic (Adewoyin, 2015; Kanter & Kruse-Jarres, 2013; Modell, 2008). The genotypes characterized by Hb SS and Hb SC are dominant in the sickle cell disease population of Ghana and form the basis of this investigation. A study among Ghanaians, indicate a carrier rate of 30% in the total population whereas 2% of Ghanaian newborns have sickle cell disease (Ohene-Frempong, Oduro, Tetteh & Nkrumah, 2008).

The hallmark of the disease is pain which imposes significant psychosocial burden on families and it’s accompanying multi-organ complications which are detrimental to the biopsychosocial- spiritual wellbeing of the individual. Ghana Institute of Clinical Genetics which has haematology and sickle cell clinic as a unit is located in Korle-Bu Teaching Hospital. Majority of patients that patronizes the sickle cell clinic at Korle-Bu, report with painful crisis (Ghana Institute of Clinical report, 2014). However, qualitative studies with respect to how patients live with the painful sickle cell crisis are limited. In view of this and coupled with the fact that sickle cell pain has enormous catastrophic effect on the individual and their life partners, threatening social cohesion and marriages (Smith & Aguirre, 2012), it is only imperative that genetic counselling unit be made available so that pre-marital genetic counselling is provided to ensure that individuals with sickle cell trait can make an informed reproductive choices in order to help reduce the growing burden of the disease (Rahman, Naznin, Giti, Islam & Khatun, 2015) and the accompanying painful episodes on the patients themselves.

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According to the Ghana Institute of Clinical Genetics, attendance at the Korle-Bu Teaching Hospital sickle cell clinic as at 2014, stood at ten thousand one hundred and ninety one (10191). The number of patient with genotype SS stood at six thousand one hundred and forty seven (6147) which accounts for 60% of all attendance, genotype SC, was three thousand five hundred and forty nine (3549) accounting for 35% of all attendance. Other genotypes (CC, Sβ Thalasemia) recorded in 2014 is four hundred and seventy (470) forming 5% of the attendance. The total number of patients reported with sickle cell crisis at the clinic for the year were two thousand six hundred and fifty five (2655) 26% as compared to two thousand three hundred and thirty one (2331) 22% of 2013 with an increase of three hundred and twenty four (324) representing 14% of all attendance. This shows that more patients reported with crises as compared to the previous year at the clinic. There is extensive data on sickle cell disease but little is known about how the sickle cell pain impact on the physical, psychosocial and the spiritual wellbeing of the patient. This shows that patients with sickle cell crisis may have certain challenges which are poorly understood. It will serve to fill this gap and add to the body of knowledge in the area of sickle cell research.

The purpose of this study is to explore how sickle cell patients live with vaso-occlusive crisis in their quest to fulfill their social and family life.

1.3 Objectives

1. Explore the physical experiences of patients with sickle cell pain
2. Investigate the psychosocial experiences of patients with sickle cell pain.
3. Determine the spiritual experiences of patients with sickle cell pain.
1.4 Research Questions

1. What are the physical experiences of patient sickle cell pain?
2. What are the psychosocial experiences of patients with sickle cell pain?
3. What are the spiritual experiences of patients with sickle cell pain?
4. What are patients’ experiences in managing sickle cell pain?

1.5 Significance of the Study

Sickle cell patients experiences countless challenges brought on by the insignia of the disease, pain. The episodic pain experience of sickle cell disease have serious implications on the physical, psychological, social and spiritual life of the patient and the significant others. The burden of pain imposes cost on the sufferer due to frequent emergency department visits and hospitalization. Access to designated centres and specialist care has remained elusive for these individuals. The study seeks to add to the existing body of knowledge in the domain of pain experience in sickle cell. The study’s findings and recommendations will attempt to shape the existing policy interventions in sickle cell pain management. Improvement in nursing and medical management of the sickle cell pain will also be sort through this study.

1.6 Operational Definitions

- Absenteeism- Staying away from work or school as a result of sickle cell pain.
- Polymerization- This is when the sickled blood cells adhere to each other clogging blood vessels.
Presenteeism- This is when an individual shows up at work or school but unable to work to his optimum due to sickle cell pain.

Sickle cell disease- An autosomal haemoglobinopathic disorder characterized by structural aberration of the haemoglobin of red blood cells.

Sickler- A known sickle cell patient

Vaso-occlusive crisis- Painful episodes as a result of blood vessel occlusion by sickled red blood cells
CHAPTER TWO

LITERATURE REVIEW

Perspectives of people living with sickle cell pain the in Accra Metropolis

This study investigated how sickle cell patients live with vaso-occlusive crisis in their quest to fulfil their social and family life, in particular those in the Greater Accra Metropolis of Ghana. Firstly, the literature explored physical experiences of sickle cell pain; secondly, it reviewed literature on psychosocial experiences of sickle cell pain. Thirdly, it looked at the spiritual experiences of sickle cell pain on the patient, and lastly, Literature on pain management experiences for sickle cell was also reviewed. (Adam, Telen, Jonassaint, De Castro & Jonassaint, 2010). This review is based only on published work. An electronic search of relevant literature relating to sickle cell pain and other chronic pain with similar characteristics, were conducted in Medline, Sciedirect, Talor and Francis, Midline, Cinahl and the Cochrane Library. Key words used in the search include; sickle cell pain, vaso-oclusive crises, conceptual framework, biological, psychological, spirituality and social.

2.1 Conceptual Framework

The conceptual framework that guided this study was Siddall et al’s, (2015) biological, psychological, social, spiritual and environmental, of Biopsychosocial-Spiritual domain of models after permission had been sort from the lead author, Professor Phillip Siddall. Correspondence attached as appendix G. The theoretical position of this framework postulates that biological, psychological, social and spiritual factors within the environment of a patient can impact negatively on his pain experience. In view of this, a holistic approach must be employed in managing the painful experience.
The biopsychosocial–spiritual (BPS-Spiritual) model seeks to address pain in a more comprehensive manner. However until the spiritual component was integrated to the biopsychosocial model, three other models had been published (Taylor et al., 2013) these are biomedical model (Maxwell, Streetly & Bevan, 1999); BPS model for sickle cell disease (SCD) pain and health beliefs model (Leavell, 1983; Rosenstock, 1974). The only conceptual framework among the three that focused on the biological, psychological and the sociological factors associated with sickle cell pain was the Biopsychosocial model (Taylor et al., 2013). The notable elements in the biopsychosocial-spiritual model of chronic pain of sickle cell patients are: biologic, psychologic, sociologic and spiritual processes. The rational of the BPS-Spiritual model
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is to ensure that patients take personal and active interest in their care and to develop effective skills by exhibiting a renewed thinking of coping with this lifelong painful experience. The major constructs in the conceptual framework are as follows; Biological, psychological, social and spiritual factors all within the environment of the patient.

Biological component of a model could refer to the fact that pathogens like germs and toxins precipitate illness. And in the case of sickle cell disease, the aberrated gene which imposes genetic vulnerability is the biological cause of the condition. SCD has pain as its major hallmark affecting the physical health of the individual with its eventual disability which manifest as nociceptive, neuropathic and neuroplastic. Various forms of pain have common biological factors. But sickle cell pain has unique factors such as genotype, the level of foetal haemoglobin (HbF) present in the systemic circulation, age, gender, race and co-morbid conditions (Smith et al., 2008).

Biologically, the patient must know his or her genotype. This will enable the patient to make informed reproductive choices (Abioye-Kuteyi, 2009; Atkin, Berghs, & Dyson, 2015; Barfield, Barradas, Manning, Kotelchuck & Shapiro-Mendoza, 2010).

Psychological component looks for potential psychological causes for a health problem such as lack of self-esteem, effective coping and social skill. Mental health is no doubt an important part of an individual and therefore is a key component in pain management. As pain becomes chronic in nature, it imposes serious psychological burden on the patient which predispose them to wide range of conditions such as depression, anxiety and poor coping strategies (Taylor et al., 2013). Psychological factors that has being looked at in sufferers of Sickle cell disease include personal believes, emotional distress, coping strategies and catastrophizing (Booker, Blethyn,
Wright & Greenfield, 2006; Smith et al., 2008). But in the case of Siddall’s modified framework, psychological factors that impacts on pain consist of cognitive, emotional and behavioural (Siddall, Lovell & MacLeod, 2015) The social part of the BPS-Spiritual and environmental model explains how different social factors such as family, friends work and community impact on pain. It is in this light that substantial consideration be given to social factors in the management of sickle cell pain (Siddall et al., 2015; Taylor et al., 2013).

The spiritual factor of the model is expressed in terms of religiosity/ spirituality. This consists of meaning, purpose and identity. Creating meaning and developing identity as an individual assist you to build resilience to the pain experience (Caird et al., 2011). Further, developing strong identity, having adequate knowledge in terms of meaning and developing your purpose in life through religiosity or spirituality enables sickle cell patients to steer multifaceted situations including the unpredictably intractable sickle cell pain experience (Clayton-Jones, 2015). Spirituality or religiosity are used interchangeably in most settings, but in recent time there is a general accepted view that religiosity and spirituality are related but they are separate concepts (Edwards et al., 2010; Selman & Higginson, 2011; Siddall et al., 2015).

2.2 Physical Experiences of sickle cell pain

Pain is fundamentally demonstrable sign of physical or emotional damage to tissues which strongly motivates behaviour (Finan, Goodin & Smith, 2013). Further, the hallmark of sickle cell disease which is the reason for emergency department visit is the unpredicted pain (Ballas, 2005; Creary, 2007; Erskine, 2012; Jenerette, Brewer & Ataga, 2014; Niscola & Cianciulli, 2009; Taylor et al., 2013). Painful episodes in sickle cell disease often does not present any warning sign before it is seen but may be short lived
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(few hours) but most painful episodes last almost a week depending on the level of intervention and how early that intervention was sort (Todd, Green, Bonham Jr, Haywood Jr & Ivy, 2006). For those experiencing acutely painful crises, 60% have at least one severe episode a year with 20% experiencing at least one severe episode each month (Todd et al., 2006). It is evident that the pain experience whether chronic or acute as seen in sickle cell patients, can lead to functional and physical impairment, preventing such personalities from engaging in healthy exercise regimen and thereby reducing the quality of life of same (de Villiers, Maree & van Belkum, 2015; Swanson, Grosse, & Kulkarni, 2011). It also limits personal and social initiatives of patients (Andersen et al., 2014; Fosdal, 2015; Hildenbrand et al., 2014).

Fatigue undoubtedly, is one of the issues that confront the sickle cell patient. Pain has the propensity of making the individual easily worn out (Ameringer et al., 2014; Creary et al., 2007) restricting activities and consequently reducing social participation (W.H.O, 2011). That notwithstanding, activity of daily living is significantly affected by the intractable sickle cell pain (Alsalman, Li Wong, Posner & Smith, 2013; de Villiers et al., 2015) Severe chest pain which is seen in acute chest syndrome is also an indicator of easy fatigability in sickle cell pain. In the research, Pain in Sickle Cell Epidemiology study (PiSCES) of 308 adults (mean age 33years). The average level of pain was highly predictive of physical activity, research confirmed the association between pain and activity limitation and indicated that higher pain scores has a direct bearing on reduced level of activity (McClish et al., 2005). The afore mentioned study although well cited, a qualitative methodology would have been appropriate in unearthing the pain experience and the tolerable level of activity.
Activity intolerance continue to afflict sickle cell patients in vaso-occlusive crisis (Atoui et al., 2015). Skeletal disease that are recurrent due to repeated bone infarction, bone pains, avascular necrosis of the femoral head, decreased bone density of the vertebral column which manifest as severe chronic pain in sickle cell patients reduce the desirability to engage in physical activity of daily living (Agaliotis et al., 2013; Atoui et al., 2015; Ohara, Ruas, Castro, Martins, & Walsh, 2012; Taylor et al., 2013). The intractably unpredictable and sometimes unresponsive nature of sickle cell pain, invariably make life extremely unbearable for patient (Dorman, 2005). In addition, chest pain is one major symptom of the disease that is able to restrict the individual from performing any activity that he could perform unaided (Jenerette, Brewer & Ataga, 2014). Further, this has direct impact on productivity (Agaliotis et al., 2013; Widanarko, Legg, Devereux & Stevenson, 2014) and impair relationship at work and co-workers are likely to prejudice patients due to frequent excuse duty as a result of emergency department visit and hospitalization (Ballas & Lusardi, 2005; Creary et al., 2007). However, it is imperative that the patients also learn how to manage both personal and professional relationships by communicating properly their concerns and predicaments in a more professional manner (Adegbola et al., 2012). Pressure is brought to bear on the few available staffs who have no option but to work extra with little or no compensation due to imbalance workers reward or compensation (Widanarko et al., 2014). This accounts for the prejudices mostly suffered by sickle cell patients.

Absenteeism is not only limited to the patients in the working environment. It manifest itself among young adults in schools which is evidenced by decreased level of performance with respect to their academic pursuits (Swanson et al., 2011). Conversely, a study carried out in the United states of America rather suggest a repetition at the grade level instead of decline in academic performance or test scores of the student as
compared to their counterparts without the disease condition. More so, with regard to job opportunities, individuals with pain episodes suffer from unemployment (Swanson et al., 2011). Persons living with sickle cell disease have high unemployment rate. Evidence abounds in literature that even if they secure employment, they are more likely to lose it as compared to their counterparts without SCD on the same job market (Idowu, 2013). That notwithstanding, ladies with the same condition and experiencing similar pain episodes are more likely to stay on the job as compared to their male colleagues (Bediako, 2010). Additionally, the pain has deleterious consequences, making the individual easily irritable and restless as a result of lack of adequate rest.

The painful episodes reduce quality of sleep and vitality leading to insomnia. Insomnia worsens the pain experience and the suffering of the individual, creating a vicious cycle (Alsalman et al., 2013; Ameringer & Smith, 2011; McClish et al., 2005). Adapting a balance approach with respect to painful episodes, activity levels and rest periods is undoubtedly the way to go. Adegbola et al, (2012) gave a vivid account of the lived experience of adults with sickle cell pain using phenomenological qualitative approach with a purposive sampling technique and came up with the above stated recommendations. That notwithstanding, the interviews were held on a telephone and therefore vital information such as gestures, identifiable mannerisms, facial expressions and non-verbal cues may have been lost out which could have enriched the analysis.

2.3 Psychosocial Experiences of Sickle Cell Pain.

There is evidence that the pain experienced by sickle cell patients can either be acute, chronic or mixed (Brandow, Weisman & Panepinto, 2011). Besides the pain, people living with chronic pain are affected in various aspects of life. There are other deleterious effect and consequences that the phenomenon of pain imposes on the
individual (Andersen et al., 2014). The surest way to cope effectively with sickle cell pain is to obtain the necessary knowledge through effective information seeking (Schlenz, Schatz, McClellan, Sweitzer & Roberts, 2013) about the sickle cell pain and discover your genotypic expression. In particular, it is evident that they experience challenges with respect to depressive thoughts and battling with actual depression (Alsalman et al., 2013; Wallen et al., 2014). The risk of getting depression and remaining depressed throughout life is high because of high somatic symptom of pain (Green & Hart-Johnson, 2010; McClish et al., 2009; Sogutlu, Levenson, McClish, Rosef & Smith, 2011). In a classic systemic review of the causal relations with cognitive and behavioural factors on knee pain, it was evidenced that cognitive factors such as depression had direct effect on pain (Urquhart et al., 2015). Societal attitude towards them, further lead to isolation and social withdrawal worsening the depressive tendencies of the patients (Anie, 2005a; Barakat, Schwartz, Simon & Radcliffe, 2007), reducing social participation and community integration. Additionally, the possible fear of death is something which constantly agitate the mind of most sickle cell patients ostensibly because of issues like acute chest syndrome which is evident to increase the mortality rate of sickle cell patients (Makani, 2013). Poor academic performance was registered in individuals with sickle cell pain. This was found to pose serious challenge to them despite the fact that most of these individuals were quite intelligent. This was mainly attributed to absenteeism (Forrester, Barton-Gooden, Pitter & Lindo, 2015; Schwartz et al., 2009).

Sickle cell patients also accepts that, there is no known cure to their predicament coupled with the fact that the disease is lifelong with no possible cure in sight especially in the adult (Adewoyin, 2015; Coleman, 2013). That notwithstanding, patients with
immense level of hope account for higher quality of life (Ziadni, Patterson, Pulgarón, Robinson & Barakat, 2011).

Additionally, the attendant fear of death as a result of the intractable pain which compound the difficulty that patients suffers as they journey through life, make it even more devastating (Dennis-Antwi et al., 2011). However, it is evident that a reduction in pain episodes, prolongs survival (Haywood Jr et al., 2014). Furthermore, individuals become more anxious not knowing when the next bout of pain episode will surface. This reduces the quality of life of patient and limit their level of fruitful engagement with peers (Jenerette, Brewer & Ataga, 2014).

