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Experiences of Sickle Cell Patients in Ghana: A Qualitative Study at the Korle-Bu Teaching Hospital, Accra

Lily Yarney
Department of Public Administration and Health Services Management, University of Ghana Business School, Legon, Accra, Ghana.
Correspondence: lyarney@ug.edu.gh

Abstract

Background: Sickle cell disease is an inherited blood disorder that causes red blood cells to become sticky and sickle in shape. This study was aimed at finding out the experiences of sickle cell patients, the care they receive from family and healthcare providers, to gain insights into what can be done effectively by stakeholders to prevent and improve care.

Methods: Qualitative methodology was employed with in-depth interview guide to collect data. Thirty-one participants consisting sickle cell patients, caregivers and healthcare providers were purposively selected at the Korle-Bu Teaching Hospital for the study. Data were recorded, transcribed, coded and categorized into themes in tandem with the study objectives and analyzed using grounded theory principles.

Results: Sickle cell patients have several experiences with ill-health, homecare, facility-care, socio-economic, psychological, and emotional issues, among other fears.

Conclusion: Individuals with sickle cell disease are vulnerable, their care must therefore be of priority importance to the government and all stakeholders to alleviate their suffering.

Keywords: Experiences, Ghana, Korle-Bu Teaching Hospital, Sickle cell Patients

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Public Interest Statement

This study was conducted to obtain first-hand information from sickle cell patients, their primary caregivers, and healthcare providers, to bring to the fore the plight of this vulnerable group of people. It is hoped that it will bring to bear the plight of sickle cell patient in the public domain, especially in Sub-Saharan Africa and Ghana.

Introduction

Sickle cell disease (SCD), sickle cell anaemia or sickle cell disorder is an inherited blood disorder that causes red blood cells to become sticky and sickle in shape. It is a common but preventable inherited disease. Sickle cell trait occurs in people with one sickle cell and one normal gene and such people can transfer the disease to their offspring though they do not have any clinical manifestation of the illness (World Health Organization (WHO), 2006). An individual is diagnosed as having a sickle cell disease when he or she inherits two sets of abnormal recessive genes (e.g. Hb S and S or C, D, E or β thalassaemia), one from both parents. The parents of such individuals are usually healthy carriers of the abnormal gene, and do not have sickle cell disease (Ohene-frempong & Dennis-Antwi, 1995; Anionwu, & Atkin, 2001). Healthy carriers inherit a normal Hb A gene from one parent and an abnormal Hb gene from the other parent (Embury, et al., 1994). These individuals have one of these combinations: Hb AS, Hb AC, Hb AE, Hb Aβ thalassaemia (Russell et al., 2017)

It is a common belief that sickle cell anemia is more prevalent among people whose ancestry is traced to sub-Saharan Africa, Saudi Arabia, India, and the Mediterranean countries than people from other parts of the world. Over 300,000 babies born in low and middle-income countries worldwide are born with Sickle cell disease with most of these children in Africa (Diallo & Tchernia, 2002). About 2% of children in some part of sub- Saharan Africa are born with sickle cell, and it is estimated that 10% to 40% of people across Equatorial Africa are healthy carriers of sickle cell. The rate in the North African coast is about 1% and 2 % and less than 1% in South Africa. The range of sickle cell trait in Ghana and Nigeria is 15% to 30% (WHO, 2007). In sub- Saharan Africa, most of the affected children are not able to survive childhood because of infections from bacteria and malaria and due to lack of or inadequate access to appropriate care. Statistics in Ghana in 2016 indicated that the prevalence rate for sickle cell disease was about 25% with an estimated two per cent of births, resulting in an approximate number of 15,000 babies being born with the disease annually (Boadu, 2018)

The median age of survival for people with sickle-cell anaemia in Africa is estimated to be less than 5 years (Akinyanju, 2006; Serjeant, 2005) and mong the under-five deaths, sickle cell anaemia contributes an estimated rate of 5%. About 25,000 sickle cell disease children and adults have been registered with the sickle cell clinic at Korle-Bu Teaching Hospital in Ghana (Sickle Cell Clinic Records, 2011). Two percent of children born in Ghana every year have SCD and about 25% to 30% of Ghanaians are carriers of SCD (Ohene-Frempong, et al., 2008).

There are several complications associated with sickle cell disease among which are: serious infections, damage to vital organs, stroke, kidney damage, respiratory problems, bone marrow failure, growth failure, cognitive impairment, maturational delay in children as well as high maternal and foetal morbidity and mortality (Ocheni, 2007; Zemel et al., 2008). Sickle cell patients also experience acute and chronic pain in their bones and joints. Acute pain which is more common can be very severe and lasts from hours to days (Umeh, et al., 2017). This painful crisis is the most distressing symptom in patients with SCD (Bakshi et al., 2017; Wethers, 2000). Other chronic complications of SCD also include pigment gallstones, delayed growth and development, avascular necrosis, pulmonary hypertension, and renal disease.