More so, stigmatization is one of the challenges faced by sickle cell patients (Jenerette, Brewer & Ataga, 2014). Society has a tendency of looking down on this category of people simply because of the condition. They are sometimes referred as drug seeking (Adegbola et al., 2012; Creary et al., 2007; Jenerette & Brewer, 2010). This is simply because of the pain episodes, unpredictable course of the pain phenomenon and the frequent visit to emergency departments and hospitalization (Adewoyin, 2015; Tsao, Jacob, Seidman, Lewis & Zeltzer, 2014).

Not all, the patients appear to suffer discrimination from doctors and other health care providers which lead to guilt and a sense of disrespect (Haywood Jr et al., 2014). The perceived discrimination is associated with increased burden of pain (Burgess et al., 2009; Sullivan, Scott & Trost, 2012). The perceived or actual discrimination suffered by patients on the hands of nurses and doctors as they seek help to deaden their unpredictable pain episodes are sometimes seen as injustice (Ezenwa et al., 2015). In a particular study it was found that persistent back pain was associated with perceived racial discrimination of Americans of Black progeny (Edwards, 2008). To give credence to this alleged mistreatment, a study was carried out to verify how opioid analgesics
were prescribed on racial basis. The findings suggested that physicians were more inclined to prescribe opioids to white patients as opposed to blacks (Pletcher, Kertesz, Kohn & Gonzales, 2008). In furtherance to this, there is the potential that when adults with sickle cell disease seek treatment during acute pain episode in an emergency department, they are likely to suffer mistrust, racial stereotyping and ineffective communication from caregivers (Lattimer et al., 2010; Todd et al., 2006). Young adults with SCD tends to exhibit late health-seeking behaviour which tend to affect their quality of life (Brousseau, Panepint et al., 2010; Coleman, 2013).

Emotional distress is seen in sickle cell patients who are in severe pain (Taylor et al., 2013). The emotional reaction to pain also lead to a drastic change in mood making the individual hostile, increasing the desire of aggression (Riva, Wirth & Williams, 2011). The indignation felt by the patient leads to isolation, presenteeism (where the individual is present at work but does not give off his best) and absenteeism at the work place (Agaliotis et al., 2013; Alsalman et al., 2013). This predisposes the individual to conflict with close relations and thereby destroying family union (Leonarda & Cano, 2006; Welkom, 2012). Again the perceived discrimination which causes emotional and psychological pain leads to poor self concept and interpersonal functioning (Haywood Jr et al., 2014).

More so, in many patients, acceptance also serves as a coping strategy. The fact that the patient come to terms that, he just have to live with the condition and not to be troubled by the incurable nature of it (Anderson & Asnani 2013, p.658) shapes their cognition and behavioural patterns. Not all, effective communication and self disclosure by the patient to significant others lead to self-worth and confidence (Jackson, Wang., Wang & Fan, 2014). The individual can easily obtain support and enjoy the sympathy of the significant other or the healthcare provider being communicated to without being
look down upon or receiving lower quality of healthcare (Derlega et al., 2014; Green & Hart-Johnson, 2010; Jenerette, Brewer & Ataga, 2014)

Even though most sickle cell patients receive support from relatives and significant others, which goes to enhance their ability to cope somehow with the condition, appropriate and working medical insurance policy that covers treatment and other services will undoubtedly reduce the layered burden that the condition present to them due to the high cost involved in hospitalization and treatment (Brown, Weisberg, & Sledge, 2015; Kauf, Coates, Huazhi, Mody-Patel & Hartzema, 2009; Sen, Clarke & Ramanan, 2014). Additionally, individuals who derive social support from family members and significant others are able to cope better with the pain experience by exhibiting higher self-esteem and obtaining satisfaction from their job (Zani & Prati, 2015). Psychologically, adherence to treatment regime, medical instructions and healthy eating practices enable patients with sickle cell pain to demonstrate resilience to the pain phenomenon (Ziadni et al., 2011). Although, findings suggest that young adult demonstrate social incompetence in dealing with sickle cell pain, resilience account positively in their ability to fight the crisis (Barakat et al., 2007) similarly, in respect to young adults with sickle cell pain, adaptation has been found to be useful. It is evident that some of the coping strategies are simply effective than others. However, there is a strong correlation between passive coping styles, negative thinking which has the propensity of mediating and internalizing pain symptoms leading to effective utilization of emergency department and healthcare services (Barakat et al., 2007). Additionally, age differences also reveal different coping strategies. While young adult cope with sickle cell pain by ignoring the pain experience and resorting to the use of massage and application of warm compresses, hence ending up at the emergency department, adult on
the other hand take to prayers and hope for transcendental intervention and also report to the out-patient clinic (Sanders, Labott, Molokie, Shelby & DeSimone, 2010).

2.4 Spiritual Experiences of Sickle Cell Pain.

The phenomenon of pain create a certain level of vulnerability in individuals who are constantly plagued by it (Smith et al., 2012), this mostly explains why people possibly turn to a higher being (God) for answers to their suffering (Dunn & Horgas, 2004). The multilayered nature of burden sickle cell pain imposes on the individual require that patient look elsewhere for solutions that are not readily available through scientific approach. Over the years religiosity and spirituality has served as an integral part in palliative and supportive care in the health continuum. But little is known when it comes to pain management in sickle patients (Siddall et al., 2015). That notwithstanding, spirituality has a role in the life of patient troubled by an unpredictable pain.

Firstly, patients who resort to prayers and church attendance as a way of communicating their pain burden and putting their hope and faith in a superior transcendence called God, is evidenced to have adjusted positively to pain (Rippentrop, Altmaier, Chen, Found & Keffala, 2005; Ryan, 2016). Furthermore, prayer offers an individual the exclusive platform to commune with God in order to present tangible concerns that cannot be addressed in the physical realm (Ryan, 2016). Additionally, those who project themselves as religious and spiritual, although may be in pain, appear to have energized mood, a sense of well-being and satisfaction with vicissitude of life than those who do otherwise (Lucchetti, Lucchetti & Badan-Neto, 2011; Rippentrop et al., 2005). Not all, prayer offers very useful platform in mitigating the pain phenomenon in sickle cell patient (Jors, Büssing, Hvidt & Baumann, 2015). Culturally is been found that people of African extraction are quiet religious and therefore are more inclined to
pray for the relieve of their pain. In a cross-cultural study, sickle cell patients in Nigeria resorted to prayer to minimize their painful episodes whiles their counterpart in United Kingdom visited the emergency department to seek help (Anie, Dasgupta, Ezenduka, Anarado & Emodi, 2007). Anie et al (2007), affirms that, this coping skills is augmented by focus of control factors such as long standing religious believe of reincarnation due to the unavailability of specialist care to treat the pain. Religiosity and spirituality as a coping strategy that is religious coping, present a feeling of support outside the physical realm as a communion with a higher transcendence capable of solving all problems that they might be going through (Morgan et al., 2014; Siddall et al., 2015).

Secondly, studies indicate that persons who engages in certain spiritual practices such as reading of Bible, listening to religious or spiritual songs, attending counseling services by the Clergy, are able to tolerate both acute and chronic pain better (Harrison et al., 2005; Rashiq & Dick, 2009; Reiner, Tibi & Lipsitz, 2013; Taylor et al., 2013; Wachholtz & Pearce, 2009). In a particular study, participants who attended Church services once a week and practiced moderate frequency of prayer reported less hostility and anxiety and decreased pain intensity (Harrison et al., 2005; O’Connell-Edwards et al., 2009). Over the years spiritual meditation has been found to be useful by influencing sensory experience and reducing the unpleasantness and intensity of pain (Zeidan, 2011).

Furthermore, there are considerable variability as to how people live with sickle cell pain (Anie & Green, 2015; Anie, Steptoe & Bevan, 2002). Studies have shown that patient who focus exclusively on the pain experience and believe that it is as a result of a damage of a body part or an organ tend to experience more pain and feel more helpless than their counterpart who ignore it and rather resort to religious activities (Babadağ & Güleç, 2015; Sooksawat, Janwantanakul, Tencomnao & Pensri, 2013). Again,
individuals who practice mindfulness coping strategy by attaching meaning to their suffering and adopting a nonjudgmental approach to issues that are being experienced have decreased intensity to chronic pain (Reiner et al., 2013).

Attributing the pain experience to the will of God and having the full assurance that he is capable of solving the problem help them to live with the condition (Morgan et al., 2014; Siddall et al., 2015). Again, despite the fact that death may be eminent in certain conditions, faith in a superior transcendence offers hope and give the individual the needed will to fight the disease and the associated pain as found in a study involving women with ovarian cancer (Seibaek, Hounsgaard & Hvidt, 2013). Effective communication and self disclosure by patients to significant others including personal pastors, leads to self-worth and confidence (Jackson, Wang, Wang & Fan, 2014) As a matter of fact, patients who have self-worth are in a better position to live normal life irrespective of the presence of pain. This is further reinforced by developing an identity separate from the pain.

2.5 Pain management experiences.

Sickle cell disease (SCD) imposes significant health burden especially to the black race (Adewoyin, 2015; Booker, Blethyn, Wright & Greenfield, 2006). Present in all the continent of the world although, the prevalence is high among people of black ancestry (Piel et al., 2010). The complex nature of the SCD with its characteristic symptom of pain requires a holistic and multidimensional management. Sufferers of this condition are burdened with high morbidity and its related life threatening complications, unbearable healthcare cost and shortened lifespan (Staci et al., 2015). For the purposes of this study, pain management strategies will be categorized into (a) Pharmacological, non-pharmacological management and (c) Psychological component.
2.6 Pharmacological and non-pharmacological management

In managing sickle cell pain, adequate analgesia, hydration, correction of anaemia (if any) and prophylactic or therapeutic antibiotic as well as oxygenation (if hypoxia exist) must be the guiding principle in order to achieve the treatment goals (Adewoyin, 2015; Delicou & Maragkos, 2013) which is directed towards alleviation of symptoms and averting of complication. The treatment regimen must be multidimensional to achieve the intended purpose. The pain is so incapacitating and excruciating that, nothing less than immediate commencement of treatment ought to be instigated by nurses and other health professionals upon arrival at the emergency department (Brown, 2012). However, due to administrative bottlenecks and staff inefficiencies, treatment can delay for as long as four hours upon arrival of patient (Haywood, 2013b; Lanzkron, Carroll & Haywood, 2013) to the emergency department. That notwithstanding, analgesia should commence between 15-30 minutes (Adewoyin, 2015). Depending upon the severity of the pain, a non-steroidal inflammatory or opioid or a combination of the two may be prescribed and administered either intramuscularly or intravenously. Besides, treatment must be individualized coupled with a concurrent pain assessment to test the efficacy of analgesia (Rees, Williams & Gladwin, 2010; Solomon, 2012). Notably, the pain variability in sickle cell patients further underscores the urgent need to individualize the treatment options and opioid administration or combination therapy could serve the intended purpose (Udezue, 2005). Both acute, chronic or mixed pain requires prompt intervention to reduce morbidity (Wilson & Nelson, 2015). Additionally, literature has it that patients who are treated in the emergency department with opioids specifically intravenous morphine had shorter duration of hospital stay, experienced less acute chest pain, had better pain relief and had reduced frequency of re-admission to the emergency department or hospital.
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(Campos et al., 2014). The use of patient controlled analgesia has undoubtedly proven to be effective and has led to patient satisfaction in sickle cell pain management (Myers & Eckes, 2012).

Sickle cell patients are sometimes referred to as drug seekers making it difficult for them to express themselves in sharing their opinion in their care (Haywood Jr et al., 2014; Haywood Jr, Tanabe, Naik, Beach & Lanzkron, 2013). Consequently, most sickle cell patients are under dosed by healthcare practitioners for fear of addiction. This oligoanalgesia and delayed administration is a bane of most sickle cell patients at the emergency departments leading to discomfort and dissatisfactory care (Curtis, 2006; Lazio et al., 2010). Additionally, it is evident that some healthcare professional’s attitude and behavior towards patients make them feel stigmatized, demoralized and simply uncared for and this is shown in the dissatisfactory nature their pain is managed and their concerns factored in their care (Adegbola et al., 2012).

Furthermore, sickle red blood cells clog the blood vessels disrupting steady flow of blood to end artery regions and organs. This causes severe pain, hence the need for intravenous fluids to help reduce the viscosity of the blood. Seemingly, some physicians find it difficult to attend to sickle cell patients mainly because of lack of approved treatment protocols and inadequate knowledge and capacity to manage the condition (Mainous et al., 2015) compounding the woes of the patient. Aside from the above management, Hydroxyurea has proven to be effective. It reduces the number of pain episodes by increasing the level of fetal haemoglobin in systemic circulation and strengthening the cell walls of the red blood cells (De Franceschi, 2009).

Additionally, when patients present with anaemia, that is haemoglobin below the normal physiologically adapted levels, blood is given (Adewoyin, 2015; Wilson &
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Nelson, 2015). However this treatment regime is not an option for sickle cell patients on an out-patient pain management basis. Hospitalization is the only choice available if this management option can be realized (Ikefuna, Emodi & Ocheni, 2009). Pain control in SCD is essentially pharmacologic. However, non-pharmacologic measures such as physical therapy with heat or ice packs, relaxation, distraction, music, menthol rub, meditation, and transcutaneous electrical nerve stimulation (TENS) are also helpful (Ballas, 2007a). Some of the patients use massage and or hydration on out-patient basis to mitigate the painful experience before professional help is sought in case these measures are unable to deal with the pain (Ikefuna et al., 2009).

Music therapy has proven to be effective in pain management. In a research conducted by Fredenburg and Silverman (2014) of the music department of University of Minnesota in United State, it became evident that live music was effective in dealing with the pain episodes of patients recovering from bone marrow transplant (Fredenburg & Silverman, 2014). Further, gaining control is also an effective strategy. Knowing yourself and listening to bodily cues offers a sense of direction. Fatigue and headache are indicative symptoms of crisis and are seen during the prodromal stage of the sickness (Ballas, 2005). However, taking warm bath is likely to avert a crisis (Anderson & Asnani, 2013). Contrary, to this, is the assertion that nothing can avert sickle cell crisis once the pathophysiological process begins (Addis, Spector, Shaw, Musumadi & Dhanda, 2007).
CHAPTER THREE

METHODOLOGY

This chapter describes the research design, the study setting, the sampling method and the sample, data collection procedure, data management and analysis, rigour and ethical considerations.

3.1 Research Design

For the purposes of this study, a qualitative research design using exploratory and descriptive approach was used. Qualitative inquiry is most often employed to describe a phenomenon which little is known. The researcher is in the position to capture the meaning from the data collected in a form of perception, feelings, behaviour, insights, thought and actions rather than figures or numbers. The researcher is capable of describing the process with respect to its context rather than outcome (Mayan, 2009). Qualitative approach is the best method in a researchers’ quest to understand individual or group subjective experiences of health among participants within a particular geographical area or a specific healthcare setting (Fossey, Harvey, Mcemott & Davidson, 2002). The focus of interest is on the individual who has gone through the problem under investigation (Polit & Hungler, 1999). This research was carried out among adult sickle cell patients resident in the Accra Metropolis. It was expected that this scientific approach would elicit rich and in-depth description from the participants in order to provide in-depth access to the meaning people attach to their lived experiences; this will consequently bring to the open issues that quantitative method cannot unravel.
3.2 Research Settings

The study was carried out in the Accra Metropolis in the Greater Accra region which has Accra as it’s capital and also double as the capital city of the Republic of Ghana since 1877. It was originally part of Eastern region until 1882 when it was carved out as a separate region. It occupies a total land surface of 3,245 square kilometers or 1.4 percent of the total land area of Ghana. It is bordered on the North by the Eastern region, South by the Gulf of Guinea, west by Central region and east by the Lake Volta. The total population of Greater Accra region stands at 4,010,054 according to 2010 population and housing census by the Ghana statistical service. The population of residents in the Accra metropolis is 1,848,614 (Ghana Statistical Service, 2010). The indigenous people are referred to as Ga-Adangbe and Ga. The Ga-Adangbes speaks Adangbe and the Gas, the Ga language. There are presence of almost all tribes in Ghana at the Greater Accra Region with Akans as the dominant migrants who are twi speaking people, and therefore can be referred to as a cosmopolitan region. The Greater Accra region has two (2) metropolis, sixteen (16) municipalities and Two (2) district assemblies. The political administration of the region is through the local government system. The head of the Accra metropolis is the Mayor. It is a multi-religious metropolis with Christians forming the majority. The participants were recruited from the sickle cell clinic at the Korle-Bu Teaching hospital which is the biggest teaching and a tertiary hospital in the southern sector of Ghana. The hospital was established in 1923, has grown from a 200 bed capacity to 2,000 and currently the third largest hospital in Africa with 17 clinical and diagnostic departments/ units. The hospital was the recruitment outlet for patients who came for outpatient services and lived in the Accra Metropolis.
3.3 Target Population

The target populations were adults (male and female) between the ages of 18 years and above who have been diagnosed with sickle cell disease and resident in the Accra Metropolis.