Blood is very critical in the treatment of acute and chronic sickle cell related conditions like

severe anemia and kidney failure. Patients usually require hospitalization for acute complications such as painful episodes, acute chest syndrome, splenic sequestration, infection, stroke, aplastic crisis, and priapism. thus, affecting attendance at school and normal play activities, work and employability in adulthood (Thomas, et al., 2002).

In Africa, SCD poses a major public health and socio-economic threat to an already stressed Continent and threatens the very existence of human lives. Being diagnosed with sickle cell is associated with several complications and requires that patients comply with treatment regimen. Additionally, patients go through several experiences that affect all facets of their lives from physical, emotional, interpersonal, to relational, among others. These problems can lead to non-adherence to treatment which may consequently contribute to substantial worsening of the disease, death, and increased healthcare costs (Aday et al., 1999; Gardiner & Dvorkin, 2006; Julius et al., 2009; Lehane & McCarthy, 2009; Sabota et al. 2015; Wamboldt et al., 2009).

Also, because the condition is chronic and does not have a cure, some patients experience stigmatization and discrimination in society. Sickle-cell patients therefore need adequate care from both healthcare providers and family. To understand individuals with SCD, their experiences with the condition is important to organize care and to obtain broader access to care for them. A study of this nature is therefore not out of place if meaningful development and effective implementation of a clearly designed national sickle cell disease control program is to be put in place. Findings of the study may influence genetic counseling and testing for people to be aware of their sickle cell status, increase public awareness, sensitization, and advocacy to minimize stigmatization and improve upon care.

Although some studies on living experiences and self-care strategies have been carried out elsewhere (Cordeiro et al., 2015), literature on care of sickle-cell patients and what they go through in Ghana appears to be limited. Thus, this study was aimed at finding out the experiences of this vulnerable group of people, the care they receive from family caregivers and healthcare providers as well as their relationship with friends, so as to provide insights into what can be done by stakeholders to improve their care to help them cope with the stresses and strains of living with the disease.

Theoretical Framework

The findings of the study can be explained and acted upon with the use of Dorothea Orem's Self-Care Deficit Theory. This theory is pivoted on the assumption that every human being is capable of self-care, and self-care is made up of all the activities that individuals initiate and perform voluntarily without any hindrance with the purpose of conserving life, health and well-being (Orem, 1985). The caregiver's role according to the theory is to help the patient undertake responsibility for self-care. The theory postulates that caregiving in nursing follows a two-step process. The first is to recognize and give precedence to the patient's unfulfilled self-care needs, and the second is to determine or choose techniques to assist the patient to make up for or surpass his self-care deficits. Sickle cell anemia being a chronic condition is costly to manage, thus, self-care management is critical for reduction of costs associated with relevant interventions. Individuals with sickle cell disease therefore must manage their symptoms and gain control over some of the negative effects of the condition to maintain health and improve quality of life and

well-being (Govindaraj et al., 1996). Thus, in line with Orem's Self-Care Deficit theory, caregivers of sickle cell patients both at home and facility levels may have to first learn to identify and give priority to the sickle cell patient's unmet self-care needs. This must be followed by carefully selecting effective methods to help the sickle cell patient to overcome or compensate for his or her self-care deficits to ensure sustained and appreciable quality of life, health, and well-being for decreased vulnerability.

Methods

Study Area, Population, Sampling and sample size The population of interest for this study was all sickle-cell patients who have been diagnosed as having Hb SS or Hb SC combinations and were receiving treatment at the Sickle Cell Units of Korle-Bu Teaching Hospital in Accra, their caregivers and their healthcare providers. The Korle-Bu Teaching Hospital, founded in 1923 (Govindaraj, 1996), situated in the Greater Accra Region and in Ghana's capital, Accra, was purposively selected because it serves as the central referral point for most cases in the city. Being the only tertiary hospital in southern Ghana, it is the final level of referrals in the health service delivery hierarchy, and home to a mix of doctors with diverse specialties. It currently houses about 2,000 beds with three Centres of Excellence and twenty-one clinical and diagnostic departments. In addition to its busy nature, it also has two units for sickle cell, and it is situated in an easily accessible location.
Sickle-cell patients, caregivers, and healthcare providers were also purposively sampled for the study. Sickle-cell patients selected were those who had been diagnosed as having the disease by a qualified medical officer, were receiving treatment at any of the two sickle cell clinics in the hospital, was 13 years and above who could give an account of his or her experiences with the condition and was willing to participate in the study. Caregivers and healthcare providers were selected because they care for sickle-cell patients, and provide institutional care respectively, and were also willing to be part of the study.

Data Collection Methods and Instrument

The Study employed qualitative methods of data collection. Thus, data for the study consisted of responses from in-depth interviews (with sickle cell patients) and key informants' interviews (with caregivers and healthcare providers) using in-depth interview guide and key informants interview guide respectively. The instruments were pre-tested at the Ridge Hospital in Accra to determine their appropriateness in collecting the desired data in English or the local Twi (spoken in every part of Ghana) languages.

The data collection team comprised the author and a research assistant who holds an MPhil degree in Social Science and is experienced in qualitative data collection methods and techniques. The sickle cell units of the study hospital were visited two times in a week from August to October, 2017, to recruit eligible participants unto the study until thematic variations had been observed (Guest, et al., 2006), with twenty-three (23) sickle cell patients. A doctor, two nurses and five caregivers were also interviewed to capture their views on the care and experiences of sickle cell patients. Thus, a total of thirty-one (31) persons participated in the study. Every participant was interviewed separately for an average time of about 45 minutes. Inductive probes and discussions were used during the interviews to broaden the narrations as possible. Interviews were recorded

using electronic recorder where participants agreed, and handwritten notes were also taken.

Ethical Consideration

Approval to conduct the study was given by the Ghana Health Service. Written consent was sought from individual participants before they were interviewed. Informed assent was also sought from children who were less than 18 years in addition to consent from parents and caregivers. Interviews were preceded by explanation of study purpose and its prospective contribution to the care of sickle cell patients. Participants were then informed about the voluntary nature of their participation and were thus, assured of their rights to withdraw from the study any time they felt like doing so without any untoward consequences. They were also informed of publishing the findings with anonymous quotes from them.

Data Analysis

Audio recorded responses and notes taken from the interviews were translated verbatim in English language separately by two data entry experts. Data were then transcribed in a word processing application. The two data entry experts came together to compare the information, subsequently, they built consensus by reviewing their transcripts and the original recordings. The transcripts and field notes were stored as files. Manual coding was then used to select themes based on the research tools and objectives for textual analysis based on grounded theory principles (Akormedi et al., 2013). The coding was done by placing blocks of text into nodes of categories and subcategories. Based on the categories, information on the themes were compared using similarities and differences in views of the participants on the experiences and care of sickle cell patients. This was followed by selection of quotes that were used to instantiate the themes.

Results

Socio-Demographic Characteristics of Participants

Sickle cell patients that participated in the study were made up of 14 males (about 61%) and 9(39%) females. Their ages ranged from 13 to 55 years with 5(about 22%) teenagers, 8(about 35%) between 20 and 29 years and the remaining 10(43%) were 30 years or above. The majority (13; 56%) were employed, 8(about 35%) were students and only 2 (about 9%) were unemployed. Approximately 87% (20) are Christians with the rest 3(13%) being Muslim, 2 were married and 21 had never married before. Of the 23 sickle cell patients, 20 have Hb SS and only 3 have Hb SC combinations (Table 1) The five caregiver participants consisted of four females and a male who were all adults, and healthcare provider participants were made up of a male doctor and two female nurses who had all worked with sickle cell patients for over two years.

Table 1: Characteristics of sickle cell patient participants

Attribute	**Number**	**percentage**
Sex		
Male	14	60.9
Female	9	39.1
Age (Years)		
13 – 19	5	21.7
20 – 29	8	34.8
30 and above	10	43.5
Employment status		
Employed	13	56.5
Unemployed	2	8.7
Student	8	34.8
Marital Status		
Married	2	8.7
Unmarried	21	91.3
Religious affiliation		
Christian	20	87.0
Muslim	3	13.0
Sickling type		
Hb SS	20	87.0
Hb SC	3	13.0

n = 23

The themes and sub-themes guiding the presentation of findings of the study are shown in table 2.

Table 2: Themes and sub-themes

THEMES	**SUB-THEMES**
Ailments and symptoms of sickle cell patients	
Experiences of sickle cell patients	Reaction to diagnosis Experiences with ill-health Limitations to normal daily activities and daily living Medications Cost of living with the disease
Homecare	
Facility care	
Relationship with friends	
Fears of patients	

Ailments and symptoms of sickle cell patients

Sickle cell patients mentioned pain in the joints and chest, anemia, headache, fever, erectile malfunction, nose-bleeding, malaria, amenorrhea, jaundice, and general malaise and infections as their main ailments and symptoms. In addition, healthcare providers explained that sickle cell disease often affects the bones, lungs, abdomen, and joints, and some patients might experience shortness of breath and or dizziness, coldness in the hands and feet, pale skin, and persistent leg ulcers. These conditions among others, according to healthcare providers vary in severity, in some patients, they are mild, and severe in others.