3.4 Inclusion Criteria

1. Adults of both sexes eighteen (18) years and above whom had been diagnosed with sickle cell disease and living in the Accra Metropolis.

2. Adults who had experienced sickle cell pain in the last six months and at least have had two crises a year.
3. Participants who were recruited in the study were able to communicate fluently in English language.

4. Participants who took part in the study gave their consent.

### 3.5 Exclusion Criteria

1. Patients diagnosed with any form of mental illness.

2. Patient who was in pain or on admission.

### 3.6 Sample size

The determination of the sample size depended on data saturation where no new information was elicited. It was achieved by interviewing between 15 participants.

### 3.7 Sampling

Recruitment was done through purposive sampling. In purposive sampling the focus of the researcher is on a particular experience the participants have (Patton, 2002) and who are in the position to enable the researcher to answer the research questions (Mayan, 2009). In this study, participants who met the inclusion criteria were carefully recruited based on their peculiar condition in order to answer the research questions.

### 3.8 Data Collection Instrument

Semi-structured interview guide was developed and used as a data collection instrument for the study. The guide consisted of open ended questions and question probes to collect in-depth information on the perspectives of sickle cell patients and how they lived with pain. The interview guide (Appendix C) was divided into two main sections: Section A comprised of the participants demographic data and B was questions that guided the researcher in his exploration of the day to day experiences of
sickle cell patients and how they managed their lives with the pain. In-depth interview has the advantage of obtaining detailed information which is fuller and richer from the subjects (Polit & Beck, 2010).

3.9 Data Collection Procedures

Data collection is a major component of a research process. The method or the instrument is chosen based on the nature of the problem (Polit & Hungler, 1999). The primary data in this study was collected through individual interviews. The investigator obtained an introductory letter from School of Nursing of University of Ghana to the hospital authorities of the Korle- Bu Teaching hospital copied to the head of department of Haematology and the nurse in-charge of the sickle cell clinic that assisted in the recruitment of participants who met the inclusion criteria.

Patient information sheet detailing the inclusion and exclusion criteria was handed over to the nurse in-charge. This enabled her to know the type of participants that were qualified to partake in the study. After the participants were recruited, a consent form was given to those who were willing to participate in the study to sign or thumbprint after everything had been explained to them in a language they best understood. Opportunity was provided to answer all questions that bordered participants with respect to the study. Participants were informed that the exercise was strictly voluntary and that they were at liberty to drop out anytime in the course of the investigation without any repercussions to them or their treatment regime and health worker behaviour towards them. However, they were assured of anonymity and confidentiality of the information given. They were given labels, P1-P15 based on when they were recruited. The researcher conducted two practice interviews with two sickle
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cell patients at Ridge hospital. Feedback from supervisors enhanced the interview skills in the actual study.

A semi-structured interview guide was used to collect data. Furthermore, interview was conducted at the convenient time and place of participants. The venue was quiet and privacy ensured. Demographic information was obtained and the interview audiotaped with permission from the participant to ensure that data obtained was accurate and reflected the view of the participants. A field note was used to record mannerisms, gestures and non-verbal cues as participants narrated their pain experience. Field notes enhanced analysis of data. Further probing questions were used to elicit in-depth information from the participants. The interview language was English. Each session lasted between 45-90 minutes. Participants who showed signs of emotional distress, had their interview temporarily suspended. The services of a clinical psychologist were to be solicited to help the participants at no cost to them in case there was emotional breakdown during the interview but there was no such thing.

3.10 Data Management

According to Miles and Huberman (1994), data management broadly refers to as the storage and retrieval of research data in a way that facilitate data analysis. All files created had been stored in a drawer under lock. The transcribed data has been filed with the tapes under lock and stored for five years. The consent forms has been kept in a separate drawer and locked up. This ensured that the right information was obtained from participants.

3.11 Data Analysis

Concurrent data collection and analysis was done to adhere to the principle of inductive inquiry. Data analysis was done using thematic content analysis technique.
The audio-taped interviews were transcribed verbatim. The transcripts were read several times and ideas, words or concepts were noted to form codes. Similar codes were grouped. Themes and subthemes were generated based on the conceptual framework. Other findings were analyzed using the principle of content analysis. Open coding which was done, involved labeling sections of text that seemed important to the research questions. Content analysis was the process adopted to identify, code and categorized the primary patterns which was in the data.

### 3.12 Ethical Consideration

Maintaining human dignity, respect, right and safety of participants, goes to the core of research, in view of this, ethical clearance was sought from the Institutional Review Board (IRB) of the Noguchi Memorial Institute of Medical Research, Permission was sought from the Sickle cell clinic of the Korle-Bu Teaching Hospital, Accra with an introductory letter from the School of Nursing, University of Ghana and a copy of the ethical approval and the research proposal. The purpose, objectives and any potential benefits and risks were explained to participants in the language of their choice (Twi) or English a week before data collection. This allowed participants enough time to consider their participation. After the participants were recruited, a consent form were given to those who willingly agreed to participate in the study to sign or thumbprint after everything had been explained to them in a language they best understood. Opportunity was provided to answer all questions bordering participants with respect to the study. Participants were informed that the exercise was strictly voluntary and they were at liberty to drop out anytime in the course of the investigation without any repercussions to them or their treatment regime and health worker behavioural change towards them. However, they were assured of anonymity and confidentiality of the information given. They were given labels P1-P15 based on when they were recruited. The participants
were informed that, the data and other study documents such as consent forms, audiotapes and transcripts had been kept in a cabinet under lock and keyed in the researcher’s office for at least five years after the study. The sheet containing the demographic data and other identifiable information have been kept under lock and key separate from the interview data in a cabinet in the researcher’s office. The participants were told that appropriate ethical clearance had been sought from the Institutional Review Board (IRB) of Noguchi Memorial Institute of Medical Research and that the same procedure will be followed in the future usage of the data or for any other purpose. The researcher arranged with a clinical psychologist whose duty was to assist the participants in a form of counseling after expressing their experiences of living with sickle cell pain at no cost to them.

Participants were told that their participation in the research was strictly voluntary and they could opt out at anytime. Any potential harm or direct and indirect benefits was thoroughly explained to the participants. They were further assured that all other ethical principles were adhered to.

3.13 Trustworthiness (Rigour)

Rigour refers to the extent to which the researcher strives for excellence and how they adhere to detail and accuracy. Parahoo (2006) highlights that although rigour can be difficult to determine in qualitative research, researchers want their findings to reflect truthfully the phenomenon they are studying and to contribute to knowledge that is beneficial to others. The researcher used the framework by Guba and Lincoln (1985) to ensure the trustworthiness of this study. This framework encompasses the following four criteria for developing trustworthiness of a qualitative study, credibility, dependability, confirmability and transferability (Lincoln & Guba, 1985).
Credibility: Credibility focuses on the truth and value relating to the findings of the study and the representation of these (Topping, 2006). The researcher, through the use of semi-structured interviewing techniques, tape recordings of the interviews and transcriptions of verbatim quotes, ensured increased accuracy of the descriptions of participants’ perspectives (Streubert & Carpenter, 2010).

Dependability is concerned with the ability of the data to remain stable over time, such that the study findings can be replicated if undertaken with similar participants in a similar context. The researcher used an audit trail to enhance the dependability of the study. It involved tracking and recording all decisions which could influence the study so an outside individual can examine the data (Streubert & Carpenter, 2010). The researcher kept all recordings regarding the study with all other information under lock and key.

Confirmability refers to the data representing the information participants provided. There were no biases or subjectivity in the study; the findings represented the participants voice (Polit & Beck, 2010). The researcher upheld this principle by clarifying all information with the participants after transcription and analysis. The researcher made follow up interviews with two participants in their respective places of abode after the transcription to confirm and clarify statements given during the interview.

Transferability involves the extent to which the findings of a qualitative study can be useful to similar groups or situations (Parahoo, 2006). It should be understood that to achieve the robustness of study, accurate records were kept of all interviews and interactions with participants, as the careful recording of data was crucial to the study. The researcher at all times, strictly paid attention to detail, adhering to procedures and ensuring consistency and accuracy throughout the research process.
CHAPTER FOUR

FINDINGS

4.1. Introduction

This chapter presents the findings of data generated from the participants who met the inclusion criteria of this study. Five (5) major themes emerged from their narrations as guided by the constructs of the conceptual framework by Siddall et al 2015 adopted for this study with sub-themes emerging from the content analysis of the data analyzed. The five major themes that emerged were; Physical experiences of sickle cell pain, Psychological experiences of sickle cell pain, Social experiences of sickle cell pain, Spiritual experiences of sickle cell pain and pain management experiences. Anonymized verbatim quotations were used to support the various themes and sub-themes using appropriate pseudonyms. Thorough descriptions of the background of participants were also captured.

4.2. Description of Study Population

The study population consisted of fifteen (15) participants. Ten (10) out of the lot were females. The ages of the participants ranged from 22 - 63 years with an average mean age of 41.7 years.

Genotypically, twelve out of fifteen of the participants were SS and three were SC. In terms of ethnic orientation of the participants, seven (7) out of the number were Akans of various tribal inclinations such as Fantes, Asante, Akuapim and Kwahu. Three (3) were Ewes and five were from the Ga/ Adangbe extraction.

Almost all the participants could speak more than one language. Seven (7) could speak at least two (2) Ghanaian languages in addition to English which was the language
used for all the interviews and other forms of communication. Five (5) could speak three
local languages in addition to English, however three (3) could speak only one
additional Ghanaian language aside English. Additionally, Eleven of the participants had
obtained tertiary status education, two (2) had post-secondary and the remaining two
had risen to the secondary level. Moreover, twelve (12) of the participants were
gainfully employed; one (1) was currently on retirement. That notwithstanding, one (1)
lost her job and currently unemployed, and the other, a student. Seven (7) of them are
married, six (6) are single, one (1) divorced and another separated.

Similarly, eight (8) of the participants have children minimum of one (1) and a
maximum of four (4), Six (6) have no children. One of the respondents had one child
who had a genotype of SS but died at age one. The one with four children is a male
participant whose partner has a genotype of AA.

In the quest to answer the research question one: “What are the physical
experiences of sickle cell pain” one major theme emerged to answer this question -
Physical experiences of sickle pain with two subthemes and one sub-subtheme.

4.3. Physical experiences of sickle cell pain.

Participants recounted the ordeal they encountered physically on daily basis as
they journeyed through life with the sickle cell disease. All the participants narrated how
the sickle cell pain prevented them from doing anything, embarking on simple activities
like bathing, attending to personal hygiene and walking. The pain also caused general
body malaise and created a sense of unwell with a nonspecific nature. Fatigue was the
sub-subtheme emerged under general malaise. Two subthemes and one sub-subtheme
emanated from this interaction under the main theme: physical experience of sickle cell
pain: The subthemes were; activity intolerance, general malaise and the sub-subtheme - fatigue.

4.3.1 Activity intolerance

All the participants indicated they were not able to do any physical activity especially when they were in pain.

“You know it makes you feel uncomfortable and you virtually do nothing” (Chris).

Equally, one participant indicated how severe chest pain alone was able to incapacitate him.

“When I’m in crisis, I’m unable to do anything” (Sisi).

“One in my numerous crises I had severe chest pains, I could not do anything. I couldn’t even walk” (Mahami).

Participants indicated that when the pain is present they had to put to a stop to whatever work they were involved in.

“Yes, for instance if I’m in the office with a lot of work to do and the pains set in, then the work will be left undone till I return to the office” (Sisi).

Others lamented that when the pain is felt in the knee, then walking became problematic.

“If it occurs in my knees, then I cannot walk for some time until the analgesics start to work. If it started at a time when I was busy I just have to stop” (Obuabasa).

Furthermore, participants reiterated that attending to personal hygiene while in pain, was difficult and every activity came to a halt.

“When the crisis is severe, sometimes I cannot even bath. When it is very severe I just have to lie down and virtually everything comes to a halt” (Moana).

Some said family members assisted in maintaining their personal hygiene.
“When I am in pain, I always stay in bed. Sometimes I have to be bathed, other times, (excuse me) I have to be assisted by my mum and my sisters to even change my sanitary towels when I am in my menses” (Djata).

“My wife virtually had to bath me like a baby whenever the pain is so severe” (Mahami).

4.3.2 General Malaise

The participants bemoaned the undefined and nonspecific nature of the sickle cell pain. The pain affected different parts of the body at different times and it later centralized.

“You could have just one part of your body or you could have one part and others join or you could have several parts starting and then the pain begins to centralize at certain places making you so weak” (Obuabasa).

However, participants contended that, the pain did not resolve after it had settled at a point it rather became severe.

“The pain doesn’t come radically but you realize that there is pain especially at the back which radiates to the knee. Just when is settling it gets severe again” (Twumwaa).

Some of the participants also indicated how the pain started at different parts of the body and then it disappeared.

“For me usually it starts with my waist and then it moves to my upper back. The pain is mostly felt at the joints throughout the night till morning. With time, it fades away yet leaves you feeling sick” (Johnson).

4.3.2.1 Fatigue

Participants indicated how they easily got tired when they were involved in any activity as a result of chest pain.

“You know I am a banker. At the head office, anytime the lift breaks down, I have to walk up the staircase to the fifth floor where my office is located I get very tired and pants” (Wudjiti).

“Mostly, the pain gets very severe in the chest, making movement very difficult because I get tired in an attempt to walk” (Mahami).
Some participants indicated their inability to work for more hours because they easily got tired.

“I easily get tired if I work deep into the night especially when I get orders from Italy” (Tweneboah).

“I easily get tired when we prepare kenkey way into the night so I am excused by my mother when she notices it” (Doom).

“I cannot really work hard the way I want, even when I am being sent to the hospital, I cannot help myself to walk” (Tenkorang).

In an attempt to answer the research question two: “What are the psychosocial experiences of sickle cell pain”, two major themes emerged to answer this question - Psychological experiences of sickle cell pain and social experiences of sickle cell pain. These are described subsequently.

4.4 Psychological Experiences of Sickle Cell Pain

The pain episodes that were experienced by sickle cell patients, brought to light a myriad of psychological experiences. These were cognitive, emotional and behavioural experiences. Participants reported fear of dying at early stage as a bother to most of them. Some of them became worried because they absented themselves from school which affected their academic performance. Almost all participants experienced sleepless night as a result of the pain episodes. The pain resulted in some of the participants becoming depressed. Most of the participants felt rejected and stigmatized by friends and working colleagues.

The subthemes derived from the data were; fear of death, worry, depression, rejection, insomnia and stigmatization.
4.4.1 Cognitive Experience

There were various psychological determinants that impacted on sickle cell pain. Some cognitive factors also emerged in the narratives of the participants; these were fear of death, worry and insomnia.

4.4.1.1 Fear of death

The participants reported fear of death because of the intractable pain that was associated with sickle cell disease. Some participants kept seeing themselves dead because they heard they will not live beyond a certain age.

“I think when I was 25, I kept seeing myself in my dreams die and I kept telling my Mum. Because I overheard somebody in their conversation that ‘sicklers’ die young and they don’t live beyond the age of thirty. Since I was getting to that age, I was so fearful” (Djata).

Some of the participants also asserted that they harboured fear of possibly dying early because of lack of knowledge about the condition.

“I was scared of death because I did not know much about the sickle cell then but I knew that when someone is a ‘sickler’ then the person has a short life”(Oboshie).

“Fear of death gripped me like a a goat being sent to the slaughterhouse by the butcher because I did not know much about the disease” (Tenkorang).

Participants stated how they became very afraid of death when they were told not to deliver more than two children.

“I became very fearful when I gave birth to my first daughter and one nursing sister advised me that, because of my condition, I should not go more than two if I want to live long ”.(Sisi)

“I was scared I was going to die on my third delivery because a gynaecologist warned me not to give birth again” (Doom.)

Participants indicated that they became fearful after losing siblings to the disease after crises.
“I feel downhearted and I think a lot because we were six in number. The first one didn’t live for that long and the second one is even dead. He’s in the morgue; we’ll bury him on Friday” (Twumwaa).

However, two of the participants were not afraid of death associated with sickle cell disease.

“I am not afraid of death or maybe fearful of something. This is because it’s normal, it’s part of life and you have to keep going. If you keep that in your mind, it means you don’t want to do anything in life” (Tenkorang).

“I don’t even think about the fact that I have sickle cell and that it can shorten my life. The only time it comes to mind that I have sickle cell is probably the times when I feel I have some pains in a part of my body” (Twenwboa).

4.4.1.2 Worry

Participants expressed how worried they became as a result of their inability to sit for their exams and again absented themselves from school that led to poor performance.

“In Secondary school during exam time I got sick, so I could not write the exams. So in form four I was even repeated during GCE, it affected me and got me so disturbed. I wrote two papers, came back and I couldn’t write again so I ended up attending remedial classes” (Twumwaa).

Some of the participants also shared how painful episodes prevented them from sitting for exams they had prepared for adequately. Consequently, they had to re-sit several times to get the needed grades.

“There was another day I was preparing for a paper, I was at home having my lunch, getting ready. It was an afternoon paper and right there at the dining table my joints started hurting so I couldn’t go to sit for that paper. So I had to re-do my O’ Level like twice or three times I think. I was losing out on some of the papers and even the ones that I wrote it was just as blur, I couldn’t even remember what I was writing” (Wudjiti).

According to some of the participants, their worry was that the sickle cell pain prevented them from staying in class for a whole term and this affected their performance.
“Truth be told, it was really a bother to me: was getting this serious pain, I could not be in class for the whole term, and it even affected my learning and performance” (Dromo).

Similarly, participants had to stop schooling because of absenteeism and poor performance.

“I got so worried because sometimes for a whole year, I wouldn’t set foot in class and my parents didn’t know what the cause was, so I decided to stop schooling because my performance was poor” (Tweneboah).

However, some of the participants said that they were not worried because the pain even though caused them to absent themselves; it never affected their academic performance.

“I was not worried despite the fact that I absented myself couple of times. I was neither repeated nor my performance affected” (Tenkorang).

“I was not worried though the pain posed considerable challenge yet it did not affect my performance irrespective of the number of times I had to absent myself from school” (Mahami).

4.4.1.3 Insomnia

The sickle cell pain imposed a burden of sleeplessness mostly from the discomfort the pain episodes presented.

All the participants indicated that they were unable to sleep because of pain.

“I do not normally sleep when I am in pain” (Tenkorang).

“I cannot sleep, when I am in pain so I just lie down” (Moana).

According to some of the participants, their inability to sleep as a result of pain affected them at work.

“You can’t sleep, night is hell. It’s proper hell, you start falling asleep around 4am and you will be up by 5am getting ready for work so you therefore reach the workplace and you are asleep behind your desk. So yes it has affected me” (Wudjiti).

4.4.2 Emotional Experiences

Derogatory statements made by individuals and the nature of the pain rendered the participants vulnerable. Some lost their sense of worth leading to extreme sadness.
that lasted for a long period, sometimes severe enough to interfere with life. The abuses suffered by the participants led to rejection.

4.4.2.1 Depression

According to the participants, they became sad because their colleagues made disparaging comments about them.

“At one point I became so depressed, I nearly died. I fell sick and when the in-charge was told, she commented thus “what’s all this, if I need a human being to work with, then you bring me a sickler” (Twumwaa).

“What a wretched life I find myself; I asked for promotion and when my boss’ attention was drawn, he said what at all is this young man looking for, after all he might die soon” (Mahami).

Some of the participants lamented on how people trivialized the death of sickle cell patients and made it appear as if they were only good to die.

“An Aunty who visited my mother called a friend and told her that Adwoa’s sickle cell patient daughter is still alive can you imagine... hahahaha! (She laughed)” (Djata).

“Just last week I felt so sad, I was told somebody had died so I asked what killed her, a lady giggled and said ‘Oh as for her she’s a sickle cell patient’. And I said she’s a sickle cell patient; so does that mean she should die? Some of these disdainful comments tend to decrease my sense of worth” (Sisi).

Some of the participants stated that, the diagnosis and the further confirmation of the disease alone was enough to make them sad.

“I became very sad when the diagnosis was confirmed at Korle –Bu Teaching Hospital,” (Delali).

“Sadness befell me and I had to lock myself indoors for days when the diagnosis of sickle cell disease was confirmed at a hospital in Lagos”. (Mahami).

Some of the participants held the view that they felt so sad because the disease and the painful episodes had really affected their progress in life.
“I feel sad all the time because sickle cell pain has affected my forward movement in life, I can’t explain that though” (Delali).

According to some of the participants, a sense of despondency struck them because of their inability to behave because of the painful episode.

“What a miserable life that I live. All my friends go out, attend parties, they can go to the beach, swim, I can’t do those things. I can’t be in water for more than 5 minutes else I get crisis” (Djata).

4.4.3 Rejection

Participants felt that their right of place in society was seriously undermined due to their condition. According to some of the participants, people avoided their company when they got to know that they were sickle cell patients.

“People began to shirk my company when they got to know my condition coupled with the fact that I had 3rd degree vagina tear which I developed fistula” (Twumwaa).

Some of the participants also suffered rejection after they conceived for their partners and their genotype status was revealed.

“My boyfriend abandoned me to my fate after I got pregnant for him. We planned to marry so after visiting the clinic together and getting to know that I was a sickle cell patient, he had a change of mind.” (Tweneboah).

“My first girlfriend left me because she was impressed upon by the parents to quit the relationship despite the fact that her genotype was AA” (Johnson).

“My guy said, no I am a sickle cell patient so he could not marry me. I went on admission at Korle-Bu Teaching Hospital over 4 months” (Djata).

Some of the participants were also rejected by their peers by virtue of their stature (body size).

“It was one form of rejection to another. I remember that in secondary school, I was very lean and it was around that time that they had discovered HIV; you know the behaviour of students” (Moana).
According to some of the participants they feared rejection more than the severe pain of sickle cell.

“Sir, my fear is not really the pain but the rejection. I hated the tendency of being rejected because I am capable of doing everything; just that I may not do it the way you will do it but I will get it done at the end of the day” (Wudjiti)

“Yes, I feel rejected by society” (Djata).

4.4.4 Behavioral Experience

Participants were confronted with shame and despair as they navigated through life with this SCD. Although sufferers have no choice of their genotype, society heap up the burden on them as though they chose to be born with this inheritable condition. They suffered unbridled stigmatization.

4.4.4.1 Stigmatization

Stigmatization is a dehumanizing experience that confronts individuals with SCD. According to all the participants, they were called all sorts of names in a disdainful manner.

“So yes, I grew up hearing a lot of things. I mean people use to call me “Kyena mewu” meaning (I will die tomorrow)” (Obuabasa).

“I could hear people make derogatory remarks, somebody dies when he’s just 39 or 32. What killed him? They will say he was a sickler. The guy suffered something; the guy fell ill, something happened to him. It’s not because he has sickle cell, it’s because he had a heart attack, he got cancer or something else. He got this bad typhoid or appendicitis that went out of control. Why not say what killed the guy and avoid disgracing people. So even that term is derogatory and I hate it” (Wudjiti).

According to some of the participants, they were stigmatized when called sicklers.

“The two key issues I have with this condition are the stigma and the misinformation. Even the expression sickler is derogatory because straight away the connotation is that, he is a sickler because he is always sick” (Wudjiti).
Some of the participants intimated that stigmatization transcended to the work place.

Once it is known to management that you have sickle cell disease, no responsibility will be delegated to you.

“Oh Sir let’s send Thomas” “I don’t want any problem; he’ll go and die and put us into trouble. The moment it gets out there that you are a sickle cell patient, you are out when they are looking for someone” (Wudjiti).

Another concern expressed by most of the participants was that sometimes they were told directly that they will die early.

“Sometimes, you are told in the face that you do not last. Up until now, there is stigmatization in every aspect of it. That is the first thing that comes to mind if it is known that you are a sickle cell patient” (Mahami).

Some of the participants revealed how working colleagues discussed them in a rather sarcastic manner.

“My working colleagues made certain comments like - people with sickle cell die early, they don’t even live up to 40 year; you do not last. Up until now, there is stigmatization in every aspect of it. That is the first thing that comes to mind if it is known that you are a sickle cell patient” (Moan).

Participants share how people who wanted to marry them were cautioned to discontinue the marital arrangements.

“Marrying a “sickler” meant that you won’t go on, you can’t do anything, all your money will finish”. His family, outsiders, friends and even church members were against it” (Twumwaa).

4.5 Social experiences of sickle cell pain

Sickle cell pain requires that individuals who have this condition will have to adjust to a lot of situations in order to live meaningful lives. Societal demands and sometimes misdirected expectations further put a lot of burden on the patients. According to the participants, stressful situations that were found at the workplace, the need to accomplish set goals triggered pain. The pain affected the interpersonal
relationship of some of the participants making them quick tempered which was borne out of frustration. Some of the participants reported that once they were in pain everything and everybody were cut off. Some even believed that the condition was caused by witchcraft. However, social support systems helped the sickle cell patients to tolerate the crisis much better. According to some of the participants, family and working colleagues understood them and assisted them to nurse their pain during crisis periods. That notwithstanding, there were periods where some of the participants experienced isolation. The following subthemes were identified: family support, friends support, social isolation, interpersonal relationships and employment.

4.5.1 Family Support

Social support systems were activated often times to assist participants to cope effectively with the myriad of challenges that confronted them. This was achieved through explicit involvement of the family through daily encouragement and physical support. The family offered a congenial atmosphere to participants.

Some of the participants affirmed how family members had to abandon going to work just to attend to them.

“They can’t go to work and ignore me. It’s affecting them as well. They have to be by me, take me to the hospital, bring me back and stay in the house with me. For instance, my daughter has to leave her husband and come to take care of me until I am better; she can then go to work ”*(Sisi).*

“They sometimes my husband will have to stop work when I am on admission, come to the hospital to buy drugs here and there among other things” *(Moana).*

Some of the participants indicated how they were fully supported by members of their family.
“My husband has been very supportive. I for example, do not wash; we use the washing machine. He does the washing of the underwear himself, we use the machine. So he does it, especially with the underwear he does it himself. Definitely when you are in pain you can’t have any intimacy, but he understands” (Moana).

“I have a supporting mother and my mother understands my condition and she supports me. Even when I want to belittle myself, she wouldn’t allow me; that is how she is. She supports me in everything” (Djata).

“And besides, she does everything - being a nurse to alleviate my pain. She has done so much for me to be able to stay on top with what I will call a setback” (Wudjiti).

4.5.2 Friends Support

According to some of the participants, friends and working colleagues offered a lot of support at the workplace, even with regard to finances.

“I have supportive friends. When I am in serious crisis and I have no money, there are some people I can call right now to give me money” (Djata).

“God being so good, I met a generous matron at work one day, I was at the clinic during the day when the pain started in my leg. She saw me massage my leg as I worked” (Twumwaa).

Some of the participants indicated how accommodating and understanding their working colleagues had been.

“They were accommodating because I work hard when I am healthy. So when they saw that I was in pain, they sympathized with me up to my retirement. I have been at Dansoman, Maamobi, Malata and Amanfrom and they were cooperative” (Twumwaa).

“Now people tend to understand our condition. I think quite recently I had crisis for about 3 or 4 weeks. As quickly as I informed my superiors, they gave me the chance to nurse that pain and when I became ok I resumed work” (Chris).

4.5.3 Social Isolation

On few occasions some participants felt let down by their friends through subtle isolation. According to some of the participants, they felt isolated because they were small in stature despite the fact that they were almost of the same age as their friends.
“Obviously I felt isolated; my peers were as young as myself, almost of the same age so they couldn’t understand why I was that lean. So they pick on you and bully you among others” (Wudjiti).

Others were also isolated by the mere admission of having sickle cell disease.

“The disease comes with so much isolation. Therefore it depends on the individual to develop the right mindset which is very important And your mindset in how you act or behave so it is not everybody I tell, some people in my closed family know, not all” (Mahami).

Some of the participants indicated how they felt isolated because they could not do what their peers could do like attending to clubs, parties and so on.

“Yea, sometimes I feel isolated because there are many things that I don’t do. Things like party, clubbing, sitting out with friends and sharing a drinking” (Johnson).

4.5.4 Interpersonal relationship

The participants indicated that the sickle cell pain made them quick-tempered and were seen by co-workers as persons that were easily provoked but this was borne out of frustration.

“The pain has made me become a short-tempered person. My former work place I was noted for being a very quick tempered person but that was merely out of frustration” (Wudjiti).

Some of participants indicated that they got frustrated as a result of the pain and displaced it on people.

“So it gets frustrating sometimes and you take it out on people and they think you are not a very pleasant person. It was out of frustration as a result of the pain” (Wudjiti).

Some of the participants indicated that everybody was cut off once the pain sets in.

“Everybody is cut off any time I have such this thing called pain,. I have to stay at home with my family, my wife and my kids. So during those times everything is shut down” (Johnson).
4.5.5 Employment

Participants had terrible work history. Employment was a major concern because of the painful episodes. Some of the participants indicated how they tried unsuccessfully to secure jobs after school.

“It took me several years to secure a job after school simply because I was a sickle cell patient. I nearly lost the job” (Sisi).

Some of the participants indicated they lost their job because of sickle cell pain.

“I had to quit my job because I had painful episodes just two weeks after I started work. I couldn’t go to school was absent most times. My boss called and said she couldn’t tolerate it anymore. So, ever since, I haven’t had the courage” (Djata).

Some of the participants reiterated how the sickle cell pain affected their promotion.

“Sickle cell pain has affected my promotion. I had to upgrade myself before I could be promoted but I could not, simply because of the pain. So I stopped there and I’m now on my way to retirement with just that scanty salary and no retirement reaping. It’s very difficult” (Sisi).

My brother, last year I was not promoted because during promotional interview, I had crisis. I could not attend the interview hence my inability to get the promotion” (Chris).

Some of the participants also revealed how the pain affected their output at work.

“My work was affected especially when I went through this pain with leg ulcers. The pain was so severe and I had to take strong pain killers, most of which made me drowsy all the time. At work, I was usually half asleep and inactive, spending the whole day on a piece of work which should take about 3-4hours to accomplish. So, Yes!, it has affected me.”(Wudjiti).

Some of the participants also suffered redeployment because of the pain.

“First I was put at Kade and then the doctor wrote that I am brought back to Accra against my will” (Twumwaa).

“I was posted thrice in one year all because my bosses got to know that I was a sickle cell patient. That made me quit the job” (Wudjiti).
4.6 Spiritual experiences of person’s sickle cell pain

This major theme looked at the diverse experiences acquired by sickle cell patients with respect to their spiritual life as a consequence of the painful experience. According to the participants, the pain affected their routine religious practices such as prayer time where they commune with their God, church attendance as well as religious meetings. However, most of the participants enjoyed tremendous spiritual support from family, friends and religious groups that they belonged to.

In the pursuit to answer the research question three: “What are the spiritual experiences of person’s with sickle cell pain” one major theme emerged to answer this question - Spiritual experiences of person’s sickle cell pain with three subthemes: Religious beliefs and practices, Religious coping and Religious support.

4.6.1 Religious beliefs and practices

According to some of the participants they got angry with God at some point because they felt that God did not heal them of the sickle cell disease and the excruciating pain.

“Yes, sometimes I get angry with God. I’ve been praying for a long time trusting that he will heal me, why has he not?” (Moana).

“Often times I get incensed and begin to ask questions in my anguish; whether God hears my prayer at all” (Sisi).

Some of the participants also shared the belief that God is the sustainer of life and one just has to believe that He can heal him of his afflictions through prayer.

“Basically that’s all and you just have to believe that it’s God who will sustain you. And as I said, I believe in divine healing and if it’s in the will of God that you get healing, then of course it’s something you can consider and even pray for it. God himself says that I’ll answer your prayer” (Johnson).
Some of the participants were of the view that, one just ought to look up to God because He does everything in His own time.

“God says he does everything in His own time. So, I always look up to God; that in his own time, he will make all things beautiful. So sometimes I say, “Oh God why have you not been listening to me” (Sisi).

Some of the participants also indicated how the pain has hindered their involvement in certain religious practices such as Bible studies and prayer sessions.

“I can’t pray, neither can I study the Bible especially when I am in pain” (Moana).

Three of the participants indicated how the pain did not permit them to embark on fasting and all-night prayer sessions.

“Like all the religious practices. We usually fast but I do not do it because I know myself as I said” (Chris).

“I do not attend ‘all-night’ simply for the fear of getting crisis”. (Obuabasa).

“Attending all-nights and embarking on a fast are impossible for me”. (Dromo)

Some of the participant asserted that the sickle cell pain did not allow them to concentrate during prayer sessions.