Experiences of Sickle cell patients

Reaction to diagnosis

Sickle cell disease according to healthcare providers is present at birth, but most infants don't show any signs until they are more than 4 months old or late in childhood. Hence, many of the sickle cell patients (14; 71.4%) indicated that they were diagnosed as having sickle cell disease when they were very young when they could not understand their condition until they were about eight years or older. Such participants indicated that coming to terms with living with a chronic condition like sickle cell disease was not easy, they had to go through stages of grieving over their condition for several days, months and even years. This is because they most of the time were ridden with one form of symptom or another, and therefore felt that they were unhealthy. Six (28.6%) of the participants indicated that they were diagnosed when they were 12 years or older, but prior to their diagnoses, they were most of the time ill. Knowing the diagnosis was devastating to them. Some of them indicated that that they had heard or read about the condition and were very sad about their diagnosis. Others were ignorant about it, yet they were sad because of their frequent ill-health.

Caregivers who were parents indicated that they were very sad and devastated when their wards were first diagnosed as having sickle cell disease, and this was done after several episodes of illness.

"I was diagnosed with sickle cell when I was a child and did not have a clue as to what it was until I turned eight years or so. From that time, I've feeling very bad and sad about my condition to date" (Male patient 33 years)

"Diagnosis was made when he was a little baby. We went for weighing and the nurses asked of his blood group, I didn't know so I was asked to run some test and through that we got to know of his sickling status. In fact, I was emotionally disturbed at the news" (Caregiver)

"That day when the doctor told me that my son has sickle cell disorder, I was very quiet and sad, I nearly wept openly." (Caregiver)

"I was told I have sickle cell when I was 12 years, at the time I was in class six. I didn't do anything because I was not having any idea about what sickle cell was. However, I was sad because of how often I became sick and couldn't stay in school" (Male patient, 30 years)

"I was 15 years old when I was told I had sickle cell (SC) I cried my heart out, to the extent of not eating. Even though the Doctor did not explain anything to me I knew about it and I had heard people talking about it. I even over-heard someone telling my mother that she thinks I'm a 'sickler', but I did not pay attention to the person. I denied it because I had also heard that people who have the condition do not live long." (Female patient, 29 years)

Experiences with ill-health

Pain: According to participants, sickle cell condition comes with a lot ill-health. The commonest ill-health problem mentioned is pain. Pain, as described by participants is inevitable, and patients experience pain anytime and anywhere. Pain, especially in the joints as participants described it could be so severe and excruciating that they become bed-ridden and they must be hospitalized every now and then for some days, so that the pain can be managed. Most participants call the painful condition "crisis", and for those who have 'crisis' more frequently, the condition according to them is unbearable. Headache was also mentioned by participants as an inevitable ill-health problem associated with sickle cell condition, and can be quite severe and very uncomfortable

"Being a sickle cell patient comes with a lot of problems, because you can go through pains anytime, day and even any minute" (Male patient, 34 years)

"There are a lot of problems I face because of this condition. I mostly have pains in my body especially joint aches" (Female patient, 27 years)

"My main problem is I always have chest and joint pains all the time, and when I'm in crisis, I have to depend on my parents for everything." (Male patient, 19 years)

Healthcare providers explained that:

"Patients also go through periodic episodes of pain, which is called crises, which is a major symptom of sickle cell anemia. Pain develops when sickle-shaped red blood cells block blood flow through tiny blood vessels to the chest, abdomen and joints. The pain can also occur in the bones." (Healthcare provider)

Anemia: was mentioned by almost all participants as a major ill-health problem associated with sickle cell condition. Some participants lamented that they are almost always anemic and feel very tired when they are even resting. Few participants complained of bleeding from the nose with the slightest exposure to the sun. For them, that could explain their anemic condition. Some of the women explained that because of anemia, they do not menstruate regularly.

"Red blood cells usually live for about 120 days before they're replaced, but sickle cells usually die in 10 to 20 days, leaving a shortage of red blood cells and this causes patient to be anemic all the time." (Healthcare provider)

"The most common signs and symptoms are linked to anemia and people with anemia do not have enough red blood cells, which deliver oxygen." (Healthcare provider)

"I'm always told that I look pale, that I'm short of blood, and that I have anemia or low hb level, as the nurses and doctors put it, and say that is why I'm always tired" (Male patient, 29 years)

"I'm always anemic and because of that I don't often menstruate like every normal female does. I also experience some sort of tiredness, small thing that I will do I become so tired" (Female patient, 29 years)

"I'm mostly anemic too so I hardly menstruate, anytime my blood is low and I menstruate, I have to be admitted at the hospital" (Female patient, 27 years)

General malaise: General weakness of the body of sickle cell patients according to healthcare providers is due low count of red blood cells. However, some patients reported of frequent general weakness in the body resulting from pain and anorexia (loss of appetite). This

according to them can be so devastating that getting out of bed in the morning and taking care of self becomes difficult.