“I don’t get too much concentration when I am in pain and I’m praying” (Oboshie).

“When I’m in pain, I can’t pray. I try to pray but the pain lingers and I can’t concentrate in prayer” (Djata).

However some of the participants shared that they prayed to God and had since not experienced any crisis for at least two (2) years.

“I prayed a prayer of faith to the Lord and I got my healing. I have not experienced any crisis for the past two years. Previously, I used to attend hospital very often and then one day, I said to Him: every time I go to the hospital, I waste money there; money which I could have used to help in the house of the Lord” (Edna).
“I prayed and cried unto the Lord and since then I have not gone on admission with pain” (Dromo).

### 4.6.2 Religious coping

This subtheme sought to find out how participants went through the painful episodes with the help of their religious orientation. Some of them were able to manage this pain through prayer and hoped that God is more than capable to either heal them or reduce the painful experience.

Some of the participants encouraged themselves through the Word of God.

“I encourage myself with the word of God and one of my best quotations is: “with God all things are possible” (Moana).

Some of the participants also said they turned to the cross of Christ and the blood of Jesus.

“Normally with me, all I think about is the cross, Him being there and His blood being shed for me. I just close my eyes, focus and get that picture on my mind. So as I think about it, some of the words He said on the cross comes to mind, I meditate on them and it makes me forget about the pain” (Djata).

According to some of the participants, prayer is able to stop the sickle cell pain.

“Prayer works in reducing the pain or stopping the pain for me” (Tenkorang).

Nonetheless some also took delight in the midst of all the painful experience with the view that there were those who had better care than they got, but are not alive.

“You know, but well who knows better than God. I thank God because there are a lot of people who had better care than I had but they are not there. So what will you say to that?” (Chris).

### 4.6.3 Religious support

According to some of the participants, their Church members visited and offered support in a form of prayer.
“Oh yes! I had a lot of prayer support, sometimes they come home. When I was sick and I was not able to go to church, my Sunday school members came home, encouraged me and prayed with me. I don’t like that but I can’t do much about it” (Moana).

Some of the participants indicated how they were supported through prayer by their mothers, entire family and friends especially when they went on admission.

“Well, my mum, the entire family and friends pray for me, especially most of my friends in Joyful Way Incorporated. But it’s not every episode that they come praying. It’s only when I was admitted at the hospital” (Johnson).

Some of the participants also indicated how people interceded for them in prayer.

“It is helpful to pray together. The word of God says that when two or three agree on something and pray about, it is effective” (Moana).

“Yes, if even someone prays for me, it’s able to help” (Twumwaa).

In the search to answer the research question four: “What are the management experiences of sickle cell pain” one major theme emerged to answer this question – pain management experiences of sickle cell pain with three subthemes.

4.7 Pain management Experiences

These were experiences shared by participants including measures that were put in place to ensure that the sufferings of the individuals in terms of pain were mitigated. It consisted of pharmacological and non-pharmacological measures. Home and hospital management as well as diversional therapeutic measures were the management approaches. Previous treatment experiences of participants were examined. Experiences with respect to access to healthcare, specialist care and the burden of healthcare cost were shared.
The following subthemes emerged: home management, hospital management, diversional therapies, access to healthcare, personnel attitude and previous treatment experiences.

4.7.1 Pharmacological

Conventional medications were the major agents that helped in managing the pain associated with sickle cell disease. It ranged from analgesics of different formulations to antibiotics and infusions. Topical applications of different formulations were applied to painful joints and other parts of the body for pain relief.

4.7.2 Home management

Home management strategies were measures that participants adopted in their various homes in addressing the pain experience before they went to hospital. All of the participants used their prescribed medications. It also involved the use of topical application to control the pain they experienced. Most of the participants used prescribed opioids, non-steroidal anti-inflammatory drugs and haematenics.

“Presently, I’m on paracetamol and morphine. I take 20mg of morphine then 500 paracetamol. The folic acid is daily, so I normally take it in the evening.” (Twumwaa).

Let me cut is short for you, tramadol, paracetamol and folic acid largely but if it’s not able to deal with the pain, I go to the hospital. Sometimes you need to take it before you go to the hospital; that’s what I’m saying” (Obuabasa).

Some of the participants indicated, taking daily folic acid and copious amount of water or Oral Rehydration salt (ORS) helped to relieve the pain.

“So when I take the folic with the ORS and I rest, before the next day, I am okay” (Sisi).

“All that is required of me is to take my folic acid on daily basis and drink a lot of water to hydrate myself and I am fine” (Mahami).
Sickle cell Pain Experience

“I start with my oral analgesics; rehydrate myself by drinking a lot of water and keep warm” (Obuabasa).

According to some of the participants, intake of tramadol and covering themselves with blanket led to better pain relief.

“Sometimes I take tramadol and cover myself with a blanket. I sweat profusely and by morning, I am okay” (Tweneboah).

According to some of the participants, they combined the folic acid with food supplements which contained anti-inflammatory properties and were capable of boosting their immunity and they benefited from them.

“I take folic acid, that’s the everyday thing, I take other supplements also. I have being on them for the past year and it’s very good. It has helped me personally. It’s anti-inflammatory; it prevents infection and boosts the immune system” (Johnson).

“There is this food supplement that my sister sent to me from Germany, when I take it with folic acid, it works for me” (Tweneboah).

Some of the participants indicated that they made sure they had in their possession all their prescribed medication at all times. This was to ensure that they were ready to treat the pain if it did surface.

“At home, I always keep some of the drugs. Not only at home, I keep some in my bag. Sometimes, I take some along when I am going to church so that I take it first in case I feel any pain even before I seek further treatment” (Moana).

“I have drugs wherever I find myself. People ask me and I tell them to mind their business” (Tweneboah).

4.7.3 Topical application

This involved the application of topical formulations such as deep heat, omega oil, breeze, robb and other pain patches to the skin or joints to reduce the pain.

Most of the participants attested to the use of substances like deep heat, robb and deep freeze.
Sickle cell Pain Experience

“Oh yes, you name it and I’ve got them: Deep heat, Robb and Deep freeze. Deep freeze has proven to be effective” (Wudjiti).

“Chocho cream, omega oil, Chinese robb. I always use warm water every morning after which I apply any of the afore mentioned stuff” (Twumwaa).

There were those who applied non-steroidal anti-inflammatory gel like diclofenac gel to relieve the pain.

“Diclofenac gel and Deep Heat: that’s what I apply to my painful joints. It is very useful” (Tenkorang).

Most of the participants indicated that they apply warm water to the painful parts before they use the topical applicant.

“Yea, I mean they used warm water. Then, I smeared “deep heat” on my joints. I remember when they applied the warm water, it relieved the pain, because of that, I do it quite often” (Johnson).

4.7.4 Hospital Management

These were types of management available to the participants at the emergency departments and the hospital as a whole.

Some of the participants received blood transfusion as a result of anaemia.

“I remember I had blood transfusion when I went to the hospital. I wasn’t eating too well so obviously the issue of anaemia came up” (Johnson).

“I was transfused at medical one in Korle-Bu Teaching Hospital when my haemoglobin level was found to be low in one of my numerous crises” (Tweneboah).

Some of the participants indicated how they were given injection diclofenac and/or morphine and some infusions which deadened the pains.

“I went to the hospital and was given injection diclofenac and infusions and the pain stopped” (Tweneboah).
Sickle cell Pain Experience

“I was given morphine and infusion when I had one major crisis of my life time in London 10 years ago and they treated the pain extremely well because they used a device called patient controlled analgesia” (Wudjiti).

Some of the participants also indicated how their pains were managed at the hospital with pethidine, blood transfusion, intravenous fluids and oxygen.

“I went to the hospital and was given pethidine, intravenous fluids and blood transfusion couple of times Mostly when I am in crisis, I am put on oxygen because my oxygen saturation gets low” (Djata).

4.7.5 Non-pharmacological Strategy

This involved the use of diversionary therapies such as music, watching of television, massage, exercise and ignoring the pain. According to some of the participants, listening to music has the tendency to lessen the painful experience.

“Of course, music has proven to work for me when I am in pain” (Obuabasa).

Some also indicated how gospel music also soothed their pain.

“But I normally listen to gospel music when I am in pain and is able to soothe my pain” (Delali).

According to some of the participants watching television, a favorite movie helped them not to focus and concentrate on the pain.

“It could be watching T.V, watching one of my series, anything that will distract me and make me not focus on the pain helps me to deal with the pain. It could be anything; so yes! on the pain help” (Obuabasa).

“When I watch television it gets my mind off the pain, because when you think of the pain it’s hurtful. But when your mind is with something else you don’t think about the pain” (Tenkorang).

Some of the participants indicated that exercise helped to reduce their pain.

“I mean when you have regular exercise, it helps with blood flow, circulation and it reduces the pain” (Johnson).
According to some of the participants they ignored the existence of the sickle cell pain and that worked for them.

“Sometimes I ignore that the pain exists. I say to the pain, “you came by yourself so you have to go by yourself”. This morning for instance when I woke up, it nearly started but I ignored it, I don’t even know when it went because I didn’t take any medicine. I even forgot that something started in the morning” (Moana).

However some of the participant indicated that one strategy that has worked for them over the years was that they have accepted the condition has no known cure and therefore ought to support themselves in order to live a decent life.

“I have come to a stage where I have no option than to accept the condition and the challenges it presents coupled with the fact that it has no known cure in other to live a normal life” (Mahami).

4.7.6 Access to healthcare

All the participants expressed difficulty in accessing healthcare and specialist services when they were in crises, with the intractable pain.

Some shared, fewer designated centers for sickle cell pain management.

“My brother we have only one sickle cell clinic in the whole of Accra so we are really suffering” (Odei).

“I cannot just understand why the Government cannot build us sickle cell hospital looking at the challenges we go through on daily basis, it such a shame” (Twumwaa).

Some of the participants indicated the high cost of treatment associated with the frequent emergency department visits with the pain episode.

“I spend quite a lot on healthcare; for someone who is practically on medication all year round. I do labs; every time I go to do labs with “Lancet” and the other labs all that it costs money. Today one of the medications - sodium bicarbonate that they wrote for me is not covered by health insurance. A month’s dose is about 185cedis so obviously I have to pay for it” (Wudjiti).
“I mean, it cost so much because it puts a lot of stress on my finances. Sometimes I’ve not budgeted for such expenditure. I use this NHIS, yet it doesn’t cover most of the medications” (Moana).

Some of the participants also lamented how lack of specialist services affects their care.

“A health assistant told me at the out-patient department that they did not have a specialist but I ignored her. Then he said, “sorry you cannot be seen here, you have to go to Korle-bu”. I said, “at least you have to give me first aid. So, they brought me out, checked me, gave me some injections and then referred me to the emergency department in Korle-Bu. I would have sued the doctor if he had left me unattended to because I was in severe pain” (Dromo).

“I was not seen at lapaz community clinic after I had been rushed there. Immediately I got there, they referred me to Korle-bu Teaching Hospital simply because they did not have somebody who could see me yet I saw a doctor there” (Moana).

4.7.7 Personnel Attitude

The participants had a wide range of experience from good to worse with some health workers. According to some of the participants, they were practically neglected when in pain.

“They wouldn’t mind you irrespective of how loud you shout and complain of pain. The treatment I received at the emergency department of 37 Military Hospital was not good at all” (Moana).

“When you are in pain, you are neglected. The nurses will tell you they have given you the medicine so it has duration. Until that time, you cannot do anything. So you’ll be lying down in pain and sometimes even when it is time to give the next medication, they won’t come” (Djata).

According to some of the participants, they felt neglected due to the fact that their concerns were not addressed as though they were not human.

“Sometimes when you take in a special complaint like cardiac pain to them, I don’t think the investigation is as thorough as it would be if a normal person had spoken to the same doctor. There are those who might be of the view that they are managing you the best way they can, you are not going to be around for too long anyway” (Wudjiti).
“When we got to Kaneshie Polyclinic the doctor said he’s not going to see me and that I should go to Korle-Bu. I said, “Doctor, do you know me?” He said, “Who are you? and I said, “I am a sickler, so you have to attend to me even if it is first aid” (Djata).

Some of the participants indicated some of the doctors had some difficulty and were not comfortable in prescribing some drugs they thought was effective.

“Oh my brother, some of the doctors appear as if they were afraid in prescribing some of the drugs like pethidine and morphine which to me were quite effective” (Wudjiti).

“Sometimes they under-dose us, when you talk about it, they shout and ask why you didn’t treat yourself. I was once scolded by a young doctor. But I told him my piece of mind” (Djata).

4.8 Summary

The above written findings were based on data generated from narrations of participants who patronized the sickle cell clinic of Clinical Genetics at Korle-bu Teaching Hospital.

The findings brought into perspective the myriad challenges they encountered with the intractable painful episodes and how comprehensively, all stakeholders can resolve to find solutions to mitigate the effect of sickle cell pain. The findings of this study will no doubt add to the existing body of knowledge and fill some of the gaps that exist in the pain experiences that sickle cell patients go through on daily basis. The conceptual framework which guided this study was the Siddall et al., (2015) model. The constructs in the framework are biological, psychological, social and spiritual within the environment of the patient. The conceptual framework fully supported all the major themes that emerged from the narratives of the participants of this study except the biological construct which supported the first major theme; Physical experiences of sickle cell pain partially. That notwithstanding, the three main components of the biological construct; nociceptive, neuropathic and neuroplastic pains impacts on the physical activity of the individual. The fifth major theme; Pain management experiences
of sickle cell, fell outside the model. The themes and the subthemes are as below in table 4.1 below.

### Table 1: Summary of Themes

<table>
<thead>
<tr>
<th>THEMES</th>
<th>SUBTHEMES</th>
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| **1. Physical experiences of sickle cell pain** | 1. Activity intolerance  
                                         | 2. General Malaise  
                                         | - Fatigue                                           |
| **2. Psychological Experiences of sickle cell pain** | Cognitive Experience  
                                         | 1. Fear of death  
                                         | 2. Worry                                           |
| **3. Social experiences of sickle cell pain** | Emotional Experience  
                                         | 1. Depression  
                                         | 2. Rejection  
                                         | 3. Stigmatization                                   |
| **Behavioral Experiences**          | 1. Family support  
                                         | 2. Friend Support  
                                         | 3. Social Isolation                                 |
| **4. Spiritual experiences of sickle cell pain** | 1. Religious coping  
                                         | 2. Religious beliefs and practices  
                                         | 3. Religious support                                |
| **5. Pain management experiences**  | Pharmacological  
                                         | 1. Home management  
                                         | Topical application                                 |
|                                     | Non-pharmacological  
                                         | 1. Diversionary therapy  
                                         | Listening to music                                  |
|                                     | Exercise  
                                         | Watching of television  
                                         | Massage  
                                         | Ignored pain  
                                         | Access to healthcare                                |
CHAPTER FIVE
DISCUSSION

5.1 Introduction

This research aimed at exploring the overall impact of sickle cell pain on the patient. It was guided by the Siddall biological, psychological, social, spiritual and environmental conceptual framework. Thematic content analysis brought out five main themes. These were physical experiences, psychological experiences, social experiences, spiritual experiences of sickle cell pain and pain management experiences. This chapter discusses the findings of the study in relation to existing literature. The main objective of this study was to explore the overall impact of sickle cell pain on the patient. The sickle cell disease which has pain as it hallmark is a lifelong condition and therefore the goal of management is to improve general supportive, symptomatic, and preventive measures as well as alleviate the stubborn pain, so that sufferers can live meaningful life in other to fulfill their expected roles in society. Furthermore, it is also aimed at reducing complications and prolonging the life of the individual through multidimensional and multimodal approaches. Activity intolerance, general malaise and fatigue were the subthemes and sub-subthemes emanated respectively from the physical experiences of sickle cell pain.

5.2 Physical Experiences of sickle cell pain

Participants encountered various challenges as far as the sickle cell pain was concerned. The pain rendered the individuals so vulnerable preventing them from functioning to their optimum. Activity intolerance was one major issue that confronted sickle cell patients in this study. The levels of pain as manifested in these individuals varied enormously and were quite detrimental and pervasive. The study revealed that
once the pain sets in, individuals were unable to do anything for themselves. Activities they could do unaided had to come to an abrupt end. Activities of daily living such as attending to personal hygiene were severely affected. This present finding is consistent with a study conducted in South Africa. The researchers found that sickle cell pain hindered the activity of daily living of participants (de Villiers et al., 2015) In a similar study in United states of America where the researchers used mixed method, it became evident that sickle cell pain interfered with activity of daily living of the participants (Alsalman et al., 2013). So based on the finding it would be appropriated if significant others and family members offer assistance to sickle cell patients when they are in crises to enable them live a meaningful life even in the presence of pain (Forrester et al., 2015) The current study revealed that participants were afraid to walk when in crises as the pain was centered in the knee. This finding was found to be in consonance with a study conducted among sickle cell African Americans in United States where it was revealed that increase kinesiophobia (fear of movement) was associated with greater painful episode (McBeth, Nicholl, Cordingley, Davies & Macfarlane, 2010; Newell & van der Laan, 2010; Pells et al., 2007). Once patients cannot walk, efforts should be made to assist them. If there is the need to move to any place at all cost, immediate caregivers should aid in the movement to whatever place they need to go. Again if it is about serving the prescribed analgesics to them, it must be served immediately to ease the pain (Riva et al., 2011)

General body malaise is a feeling of overall discomfort, illness, or not feeling well. In the case of sickle cell disease, the uneasiness is manifested by the nonspecific and unpredictable plausible evidence of pain leading to disability (Andersen et al., 2014). The overall discomfort which was as a result of pain and made the participants fatigued emerged as one of the findings under the physical experiences of sickle cell
pain. This finding is consistent with the findings made by Ameringer, Elswick and Smith (2014) and Dampier et al (2010) who found in separate research pieces that sickle cell pain leads to fatigue. Undoubtedly, fatigue renders an individual incapable in indulging in any activity as noted by World Health Organization in 2010. Fatigue has consequences on the social life of sickle cell patients preventing them from actively engaging in social obligations (Alsalman et al., 2013; Atoui et al., 2015). Beside this is the tendency to disengage the patient from activity of daily living as found by this present study where participants easily got tired as a result of chest pain. This finding is in consonance with a finding which indicated that pain depicted fatigability among individuals with sickle cell disease (Dampier et al., 2010). If patients find themselves at the emergency department or hospital, nurses should assess the need to provide oxygen to these patients (Adewoyin, 2015). The study also found how fatigability as a result of pain also prevented participants from working into the night as they would have wished hence reducing productivity and increasing the financial burden on the patient and the family as found in a similar study (Agaliotis et al., 2013). Financial burden will certainly prevent participants from assessing emergency service. They will end up at the wrong places to seek for care instead of the hospital. So assistance in a form of finance ought to be extended to this category of people. Again, an alternative health financing should be put in place for them. Strengthening the health insurance scheme to provide free emergency health service will be appropriate (Kauf et al., 2009).

5.3 Psychological Experiences of Sickle Cell Pain

Pain imposed tremendous psychosocial and behavioral challenges rendering sickle cell patients in unending vulnerability, dissipation of energy and a diminished sense of worth. Optimum psychological functioning is an integral aspect of wholeness. Any alteration is likely to affect the overall function of an individual and his
contribution to society. There were cognitive determinants of pain experience that came up in this study, all of which had varying degrees of negative effect on the participants. The cognitive experiences espoused by participants with respect to this study were; fear of death, worry and insomnia.

The serious nature of sickle cell pain and the fact that the disease has no known cure put a lot of fear in patients, coupled with the high level of mortality among sickle cell patients. In the current study, participant expressed concerns about how they harboured the fear of death especially when they were in severe painful crises, which was consistent to the findings of a study where participants harbored the fear of dying early (Anie, 2005b; Forrester et al., 2015). This fear became pronounced when they had witnessed friends and relatives dying from complications of the condition because there is no known cure insight especially for adults with sickle cell disease. Individuals with sickle cell pain should receive psychological support and appropriate counseling to dispel the notion of early death (Ilesanmi, 2013; Jenerette & Brewer, 2010).

Also, sickle cell patients accepts that, there is no known cure to their predicament coupled with the fact that the disease is lifelong with no possible cure in sight especially in the adult (Adewoyin, 2015; Coleman, 2013). Additionally, the attendant fear of death as a result of the intractable pain which compound the complexity that patients find themselves as they journey through life, make it even more demoralizing as found in Kumasi, Ghana (Dennis-Antwi et al., 2011). However, it is known that a reduction in pain episodes, prolongs survival and mitigates the benign fear of death so such support should be rendered to individual who unfortunately were born with this lifelong disease and the attendant painful episodes (Haywood Jr et al., 2014; Clayton-Jones, 2015). However, most of the participants were still troubled because the pain still posed a challenge to them in diverse ways. These notwithstanding, others were
confident in that God was and is the sustainer of life and they were not going to allow the fear of death to prevent them from pursuing their ambitions. These participants appeared to have developed a high sense of positive self-concept mostly grounded in self identity through meaning and purpose of spirituality. Participants were confronted with various worrisome tendencies. It was found that one major concern was their inability to sit for examination because of the sickle cell pain. They mostly absented themselves from school because of emergency department visits; most of which were not planned leading to absenteeism and poor academic performance. This current study’s results established consistency with a study conducted in Kingston- Jamaica where participants were found to absent themselves from school due to sickle cell pain crises. In the same study participant had to be repeated in the same form due to poor performance (Forrester et al., 2015). In a similar study participants absented themselves on an average of 12% of that year’s attendance and 35% of the participant missed a whopping one month of School (Schwartz et al., 2009). Although this study was not about students, almost all the participants indicated how the pain served as an obstacle in their academic performance; it confirms earlier findings with respect to how sickle cell pain had negative impact on school performance of sickle cell patients (Atoui et al., 2015; Day, 2006). Absenting oneself from school as a result of the sickle cell pain can halt academic progression therefore regular checkups and review time should be adhered to so that painful crises can be minimized (Ezenwosu, Emodi, Ikefuna, Chukwu & Osuorah, 2013).

Insomnia was another issue that confronted participants in this study. It was revealed that they had difficulty in falling and staying asleep despite the fact that they had the chance to do so. The problem of insomnia was mainly due to the severe pain of sickle cell crisis. Categorically speaking, they stated that they were unable to sleep while
in pain. This was consistent with most findings some of which revealed that 47% of adults with sickle cell in that study experienced insomnia while 15% of the participants in that same study had sleep impairment (Mann-Jiles, Thompson & Lester, 2015). There was significant association of pain and insomnia with its effect on productivity. A causal relationship between poor sleeping pattern and reduced work output therefore existed. In a similar study of adults with sickle cell it was found that 70% of the respondents had sleeping disturbance (Wallen et al., 2014). Patient’s length and pattern of sleep were also affected by insomnia leading to sleep fragmentation and possible fatigue (Graves & Jacob, 2014; Ilesanmi, 2013). Insomnia, as a result of sickle cell pain, leads to poor concentration and reduced productivity. The cost to a nation cannot be overemphasized hence the need to pay equal attention to insomnia sickle cell pain management to ensure that individuals remain productive in the field of work (Kessler et al., 2011).

Emotional experiences formed part of the psychological challenges that were narrated and found in this study as an outcome of pain. Derogatory statements made by individuals and the nature of the pain suffered by the participants led to depression and rejection and the resultant difficulty. In the current study participants suffered from depression as a result of disparaging and condescending comments made by people. This had profound effect on them virtually affecting their output and social interaction as well as community integration. In a study conducted in Lagos – Nigeria, it was found that participants with sickle cell disease, lived with depression which affected their social performance with respect to employment, education and parenthood (Ola, Yates & Dyson, 2016). Depressed individuals tend to have reduced locust of control as a result of diminished self efficacy. Locust of control in sickle cell patients who were depressed were enhanced by autonomy which led to energized mood (Gibson et al., 2013). Further, early diagnosis of signs of depression and treatment also enhances locust of control. The
study also found that pain led to depression which resulted in some of the patients going on admission and affecting the quality of life of the individuals (Andersen et al., 2014; Ilesanmi, 2013). This is consistent with a study of similar finding (Wallen et al., 2014). Depressed patients tend to experience inconsistent sleeping patterns, they tend to wake up tired and it affects their output at work which could negatively impact employer-employee relationship. Further, Sleep disturbances lead to decline in employee out and productivity with attendant high cost to the employer (Rosekind & Lerner, 2010). In a systematic review of cognitive and behavioral factors, pain was found to correlate with depression as found in the present study (Urquhart et al., 2015).

Further, deaths involving sickle cell patients are trivialized as though SCD patients are born to die. Participants in this study bemoaned how death involving sickle cell patients were seen as normal because after all, they were not here to live long and accomplish anything anyway. This behaviour by society tends to grief sickle cell patients. As found in current study which was consistent with a study where participants failed to pay attention to their relatives and significant others in sickle cell crises simply because they were waiting for their death since they were not supposed to live beyond age 25 (Dennis-Antwi et al., 2011). If depression is not addressed it could lead to suicidal ideations which can predispose the participant to committing suicide. Family members should create an atmosphere of love so that sickle cell patients can freely share their frustration brought about by the pain. This will lead to effective coping as they freely pour out their concerns and having the assurance somebody out there listens to them and share their problem (Minniti, Lu & Groninger, 2013).

Participants felt rejected in the current study. This went in tandem with Alsalman’s finding that sickle cell pain inhibited social interaction and reduced involvement in the affairs of the community (Alsalman et al., 2013). People avoided the
company of sickle cell patient as soon as they got to know their status and the severe pain episodes. Participants were denied of delegated responsibilities by their immediate supervisors because of rejection and this worsened the pain experience of these patients. Conversely, participants who felt accepted had a renewed strength despite the presence of pain. Some of which had remarkable improvement with respect to the sickle cell pain crises (Caird et al., 2011; Cederberg, Cernvall, Dahl, von Essen & Ljungman, 2016; Vowles, Witkiewitz, Sowden & Ashworth, 2014). Rejection is a painful phenomenon and therefore society must take steps to embrace all minority groups with special needs in order for them to contribute meaningfully to the socio-economic transformation of society (Fiester, 2012; Minniti et al., 2013).

Participants mentioned how they suffered dehumanizing experience where by virtue of their condition, people called them all sorts of names some of which were quite demoralizing. This is consistent with findings where doctors and healthcare providers treated sickle cell patients who called at the emergency department with disdain by making cursory statements that amounted to discrimination (Jenerette & Brewer, 2010). The pain experience of these participants led to behavioural changes such as hospital attendance and emergency department visit (Adegbola et al., 2012; Jenerette & Brewer, 2010; Jenerette, Brewer, Edwards et al., 2014) Additionally, young adults even preferred to stay at home to manage their pain rather than to avail themselves to be ridiculed and stigmatized by healthcare providers. This again was in agreement with Jenerette et al., (2013) study where participants in that study stayed at home to avoid stigmatization (Jenerette, Brewer & Ataga, 2013) confirming the findings where attitude of nurses contributed to stigmatization which affected patient’s care seeking behaviour. Sickle cell pain cues are expected to be picked by nurses which will enhance effective pain management, that might lead to desired health outcomes (Jenerette, Pierre-Louis,
Sickle cell patients suffered stigmatization in almost all settings. In the current study patient whose statuses were known to their colleagues both at school and at work were mocked. This worsened their pain experience as found in a similar study (Wesley, Zhao, Carroll & Porter, 2016). This could explain why sickle cell patients in pain crises resort to other sources for help rather than proceeding to emergency departments of hospitals. Negative attitude of some nurses and other healthcare workers were evident in the findings of the current study where nurses neglected complaints of patients in pain. Patient concerns and suggestions must count if they are to cooperate with healthcare providers which would lead to mutual respect. There are instances that patients were addressed as biological units instead as unique individuals (Haywood, 2013a).

Participants did not feel trusted by their healthcare providers with respect to pain management. This was evident in the responses and attention elicited from doctors and nurses by patients. Some of the participants indicated that their views and concerns did not matter in their own management, this they considered disrespectful, a treatment which had the tendency to undermine patient-nurse or patient-doctor relationship (Brousseau, Owens, et al., 2010; Haywood, 2013a; Haywood et al., 2011).

Findings in the current study indicated how people underestimated the capability of some of the participants to marry and lived a normal life as couple. That notwithstanding, family members and significant others were cautious so that people could make informed reproductive choices. This led to some participants losing their prospective suitors all because of the stigma that came with the disease and the painful episodes. This is consistent with findings in a study where individuals were advised to get to know their status to enhance prudence in reproductive decisions (Anglin, 2015; Ezechukwu, 2014). Sickle cell patients need to be empowered so as to help them make
informed reproductive choices. Once they become knowledgeable they will prospect for people with genotypes that will not create challenges for them if they decided to consummate the relationship with their partners (Wilkie et al., 2013).

5.4 Social Experiences of Sickle Cell Pain

There are social determinants of sickle cell pain and some of these factors may mitigate the painful experience or worsen this life-long predicament that confronts individuals with sickle cell disease. Inevitably, anybody healthy or unwell requires a certain level of support in every context in life. The family offered immense support in diverse ways to ensure that the suffering of a member was alleviated or lessened. Family support was conspicuous in the findings of the current study. The study found significant others of participants abandoned their work in order to attend to them. Such physical support was essential to enable the individual cope with the intractable pain. The pain was such that the sufferers virtually had to depend on people. In a similar study, it was found that family support helped sufferers of pain (Caird et al., 2011). Unwavering family support from parents was the surest way to mitigate the effect and the burden of pain as found in the study. Participants had assurance in the fact that they were not alone in fighting the burden of pain. Good quality family support predicted higher psychological and emotional wellbeing for patients with sickle cell and chronic pain which agreed with the findings of the study: “Psychosocial functioning in adults with beta-thalassaemia major: Evidence for resilience” (Zani & Prati, 2015). This type of support enable patients to stay at work which prevents unemployment (McCluskey, de Vries, Reneman, Brooks & Brouwer, 2015).

Friends offered remarkable support to participants in this study, some of which came in a form of financial assistance. This ostensibly enabled the participants to attend
to hospital bills because of frequent emergency department visits and hospitalization. This agrees with a similar finding where friends support was integral in assisting sickle cell patients to handle the pain experience with little difficulty (Forrester et al., 2015). Supportive social environment help the sickle cell patient in diverse ways to develop the capacity and the will to fight the pain even in the face of worse complications that come with the disease burden (Tsaras, Owusu-Ansah, Boateng & Amoateng-Adjepong, 2009).

Variously, participants suffered isolation some of which were quite subtle, others very noticeable. Individuals in this study suffered this fate because of rejection by friends and colleagues. Also the unpredictable nature of the painful experience made matters worse because, one did not know when the next bout of painful crisis was going to come. Sickle cell pain led to isolation tendencies in majority of participants in this present study which agrees with the finding of Alsalman et al. (2013) as well as Agaliotis et al. (2013). Where some participants in both studies indicated that they felt socially excluded because of the pain. (Agaliotis et al., 2013; Alsalman et al., 2013; Minniti et al., 2013). Anie et al., (2010) found how sickle cell patients could not cope adequately as a result of lowered self esteem which made some of the participant’s lived secluded lives. The study is in harmony with the findings in the present study, where participants felt inadequate because of their stature. Hence were unable to mingle with their colleagues for fear of being mocked and looked down upon, further compounding effort to socialize (Anie, Feyijimi, Egunjobi & Akinyanju., 2010; Atoui et al., 2015). It was also revealed that participants’ encountered feeling of being ignored consequently leading to mistrust and isolation. This was consistent in the finding of Riva et al., (2011). The mistrust that was likely to be encountered by patients in the hands of healthcare workers in their quest to seek help for their pain was a reason for the feeling of isolation. This explains why greater effort should be put in place by nurses and
doctors to desist from making utterance that has the propensity to further widen the communication gap between healthcare workers and patients (Minniti et al., 2013).

Good interpersonal relationship is an important attribute that is expected to be exhibited by all right thinking beings. The study revealed that pain led to frustration which then resulted in some of the participant becoming quick tempered as though that was their nature. The finding seems to concur with another study where pain led to conflict in social relations with significant others (Andersen et al., 2014). Excellent relationship between health workers and health seekers could promote healthy dialogue and create opportunity for patients to freely share secrets and information that might go to help in their management. Thus, active and tactical listening to patients unique individual concerns will lead to direct and accurate interventions (Adegbola et al., 2012).

Participants in this study had difficulty in securing employment and staying employed due to the painful episodes which comes uninformed. Some were redeployed from their original place of work against their will simply because of dislike for and discrimination against people with SCD. Pain and reduced productivity were inextricably linked. In this study, it was found that pain affected output of work. This is in tandem with a longitudinal study which found that pain led to reduced productivity as a result of “presenteeism” (where individuals though present at work were unable to work to their optimum simply because of pain) instead of absenteeism (Agaliotis et al., 2013). In a similar study, pain interfered with productivity (Adegbola et al., 2012; Alsalman et al., 2013; Chen, Cole & Kato, 2004). Participants indicated how they suffered chronic unemployment. This probably accounted for their lack of interest in successful pursuits of life. This validates a similar study where unemployed sickle cell patients were less satisfied with life and the opportunities therein (Thomas & Lipps,
Little or no satisfaction in life could explain the depressive thoughts that are experienced by sickle cell patients sometimes resulting in suicidal ideations.