"……., without enough red blood cells, patient's body can't get the oxygen it needs to feel energized, causing them fatigue all the time." (Healthcare provider)

"……. fatigue is one of the most common symptoms of sickle cell anemia." (Healthcare provider)

"….. I always feel very weak, and I think my general body weakness is because of the pains in my body and the fact that I most of the time do not have appetite for food" (Male patient, 30 years)

"I feel weak, loss of appetite, generally ill most of the time, so I have to rely on my parents and to help me with getting out of bed, movement, bathing, feeding and the likes" (Male patient, 29 years)

"…… He can become weak even to the point of not being able to wake up from bed to the washroom" (Caregiver)

Erectile problems: According to some male participants, erection can last for several hours because of sickle cell condition, and it is associated with pain. At times it persists for so long a time that patients must be rushed to the hospital for surgical intervention. This affects their sexual functioning negatively.

"…… now my major problem is the fact that I have been experiencing erectile problems. At time when I get erection it takes time before it goes down and sometimes I don't get erection at all" (Male patient, 34 years)

"…… the worse of it was that I woke up one dawn and had an erection which lasted for 8 hours and wouldn't drop. It was so painful that I had to be rushed to the hospital. They tried using a needle to draw out the blood, but it didn't work so I was sent to the theatre for a surgery. Since then, I can hardly erect." (Male patient, 36 years)

Jaundice: according to participants jaundice is also an ill-health condition associated with sickle cell condition. Some of them declared that discoloration of the eyes associated with jaundice makes them uncomfortable in public, especially when people ask questions about their condition. "I quite often have yellowish-green eyes because of jaundice, and people will always be asking you what is wrong with you when they see the eye color change, so I've been to myself most of the time" (Male patient, 36 years)

Malaria and fever: were also mentioned by participants as ill-health conditions that they have to battle with very often.

"…… I also get ill of malaria with fever very often. I think it's all because of my condition." (Male patient, 19 years)

"…… She falls ill all the time, if it's not malaria, its fever, or something else." (Caregiver participant)

Limitations to normal daily activities and daily living

Participants indicated that, because of their condition, they must lead 'restricted life'. According to participants there are quite a number of 'don'ts' in their lives. These include:

Inability to withstand cold temperatures: Participants explained that exposure to cold air or

water causes them to have crisis, so they are not supposed to swim or visit places that have low temperatures and must cover themselves adequately all the time.

"…… you can't be at the pool side or at the beach never it is a holiday. This is because as SS patient you have to cover yourself and not be swimming just as the others will be doing in the sea, so there is no need going to the beach" (Female patient, 23 years)

"Her mum travels abroad, but because the place is cold she can't go with her because she is not supposed to be exposed to the cold weather." (Caregiver)

"…… I cannot go out to swim with my friends because any cold water makes me have crises." (Female patient, 27 years)

Inability to engage in vigorous physical activity: Some participants indicated that anytime they take part in any vigorous activity like dancing, running, playing football or engaging in other outdoor games with friends or colleagues, they enter into crisis during or after the activity, so they have to avoid partaking in all vigorous activities including walking long distances. This limits them even in their choice of entertainment activities, and places to attend school. For instance, some of them said they had to avoid choosing schools situated on mountainous areas because of the cold weather and low levels of oxygen associated with high grounds.

"……, things that people can do at any time you can't do them. Like in school whenever there is entertainment, I can't enjoy or participate in even dancing, because any time I involve myself, I wake up the following day feeling more pains all over my body. Even when I go for inter-schools games, I don't involve myself in any of the physical activities." (Male patient, 15 years)

"……., also, I'm not allowed to play soccer with my friends or colleagues, because of my condition." (Male patient, 30 years)

Dietary restrictions: Sickle cell patients cannot eat anything at all. They have dietary restrictions, they are supposed to eat foods that will boost their red blood cells, like green leafy vegetables, meat, fish, cereals, etc, in their right quantities because of their anemic condition. Participants complained that at times they wish they could eat what everyone else is eating without any restrictions.

"……, patients like me are supposed to take special diet, so we can be healthy. It's not like you feel for roasted plantain and groundnuts and you can just eat it, no!" (Male patient, 23 years)

"We tell them not to eat any kind of food at all, but nutritious foods that will boost their hemoglobin levels." (Healthcare provider)

Other Problems

Medication: According to healthcare providers, sickle cell patients: "have to be on medication throughout their life-time"

Participants complained of being constantly on medication as a problem. Some felt it was too much of a bother to be constantly on medications and they felt the side effects of the medications are also detrimental to their health. Psychologically, it puts a lot of stress on them, especially when they have to go for refills.

"Oh! the medications are too much if there is any alternative it will be better, because I know every medicine has its own side effect and taking it on daily basis kills us gradually." (Female

patient, 29 years)

"I'm always taking folic acid just like I've been putting on clothing every day, what is most stressful about the medications is travelling to the pharmacy shop and buying them when they get finished." (Female patient, 33 years)

Cost of living with the disease: Participants described the condition as being very expensive and problematic. They lamented that they must bear the cost of medication, hospitalization and special diet. In addition, they complained of limitation to earn money as they cannot engage themselves in any work that requires a lot of physical energy for extra income or even lose their job because of frequent ill-health. All these facts were reiterated by the home-caregiver and facility caregiver participants as well.

"Financially you need to be sound before you can live comfortably with sickle cell. This is because you always must take medications, and the medicines are not free you have to buy them. Most often, you get severe pains and you need to go to the hospital for treatment at a charge. Sickle cell is not easy to manage, it's very expensive." (Male patient, 33 years)

"……, there are also financial constraints due to the frequent visit to the hospital, special diet, and buying of medicines, and as I sit here, I cannot do any extra work to earn a little more income, so it's difficult to manage." (Male patient, 30 years)

"……, I lost my first job because of my frequent ill health, currently I work as a waitress and it has not been easy at all, the strength is not there, however, more than half of the money I earn goes into medications alone." (Female patient, 31 years)

"My son's condition has drained us financially; the condition is very expensive to manage." (Caregiver)

Experiences with home care

Most of the sickle cell patients (18; 78%) reported that their caregivers at home were mostly their parents, especially their mother, 3 had no caregivers at home and 2 had their spouses as their caregivers at home. According to those who have caregivers, the caregivers provide services ranging from personal care through psychological support and encouragement to financial support. They reported that when they are in crises and cannot personally care for themselves, their primary caregivers do everything for them in addition to paying for their hospitalization and medical expenses. Thus, these individuals are very much dependent on their primary caregivers, though most of them are adults.

"At home my parents help me with my daily life, especially my mother. When I'm in pains, she prepares hot water for me and helps me with everything I need." (Male patient, 33 years)

"At home my mother gives me words of encouragement anytime I'm down with illness and does what I can't do." (Female patient, 23 years)

"My parents attend to every need of mine when I'm in crisis, financially they are always there to support, they get all the medications I need in order for me to healthy." (Male patient, 15 years)

For the few patients who do not have primary caregivers, they mostly depended on friends for support of fend for themselves

"There is no care at home, so I've been living with one friend or the other, they support me

when I'm in crisis." (Male patient, 31 years)

"I don't have any caregiver at home, I live at home alone and so I cater for myself. When I'm ill I go to the hospital alone, if I can't walk, I pick a taxi." (Male patient, 36 years)

Most participants reported general satisfaction with the care they receive at home except a few who indicated that though their primary caregivers show a lot of affection and empathy toward them, occasionally they throw in statements or comments that are worrying.

"…… I'm very satisfied with the care given me by my husband and only daughter, they have been so supportive, and they do all I want and need." (Female patient, 55 years)

"I'm very satisfied with the care, affection and financial assistance my mum gives to me." (Male patient, 19 years)

So far so good about the care I receive from the house, and I'm very grateful to all who are involved in taking care of me (Female patient, 27 years)

"I'm satisfied with the support that my family offers me, they treat me well and you can see that they care so much, but I dislike the fact that they keep on reminding me of my condition and the things I have to do and the ones I don't have to." (Male patient, 15 years)

"I am satisfied so far, the treatment I get from the family is great. However, they always see you as a kid because they feel like you can't do certain things on your own and you depend on their help" (Male patient, 34 years)

"I'm satisfied with the care my family provides, but it's also disheartening to hear your father say, this my child has drained all my money out, or my mother say to other people, be careful with him, he's not strong and all that" (Female patient, 23 years)

Experiences with facility care

Sickle cell patient participants reported mixed experiences with facility care. While some were satisfied and happy with the services that are provided at the clinic (medical management of their condition, health education on what they can and cannot do including when to seek medical assistance), others were of the view that some of the clinic staff can be too harsh on them. They specifically mentioned that some nurses are not polite and empathetic in their dealings with them. Some commended doctors and reported that they are supportive and forthcoming with information on the condition and suggestions for improvement in their condition.

Some patients also indicated that because they all join one queue, patients in crisis are not attended to as emergencies, and they have to go through a lot of pain till it gets to their turn for attention and care.