### 5.5 Spiritual experiences of sickle cell pain

Several data support the view that patients now find it expedient for healthcare providers to attend to their spiritual needs in addition to the physical aspect of life. According to Taylor et al. (2013), the spiritual component of pain cannot be left out if pain is to be managed in a more holistic and comprehensive manner with the widely accepted view that man is made up of mind, body and spirit (Dedeli & Kaptan, 2013; Holt & McClure, 2006; Taylor et al., 2013). Majority of the participants turned to God for answers to their pain burden. This enabled them to live meaningful life and to find meaning in their existence on earth. Religious beliefs and practices were hampered in the study. Some of the participants expressed anger with their maker because they felt God did not answer their prayers with respect to sickle cell pain. Anger is seen as ineffective coping strategy and therefore individuals who tend to resort to anger as a way of dealing with pain experience, tend to develop reduced capacity and the needed resilience to survive it leading to reduced self efficacy. Participants in this study who employed anger experienced higher number of painful episodes than the rest. This confirmed Adegbola’s (2012) study findings in which participants with lowered self-efficacy had reduced quality of life due to their failure to develop resilience to endure the painful experience. According to Edwards et al. (2014) self-efficacy was inversely related to altered physical symptoms in that study and went on to suggest a positive correlation between self-efficacy and quality of life of patients (Edward et al., 2014). It is therefore incumbent on health workers to help sickle cell patients to develop the needed confidence in the health system and their treatment regime through effective psychological counseling and positive self confession (Anie & Green, 2015).
comfort in faith helped participants to survive the vagaries of sickle cell pain. In this study it was found that participants saw God as the sustainer of life and therefore could heal them of the painful experiences through prayer. In a similar study participants who had faith in God through prayer, obtained comfort. (Cotton et al., 2009; Lucchetti et al., 2011). Several studies have given vivid account of individuals who engaged in religious and spiritual practice and also saw themselves as doing better and having energized mood, increased emotional wellbeing and higher adaptation to pain as compared to those who did not see themselves and practiced as such (Lucchetti, 2014; Rippentrop et al., 2005).

Religious coping assisted participants in the study to withstand the pain of sickle cell disease. It was found out that majority of them were Christians and they stood on the word of God and relied on Him for answers as a way to cope with the pain. It was found in a study conducted in Pakistan where participants in that study relied on God (Allah) for comfort and cure (Ghasemi & Rezaee Najafabadi, 2012). The study also reported how participants depended on prayer to mitigate the sickle cell pain. This confirms a reported finding where individuals experiencing chronic pain relied on personal prayers to overcome the pain (Jors et al., 2015). This explains why patients in this study were troubled anytime they were in crises since that affected their prayer life. Some of them even reported how pain did not allow them to concentrate fully during prayer sessions and other religious activities. According to some of the participants, they turned to the cross of Christ and the blood of Jesus. Christians believe that Jesus Christ died on the cross to save them from all afflictions and since all the participants were Christians; they appeared to share this faith and identify with it. They drew meaning from it and that strengthened their resolve to battle with the painful experience. Meaning making, identity and knowing your purpose in life within the context of turning to a
superior transcendence through religion and spirituality, to cope with chronic pain and its management are inextricably associated since it contribute in building resilience (Caird et al., 2011; Clayton-Jones, 2015; Dedeli & Kaptan, 2013).

Religious/spiritual support systems are extremely important in helping sickle cell patients to cope effectively. Participants in this study found prayer as one such unique area of support. Prayer offers an individual the exclusive platform to commune with God in order to present tangible concerns that cannot be addressed in the physical realm (Ryan, 2016). Participants had prayer offered to them by Church members and significant others which gave them hope. This finding was reported in several studies (Forrester et al., 2015; Glover-Graf, 2007; Majumdar, Thompson, Ahmad, Gordon, & Addison, 2013). Prayer could offer a lot of assurance that a superior being is in a position to solve problems out of reach of medical science. People must respect the belief and religious orientation of patients and be given the freedom to exercise their choice of religious orientation. Under no circumstance must patients be given the slightest impression that they are being condescended upon by virtue of their religious persuasion.

5.6 Pain management Experiences

Participants reported lack of access to hospital to lack of access to specialist care. Participants also felt discriminated against. Neglecting sickle cell patients and their concerns were some of the challenges that participants encountered.

Pharmacological pain management was the major pain management experience participants shared. Pain is the major concern of patients with sickle cell disease (Ballas, 2007b). The acceptable gold standard of sickle cell pain management is pharmacological and by that extension, the judicious use of opioids and non-steroidal anti-inflammatory
drugs (Adewoyin, 2015; Campos et al., 2014). However, other non-pharmacological measures such as physical therapy and psychological measures have proven to be effective (Anie & Green, 2015). The complex nature of sickle cell pain requires multimodal and multidimensional pain management strategies to ensure that patients are properly taken care of (Brandow et al., 2011).

Home management of pain was one such strategy adopted by participants in this study. Paracetamol and morphine patches were used at home. This was reported in a study where paracetamol was used to minimize hurtful feelings of patients (DeWall et al., 2010; Riva et al., 2011). The home environment offers excellent therapeutic environment so most patients always prefer to be with the family whilst their pain concerns are being addressed. Fear of unknown of hospitalization and needle pricks may account for the reason why adolescents and young adults prefer to stay at home even if they were in crises instead of going to the hospital. Topical applicants were used by participants in this study to manage their pain and it was effective. This study discovered that people used physical therapy such as application of warm water to painful joints and parts of the body. Later topical applicants like robb, deep heat and deep freeze were applied; this finding is consistent with the application of physical therapy as reported by Ballas, (2007). Physical therapy was reported to have relieved sickle cell pain (Ballas, 2007b). The unpredictable nature of sickle cell pain and the desire for people to tag sickle cell patients as drug seeking and difficult, might explain why sickle cell patients would rather use physical therapy as first line pain management measure in this study instead of drug use. On the other hand, high cost of treatment of sickle cell pain and frequent hospitalization might also account for the choice of physical therapy since it is less costly (Ballas, 2009).
Hospital Management formed part of the pain management experiences. The unpredictable and throbbing nature of sickle cell pain and the complexities involved in the management of acute vaso-occlusive crisis and the complications of sickle cell disease makes it expedient to be managed in a hospital. In the current study, it was found that participants received blood transfusion to correct anaemia. This was also reported in the following studies (Adewoyin, 2015; Brandow et al., 2011; Howard et al., 2013; Inati, 2009). Sickle cell patients have close to acceptable physiological range of haemoglobin and therefore any alteration imposes severe physiological derangement which affects the normal functioning of body cells (Staci et al., 2015). The study found that most of patients who reported to the emergency department with vaso-occlusive crises were given infusions mostly crystalloids in addition to opioids such as pethidine, morphine and tramadol and non-steroidal anti-inflammatory drugs like diclofenac injection. This finding is consistent with Gregory, (2012) study who intimated that the standard treatment for sickle cell pain management was hydration, non-steroidal anti-inflammatory and opioids (Gregory, 2012). This implies that hydration might offer an excellent medium for blood cells to flow freely and this could help to reduce haematocrit levels of the circulating blood volume. However opioids are preferred for acute as well as breakthrough pains despite the concerns of addiction which leads to under dosing by healthcare providers.

Non-pharmacological pain management strategies mitigated the pain experience of sickle cell patients. They are measures which served to divert the attention of the patient from the hurtful feeling of the pain episodes which includes: Listening to music, exercise, massage and ignoring the painful experience even if it was present. The study found that music of choice reduced the perception and the pain experience of participants. Similar findings were reported in many of such studies in different parts of
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the world (Bernatzky, 2011; Jafari, Zeydi, Khani, Esmaeili & Soleimani, 2012; Pothoulaki, 2008; Roy, 2008; Tanguay, 2008; Zhao, 2009). This means that music could create an atmosphere of serenity and a calming effect for pain (Thompson & Eriator, 2014; Williams & Tanabe, 2016). Music remains a non-invasive therapy and could have positive correlation with pain; its usage should be further explored to the benefit of humankind because of the transcultural effect. Watching favorite movie or a soap opera on television offers unique advantage and unmatched experience to individuals afflicted with pain and discomfort. Evidently participants watched favorite movies and that helped them to avoid concentrating on the myriad of challenges notable amongst them, was pain which faced participants in this study. Same account was expressly given in other studies (Ali, 2014; Forrester et al., 2015) Stressful situations could exacerbate pain and therefore watching of a movie might reduce stress hence contributing to pain reduction and enhancing the psychological wellbeing of the individual. In this study, participants indicated that exercise helped them to relax which consequently led to a reduction in pain. This was reported as a finding in other studies in which they revealed that guided relaxation reduced pain (Ezenwa et al., 2016; Majumdar et al., 2013). Exercise free joints and body parts preventing muscle aches through muscle relaxation; this means that patients should be encouraged to embark on exercise. This could probably help them to exercise their limbs and other body parts Massage relaxes smooth muscles promoting a feeling of peace within the body. This study found massage as a useful tool in reducing sickle cell pain. This was also reported in Majumda et al., (2013) where 35% of the participants in that study used massage to reduce pain and a similar study also reported same (Adegbola et al., 2012; Netchanok, Wendy, Marie & Siobhan, 2012). Massage could help to reduce frigidity in patients with sickle cell pain and promote good health and a sense of well-being. Therapeutic massage can
be encouraged in sickle cell patients. It was also found that participants in the study also adopted the concept of ignoring the presence of pain in their life as though the pain did not exist. This was done through acceptance of the pain experience but separated them from the pain, which is regarded as positive coping strategy. This was reported in the works of others (Cederberg et al., 2016; Vowles et al., 2014). Ignoring sickle cell pain might be difficult but it is possible that a strong willed person might benefit from such suppressive tendency.

Accesses to health, specialist care and designated centers for sickle cell pain management were major concerns for participants in this study. Cost of treatment and hospitalization was also a serious border to most of the participants because of the weakened ability of the health insurance scheme to pay for the cost of treatment. Participants indicated how unavailability of sickle cell designated centre to manage sickle cell pain affected them. This is consistent in the findings of a study conducted in Nigeria and other parts of the world (Adewoyin, 2015; Kanter & Kruse-Jarres, 2013). This might have arisen as a result of fewer hospitals and designated clinics. Poor road network might also discourage patients from accessing the few hospitals far from their communities. There are fewer hospitals set aside and staffed with the needed skilled personnel to manage sickle cell pain. Poverty will account for this which may lead to increased mortality especially in adults sickle cell patients as found by (Lanzkron et al., 2013). The study also found that cost of procuring treatment was out of reach of most of the participant in this study. This was reported by Dennis-Antwi et al., (2011) in their study in Kumasi, Ghana. This present study and that of Dennis-Antwi et al’s., (2011) work, were both conducted in two different Metropolises in Ghana with similar findings depicts that these metropolises may share similar characteristics of lower socio-economic status of the participants.
Attitude of healthcare providers have varying consequences on health outcomes of sickle cell patients. A therapeutic environment is required from care givers as participants’ battle with their pain experience. The study found that patients were neglected, disrespected and their inputs and concerns were not factored in their management. This was consistent with the findings of similar studies (Haywood, 2013a; Haywood et al., 2011; Haywood Jr et al., 2014). Sickle cell patients were considered drug seekers irrespective of the concerns they might. This abusive stance of care givers is equally upsetting to care seekers. These negative attitudes have the tendency to worsen the pain experience of sickle cell patients and therefore it behooves health workers to develop a receptive attitude. Doctors and prescribers find it somewhat difficult to prescribe some medications that sickle cell patient find efficacious. This is probably due to lack of prescribing protocols and adequate knowledge on the part of prescribers as found in these studies (Adewoyin, 2015; Williams-Gray & Senreich, 2015). There is great deal of mistrust that exists between sickle cell patients and healthcare providers. This can be traced to the fact that suggestions and complaints of patients are not critically analyzed before the commencement of treatment simply because some patients are labeled as difficult. This may be due to legitimate concerns that are shared by patients in pain (Adegbola et al., 2012; Fiester, 2012; Lattimer et al., 2010) These were also found in the present study where doctors found it difficult to prescribe adequate analgesia to relieve the pain of participants in this study. This led to under dosing and oligoanalgesia hence poor pain relief. Poor pain management could lead to mistrust and frustration on the part of patients and therefore every effort should be made to resolve these major concerns of health seekers (Walker, 2013; Wilson & Nelson, 2015).
5.7 Summary

Sickle cell pain is the insignia of sickle cell disease and therefore researching into the overall impact of the pain experience was the heartbeat of this study. The discussion centered on the findings that emerged based on the themes and the subthemes. In some instances, sub-subthemes also generated some findings as well. Physical Experiences of sickle cell pain was the first major theme emerged from this study. The theme anchored on two subthemes and a sub-subtheme. These were; Activity intolerance and General malaise and the sub-sub theme fatigue. Several findings surfaced as per the narrations of participants in this study. All the participants indicated how they were not able to do any physical activity especially when they were in pain. Further, it was reported that, chest and knee pains easily led to fatigability. Most participants in this study had to be assisted in their personal hygiene by significant others when the unpredictable vacillating pain was present.

Furthermore, Sickle cell pain imposed myriad of psychological challenges on the patient. There were cognitive, behavioural and emotional consequences. Fear of death, worry and insomnia were the cognitive experiences that were shared by the participants. Further, depression and rejection constituted the emotional experiences whiles stigmatization was isolated as behavioural test that confronted the participants in this study. Participants were faced with the fear of dying after a certain age which was purely informed by ignorance of the disease process. Disdainful statements made by some individuals led to rejection and depressive thoughts.

Human beings are social beings and therefore anything that has the propensity to undermine effective social interaction and cohesion is certainly an anathema to humanity. Pain is one such thing. In this study, participants were confronted with
difficulties as they sort to live meaningful lives with sickle cell pain episodes. The subthemes that supported the main theme: Social experiences of sickle cell pain were family support, friends support, social isolation, interpersonal relationship and employment (unemployment and redeployment).

Holistic pain management cannot be achieved without critically providing the spiritual needs of clients since man is made up of body, mind and spirit. In this study the spiritual component of care was inculcated in ensuring that participants coped effectively by discovering and identifying themselves with a superior transcendence called God. The following subthemes supported the major theme; spiritual experiences of sickle cell pain; Religious coping, religious beliefs and practices and religious support.

Finally, sickle cell pain required multimodal and multidimensional approach to ensure that the painful experiences are minimized. Management experiences ranged from pharmacological, non-pharmacological in a form of diversion therapy. Challenges with respect to access to healthcare with associated cost and availability of specialist care were looked at. Lastly attitude of care givers were also examined. Participants gave vivid account of the intricacies in procuring healthcare.
CHAPTER SIX

This chapter presents the summary of the entire study. It also describes and share light on implications of nursing education, policy and avenues of future research. Limitations of the study, recommendations and finally the conclusion of this study will be captured.

6.1 Summary

This study employed qualitative approach and used exploratory descriptive design to explore the experiences of individuals living with sickle cell pain in the Accra Metropolis. The sickle cell Clinic at Korle-Bu Teaching Hospital served as the recruitment outlet. Participants who met the inclusion criteria were recruited after detailed explanation concerning the study had been thoroughly done in a language they best understood. Fifteen (15) participants were recruited for this study. One-on-one interviews were conducted and audiotaped with participants’ consent. The interviews were transcribed verbatim and analyzed concurrently using thematic content analysis. The study was guided by the Siddall et al, (2015)’s conceptual framework of biological, psychological, social, spiritual and environmental of the Biopsychosocial-Spiritual Concept of Pain. The adoption of the model was done after a written permission was sort from the lead author.

Five themes emerged from the thematic analysis of the narratives of participants. These were: physical experiences of sickle cell pain, psychological experiences of sickle cell pain, social experiences of sickle cell pain, spiritual experiences of sickle cell pain and lastly the pain management experiences of sickle cell. In exploring the patient experiences of pain in this lifelong condition, certain subthemes emerged which supported the major themes.
It emerged that most of the findings were consistent with other literatures. Firstly, two subthemes and one sub-subtheme emerged to support the first major theme. These were activity intolerance and general body malaise and the sub-subtheme was fatigue. Participants indicated how they were unable to do anything for themselves once the painful crises were present. The study also found that when patients were in severe pain, significant others had to help them attend to their basic health needs such as personal hygiene. Participants again indicated how they easily got tired because of chest pains.

Secondly, this study found serious psychological challenges that participants went through as a result of pain. The study found that participants went through cognitive experiences such as fear of death, worry and insomnia. Fear of death was one such issue that agitated the minds of participants in the study. The study also reported how participant became worried due to their inability to sit for examinations because of the painful episodes. Stigma was another finding of this study. Participants felt stigmatized by some negative comments that were made by school mates and working colleagues. Depression and rejection were also reported as a consequence of pain.

Thirdly, social interactions and partaking in social obligations were hindered by sickle cell pain. The study found that participants felt isolated because of pain. This also had serious effect on family members and significant others. The study found that family members had to abandon work just to assist a member in sickle cell pain crises. Some lost their jobs because of pain and associated frequent absence at work. Delayed promotions were also encountered by some of the participants as a result of their inability to attend in-service training and promotion interviews because of pain.

Fourthly, participants developed meaning and purpose in life and also found identity in the experience of pain through faith in God. Spirituality helped participants to
develop resilience to cope effectively with unpredictable painful episodes of sickle cell disease. The study found that participants believed that God is the sustainer of life. Pain prevented participants from engaging in religious practices such as prayer, Bible reading and all-night prayer sessions.

Lastly, multimodal pain management strategies were used to mitigate sickle cell pain. Poor attitude of caregivers and lack of knowledge of prescribers was a disincentive to hospital attendance. Lack of access to health and specialist care was another finding that worsened the plight of sickle cell patients.

6.2 Implication

The study set identified useful implications such as nursing practice education and policy formulation. It also presents avenue for future research.

6.2.1 Implication for nursing education

There are implications for nursing education in the sense that nurses constitute the majority of healthcare providers and therefore adequate knowledge of sickle cell disease and the pain process will lead to the benefit of clients and their families. Nurses and medical staff must be knowledgeable enough to be able to render effective care that will meet the demands of healthcare by prospective patients. Sickle cell pain presents serious challenges to the sufferer and the care giver hence the need to be knowledgeable handling people with such unique health needs. Sickle cell management must be included in the curriculum of training. Postgraduate training in haematology currently ongoing must be strengthened so that specialist haematological nurses can be trained to meet the increasing disease burden of sickle cell patients. Continuous professional development must be put in place for care givers to update the knowledge and skills of rendering safe healthcare. Treatment of sickle cell pain imposes serious challenges and
therefore other providers such as biomedical scientist and other support staffs should be educated so that investigations and laboratory requests that belong to sickle cell patients that report to emergency departments are worked on expeditiously for them to be taken care of as quickly as possible.

6.2.2 Implication for clinical practice

Sickle cell pain management requires a concerted effort and wider stakeholder collaboration to ensure coordinated management. Emergency department workers must be trained in such a way that their skills of assessment can be sharpened to be able to identify life threatening cues. Treatment must be individualized to address the unique analgesic needs of patients. Adequate pain management has remained a problem for sickle cell patients in many hospital settings because of fear of addiction (Uzun, Kekec, & Gurkan, 2010).

Also, healthcare workers must desist from acts that are perceived by patients and their significant others as discriminatory and disrespectful. Pain assessment must be comprehensively and timeously done and individualized pain management also promoted.

6.2.3 Implications for policy

Efforts should be made to strategically put in place a deliberate national policy for compulsory new born screening as part of prenatal and postnatal services. Cost of hospitalization is a disincentive to effective management of sickle cell pain. Government should take steps to enroll sickle cell management on the national health insurance scheme. All investigations towards the management of sickle cell pain treatment must be covered as well. The findings of this study revealed poor access to healthcare. Steps
should therefore be taken to ensure accessibility to prevent people from accessing health from unauthorized sources.

6.2.4 Implication for future research

Considering the themes that emerged from the narratives, useful areas of future research emanated: Physical experiences of sickle cell pain as an area does not seem to have been explored. This offers a great deal of opportunity for future research.

Psychological Experiences of sickle cell pain: There are cognitive, emotional and behavioural challenges that confront the sickle cell patient with varied consequences. These can also be studied further.

Social Experiences of sickle cell pain: The pain episodes brought in its wake a myriad of social burden that prevented participants to partake in certain vital social obligates. This opens an avenue for future research.

Spiritual experiences of sickle cell pain in no uncertain terms offer another dimension for future research. Pain exposes the vulnerability of man to which solace is sort in a superior transcendence, which brings strength and resilience to cope effectively. A closer look is therefore recommended.

Pain management experiences certainly offers rich areas of research for future researches because effective pain relief from painful sickle cell crises has eluded mankind for decades. This will lead to satisfaction in both the health seeker and the health provider.

6.3. Limitation of the study

The study employed qualitative methodology which makes finding not generalisable to the larger sickle cell population although qualitative study does not aim
at generalisability (Lincoln & Guba, 1985). Purposive sampling technique was used in sampling fifteen participants and it could mean there were other patients whose experiences would be different.

However the demographics present adequate male and female representation but on the religious dimension, all the participants were Christians. A different religious orientation would have enhanced the spiritual experiences that were shared and the findings thereof.

6.4 Conclusion

The overarching experiences of sickle cell pain have negative effect on patients with little insight into remedy. A well trained staff, accessibility to specialist care and a multimodal and multi-dimensional approach is the way forward if pain management among sickle cell patients can be improved to the satisfaction of all. The Biopsychosocial-Spiritual conceptual framework which was adopted for this study should remain the management approach. The constructs in the model supported the findings of this present study. However, some of the findings fell outside the model. Integrating a pharmacological pain management dimension could proof useful. Effective protocols for sickle cell pain management will create confidence in the healthcare provider’s quest to treat sickle cell pain and the associated complications.

6.5 Recommendations

The following recommendations were made based on the findings of this study.

6.5.1 Ministry of Health (MOH)

- Ministry of Health must institutionalize sickle cell management services in all hospitals across the country.
Ministry of Health must build a specialist hospital for sickle cell management with well equipped emergency department to manage vaso-occlusive crises.

Ministry of Health must train enough haematologists to handle the management of sickle cell patients.

Adequate specialist haematology nurses must be trained by the Ghana College of Nursing and Midwifery.

Ministry of Health must adopt a policy of prenatal and postnatal screening for sickle cell disease.

Ministry of Health must adopt a policy of free emergency services for sickle cell patients.

**6.5.2 Ghana Health Service (GHS)**

- Ghana Health Service must ensure that all hospitals and clinics institutionalize the management of sickle cell disease.
- Ghana Health Service must ensure that emergency departments are well equipped with the necessary material and human resources.
- Ghana Health Service must establish in-service training for all nurses, doctors, pharmacist, biomedical scientists, and physiotherapists, radiotherapist and other support staffs on sickle cell management.

**6.5.3 Nursing and Midwifery Council (NMC)**

- Nursing and Midwifery Council must inculcate sickle cell disease and vaso-occlusive pain management into the curriculum of nurses and midwives.
6.5.4 Other Hospitals

- All hospitals must create separate, well equipped emergency units and wards for sickle cell disease and vaso-occlusive pain management.
- Nurses and Midwives should institute strong advocacy groups for genetic counseling
- All staff should be trained on sickle cell disease and management.
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APPENDICES

Appendix A

NMIMR-IRB CONSENT FORM
Title: Living with sickle cell pain: Perspectives of patients in Accra Metropolis
Principal Investigator: David Tenkorang-Twum, M’Phil Nursing Student
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General Information about Research
The objective of this research is to explore the overall impact of sickle cell pain on the patient and family. The study aims at exploring how sickle cell patients in Accra Metropolis live with sickle cell pain and how it affect their activity of daily living. Incidence of sickle cell disease is high in Ghana and especially people of black descent. The sufferers of this condition on daily basis battle with physical discomfort, psychosocial and behavioral tendencies with its accompanying spiritual consequences which causes significant public health problems. It is in the light of this that this study is being carried out.

Participant to be recruited in this study will include Adults of both sexes of eighteen (18) years and above who have been diagnosed with sickle cell disease and living in the Accra Metropolis. Must be of sound mind without any diagnosis of mental illness and should be able to communicate fluently in English and or Twi languages and above all, must be willing to provide informed consent and ready to participate in the study. If you agree to be part of this study, you will be interviewed and the interview audio-taped. You shall be interviewed once and the session will last between 45-90 minutes at your own convenient time and a place of your choice. The interview will be held once and that will be all what will be required from you. Demographic information will be solicited from you before
the commencement of the actual interview. This will include age, educational
background, occupation, ethnicity, number of children if any and how long you have
lived with the condition to enhance the description of the overall findings of the study.

Possible Risks and Discomforts
It is not anticipated that you will suffer any harm by virtue of partaking in this study,
however, you might suffer some psychological distress as you share the challenges you
face on daily basis. At any point of your narrations if you want to stop you will be free to
do so. In event of you becoming unstable emotionally, the interview will be suspended
immediately and rescheduled. A counselor will be readily available to assist you if you
exhibit severe emotional reaction at no cost to you.

Possible Benefits
You may not get any direct benefit for participating in this study. Nonetheless, your
narrations and the findings of this research will help you and the larger community as to
how to contain this life-long condition.

Confidentiality
The interview will be held in a very conducive environment where maximum privacy of
both you and the investigator is absolutely guaranteed to the extent that no one can hear
what is being discussed. It must be noted that no sensitive personal information which
has no bearing on this study will be discussed and audio-taped in the course of the
interview. However, whatever information that will be solicited will be known only to the
investigator and the supervisor alone. You would be required to provide your name in the
consent form. All materials such as tape recorders, transcribed data, and consent form

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INTEGRI PROCEDUNG S

VALID UNTIL
12 NOV 2016

APPROVED DEC. 2015
would be kept under lock and key and preserved for a minimum of five years before it will be destroyed. In the event of future use of the materials, ethical clearance would be sought.

Compensation
You will not be paid for participating in this research. However, time spent shall be compensated with refreshment. In event that you commute to the point where the interview is held, your cost of transport will be borne by the investigator. The refreshment and the transportation shall add up to Twenty Ghana cedis (Gh¢20).

Voluntary Participation and Right to Leave the Research
Your participation in this research is voluntary. You reserve the enviable right to decide on whether or not to participate in the research or to opt out at any stage with no consequences to your person. You may notify the investigator of your intention to withdraw and you may not be required to provide reasons for your withdrawal.

Contacts for Additional Information
If you have any questions regarding the study, feel free to ask the investigator. You can also make any enquiries about this research from the contacts listed below. English and/or Twi will be used in communicating information.

David Tenkorang-Twum
School of Nursing
University of Ghana
Legon
P.O Box 564
Accra-Madinina,
kingsprop@yahoo.com
Sickle cell Pain Experience

Detailed Information about the counselor:
Rev. Hayford Laryea
Ghana Registered Nurses and Midwives Association
Okponglo- Accra
Tel. +233 244413383, 205462228
Email.royalvessel2002@yahoo.com

Your rights as a Participant
This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NIMIR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nimb@noguchi.mim.cam.org.

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title (Living with sickle cell pain: Perspectives of patients in Accra Metropolis) has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date __________________________ Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date __________________________ Name and signature of witness

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I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date

Name Signature of Person Who Obtained Consent

VALID UNTIL
12-NOV-2016

INTEGRI PROCEDA Nous
Appendix B

APPENDIX C
Interview Guide

Demographic Information

1. Age (years): 18 - 29 [ ]; 30 – 49 [ ]; 50 – 69 [ ]; 70 and above [ ].

2. Sickling status

3. Average number of crisis per year: (1-2) [ ]; (3-4) [ ]; (5 and above) [ ].

4. Marital Status

5. Religious background

6. Level of education

7. Language(s)

8. Employment

9. Ethnicity

10. Number of children

Main questions

1. Please can you share with me, at what age you were diagnosed of sickle cell disease and where?

2. Please tell me how you felt when the diagnosis was confirmed?
   Probe - So what came to your mind first?
   - So what did the doctor/nurse do?

3. What are the possible causes of your pain?
   Probe - How does the pain occur?
   - Onset, duration

INTEGRIS PROCEITAMUS
1. At what time/ season do you experience the pain most?
2. Do you have any warning signs?
3. Can you describe how the pain begins?
4. How long does the pain last?

4. Tell me activities you are able to do unaided when you are in a stable condition
   - Share with me activities that you are unable to perform during sickle cell crisis?
   - How does the pain affect your everyday activities?

5. Please can you share with me how you have been managing yourself after the diagnosis?

   Probe - Work
   -Family
   -Marriage
   -Financial /economic life

6. What can you say about this disease?

   Probe - How do people often relate to you?
   - Acceptance
   -Rejection / Ignored

7. What can you say about your treatment regime?

   Probe - How often do visit the clinic?
   - How do the nurses and Doctors treat you?
   -What normally takes you to the hospital?
- what type of treatment is giving to you?
  - Psychological
  - Medical
  - Non-pharmacologic

8. Please tell me how the disease has affected your religious routines.
  - Church activities/ablution
  - Prayer

9. Tell me more about the pain you go through

10. How do you manage the pain?
  - Self
  - Listening to music
  - Ignore the pain
  - Hospital

11. How do you cope with the pain?
  Do you pray whiles in pain

12. Is there anything you want to add to our discussion?
Appendix C

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979
A Constituent of the College of Health Sciences
University of Ghana

INSTITUTIONAL REVIEW BOARD
Post Office Box LG 581
Lagon, Accra
Ghana

13th November, 2015

ETHICAL CLEARANCE
FEDERAL WIDE ASSURANCE FWA 0001824
NMIMR-IRB CPN 034/15-16
IRB 00001276
IORG 000908

On 13th November 2015, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL : Living with sickle cell pain: Perspective of patients in Accra Metropolis

PRINCIPAL INVESTIGATOR : David Teakorant-Twuam, Mphil Cand.

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 12th November, 2016. You are to submit annual reports for continuing review.

Mrs. Chris Dodzie
(NMIMR – IRB, Chair)

cc: Professor Kwadwo Koram
Director, Noguchi Memorial Institute for Medical Research, University of Ghana, Lagon

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Appendix D

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

Telephone: 0302-513255 (Dean)
Ext. 6206
0302-513280 (Secretary)
028 9531213
Fax: 513255
E-mail: nursing@ug.edu.gh

Our Ref: SON/F.1
Your Ref: ________________

The Medical Director
Sickle Cell Clinic
Korle-Bu Teaching Hospital
Accra.

Dear Sir/Madam,

PERMISSION TO CONDUCT A RESEARCH

I write to seek permission for David Tenskorang-Twum, an M.Phil student of the School of Nursing, College of Health Sciences, University of Ghana, Legon, who is conducting a research in your institution. The title of the research is “Living with Sickle Cell Pain: Perspectives of Patients in Accra Metropolis”.

I would be grateful if you would be given the necessary assistance.

Thank you.

Yours faithfully,

Dr. Lydia Aziato
Senior Lecturer

March 17, 2016
Appendix E: Correspondence with Professor Siddal

Dear Prof.
Thank you so much for your prompt response and having permitted me to adopt your model for my thesis. Wish you could allow any of your co-authors to throw a little more light on the constructs of the spiritual component to assist me in my explanation and mock defence since you might be too busy.
I await in anticipation.
Thank you

Sent from Yahoo Mail on Android
On Mon, Jul 4, 2016 at 7:06 AM, Philip Siddall <psiddall@hammond.com.au> wrote:
Hello David

Thanks for your email and interest in the paper. I am certainly happy for you to adopt the model as part of your research.

Most of the constructs in the model are based on common views of biological, psychological, social and environmental factors that have been used by many not only in pain management but other branches of health for many years.

The spiritual construct is more difficult. We explain a little in the paper but it is based mainly on the construct that has been put forward by many people in the palliative care field, particularly around issues of meaning, purpose and identity. I realise that this is still very loose. It is certainly a challenging area and I am glad to hear that you are exploring it.

kind regards

Philip Siddall

Director of Pain Management Service, Greenwich Hospital, HammondCare
Conjoint Professor in Pain Medicine, University of Sydney
E: psiddall@hammond.com.au  |  P: +61 2 8788 3941

Our passion is improving quality of life for people in need.

From: Daivd Tenkorang-Twum [mailto:kingsopre@yahoo.com]
Sent: Saturday, 2 July 2016 2:00 AM
To: Philip Siddall (External)
Subject: Model

Good afternoon Prof.
I write to remind you of the request to adopt your model; Biological, psychological, Social, Spiritual and Environmental of your article spirituality in pain medicine to guide my MPhil research.
I also requested for further explanations to the constructs in the model.
Thank you
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KEY--M-Male  F-Female,  SS- Sickle cell Genotype SS,  SC- Sickle cell Genotype-SC