"The nurses and the doctors are very good, and they take very good care of their patient, so I feel comfortable with them." (Male patient, 30 years)

"The way the doctors and the nurses relate and talk to me is good enough, but I don't know if they do that to everybody" (Female patient, 29 years)

"……, some of the nurses are too rude and they shout at you. Whenever you are in pain and you call them, they will be shouting can't you endure this small pain, and you are shouting?" (Male patient, 33 years)

"Sometimes, I'm scared of going to the clinic because some of the nurses are rude, and shout at patients unnecessarily." (Male patient, 19 years)

"I appreciate the education the health staff give at the clinic, because it is helpful, but some of the nurses just like shouting and getting angry at any small thing, it's like they are petty" (Female patient, 23 years)

"The doctors are very professional, and they always talk about adherence to the medication." (Male patient 28 years)

Some patients also raised concerns about how patient records are handled in the facility. They explained that patients are allowed to take their folders home, and when they are in crisis and are rushed to the hospital, they leave the folders at home. This according to them, creates delays in their care and disrupts continuity of care.

"…… I think that patient folders must be kept at the clinic, because when we're in crisis, we are most of the time rushed here leaving our folders in the house, and the nurses would be asking for the folder before they attend to you when you need them to do something to alleviate your suffering." (Male patient, 34 years).

Social Interactions and relationships with friends

All the sickle cell patient participants reported having friends, but not many, and have good and cordial relations with their friends, except that they are restricted when it comes to engaging in certain vigorous activity or games with them. As such some friends are cautious in approaching them, because they (friends) feel they (sickle cell patients) are unhealthy.

"I have good relations with the few friends I have, so they're always there for me." (Male patient, 31 years)

"Oh I am very free with my friends. In fact, I even called my friend after diagnosis from the doctor. She was the one who calmed me down and explained the whole condition to me, I was 15 years then. She even sent me some materials on sickle cell to read, and she's still there for me, we go out to have fun together." (Female patient, 33 years)

"I like to be among my peers because they are fun to be with, but I can't indulge in all activities that they indulge in, and some are cautious in dealing with you because they feel you're fragile." (Male patient, 29 years)

"I don't have a lot of friends because of my condition and my relationship with the few friends that I have is very cordial, but the extended family, some of them don't want their wards to even have anything to do with me because some think I'm an evil child that has come to worry them." (Female patient, 27 years)

Fears of patients

All the Patient participants reported one fear or the other to include, fear of complications with ageing, fear of not having spouses, fear of not being able to bear children, fear of ageing parents not being able to provide financial and physical care, and the worst of all, fear of death at any time.

"……, it's because of sickle cell that I'm currently using crutches, I can't do any hard work, I can't even lift a bucket of water to the bathroom to take my bath. I can't do anything active anymore. At first when I was young, I could do things for myself, so I'm very much afraid of what next will happen to me as I keep on growing" (Female patient, 55 years)

"My boyfriend is very supportive but sometimes I feel scared that he will not marry me because I'm always sick." (Female patient, 29 years)

"…….. and this is my biggest issue. I'm 34 years and I'm not married, because when the ladies come and I tell them of my condition, they just spend my money and later they leave." (Male patient, 34 years)

"…….. presently, I'm very much dependent on my parents financially and when I'm in crisis. As I see them ageing, my father is 67 years and my mother is 65 years, and becoming weaker and weaker, I become so much afraid, because if they die, there'll be no reliable person like them to take care of me. I'm their only child." (Female patient, 27 years)

"……, my father told me some time back that I should live life like there is no tomorrow, because I can die at any time. I didn't understand him till I was in Senior High School and one of my mates died, he was a sickle cell patient. Then, I heard people saying that its normal for SS individuals to die very young because they don't live up 20 years. I was 16 years at the time, so I took the information seriously and I told myself that I have to live life to the fullest. So I didn't take my education seriously, this has really affected. I'm not dead yet, but I still know I can die at any time, and it scares me a lot." (Male patient, 31 years).

"……a lot of scary thoughts run through my head most of the time, I wonder if I'll ever get married, and if I do, will I be able to have children, will my children also have sickle cell disease? I live with these fears, but the most frightening one is, I can give up my ghost any time." (Female patient, 33 years).

Discussion

The World Health Organization in 2006 recommended that by the year 2020, 50% of its member states should have functioning sickle cell control programs (WHO, 2006). This is because WHO has recognized the high illness and death rates associated with the condition, and the need to tackle it as a public health problem. Such a control program, it is believed, would put preventive and therapeutic measures in place to effectively manage SCD. Ghana is yet to establish one.

From the interviews with the participants of the study, most diagnosis of sickle cell disease in Ghana is made when children had had frequent episodes of illness. However, it has been documented that early diagnosis of sickle cell disease is critical to the prevention of complications associated with the condition, and fortunately, diagnosis can be made with simple blood tests (National Institutes of Health, 2011). It is therefore imperative on healthcare providers in their quest to minimize illness and prevent complications in patients to institute measures to detect hemoglobin abnormalities in infants especially those born in healthcare facilities for early intervention.

Pain as described by participants of the study is inevitable among sickle cell patients. Thus, experience of acute or chronic pain (Umeh, et al., 2007) with varying intensity (Bakshi et al., 2017) makes most patients uncomfortable throughout their lives and this calls for effective management of pain and other illnesses associated with the disease.

Knowledge on sickle cell disease appears to be limited in Ghana, though some studies elsewhere have found knowledge on the disease to be quite high (Smith & Brownell, 2018). Hence, efforts to reduce incidence of the condition can be tackled through education and counselling. This

can be taken up by the mass media, educational institutions, Religious bodies, governmental and non-governmental organizations, and other organized groups and institutions. Also, education targeted at affected individuals (both patients and family) would go a long way to preventing frequent episodes of crisis. These should include education on diet and nutrition, and general management of the condition. Education targeted at the public on sickle cell disease in general can help minimize stigmatization against sickle cell patients.

Home care-giving is a major component of the management of sickle cell disease as the study has shown. It is thus, important that family members and caregivers show love, compassion and empathy as well as provide psychological support to their sickle cell members throughout their lives, and for those home caregivers who pass negative comments on the condition to unintentionally demoralize patients, special education plans should be targeted at them, for behavior change.

At the facility level, it is suggested that healthcare providers, especially nurses be trained on customer care and relations to improve upon their relations with clients. They must also be trained to perform their duties professionally. Nurses should be empathetic in their dealings with patients and the hospital's administration should take the complaints and grievances of patients seriously and address them. Additionally, the laws on infringement on the rights of patients should be enforced to deter healthcare workers from maltreating patients (Yarney, et al., 2016).

The study has also revealed that patients on review of their condition and those in crisis all attend one clinic and for that matter join the same queue for consultations. Hence, separate clinics should be organized for patients on review and patients in crisis. This would facilitate care for those in crisis and give them some relief without waiting for long periods at the hospital before they are attended to. This can only be possible when the facility for sickle cell is expanded and more doctors and nurses are trained to comfortably accommodate patients.

Keeping of patient records and folders as found by the study needs to be revised for easy access and continuity of care by healthcare providers. The hospital should therefore consider taking steps to move from paper records to electronic records keeping. This would go a long way to facilitate and improve upon continuity of care of sickle cell patients.

Sickle cell disease being a chronic condition without a cure as the study has shown is very expensive to manage, as patients find it difficult to find gainful employment because of their condition. Hence, cost of management is difficult for both patients and caregivers to bear. It is therefore recommended that cost of medication and hospitalization be listed on the national health insurance scheme, reduced, subsidized or provided for free by the government, so that patients and their caregivers would use their limited resources in providing nutritious meals to improve and maintain the health of patients.

The study has revealed that sickle cell patients in Ghana live with a lot of discomfort, uncertainty about life, stigma and fear especially of the unknown and therefore much attention should be given to them. The establishment of an effective sickle cell program in the country is therefore, long overdue.

Study Limitations

The small sample size of thirty-one participants, and the use of one health facility for the study is acknowledged to be a limitation to generalizing the findings to other sickle cell patients in other parts of the country, since contextual issues may influence experiences. However, because the study employed qualitative methods and was conducted in the largest teaching hospital in the country with the largest referral cases from most part of the country, replication of the study elsewhere in the country may yield similar findings.

Conclusion

Sickle cell patients in Ghana go through a lot of health problems making it difficult to live with the disease psychologically, emotionally, physically and financially. Thus, individuals with sickle cell disease are extremely vulnerable, and their care must be of priority importance to the government and all stakeholders. Structured, systematic and clear policy guidelines must be put in place regarding the care and management of sickle cell disease, and these must be aimed at alleviating both the physical and psychological pain and suffering associated with the disease and reduction in the incidence of the condition.

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Author Biography

Lily Yarney is a Senior Lecturer and Researcher in the Department of Public Administration and Health Services Management, University of Ghana Business School. She holds a PhD in Public Health and Master of Business Administration from the University of Ghana, and a postgraduate certificate in Management for International Public Health from the Centers of Disease Control and Prevention (CDC) and Emory University Rollins School of Public Health in Atlanta Georgia, U.S.A. Before she joined academia, she had worked with three international non-governmental organizations as the HIV/AIDS Programs Coordinator. Lily has passion for scientific enquiries and has published research articles in reputable peer reviewed journals. She continues to conduct research in the areas of health and gender, socio-cultural determinants of health, health of vulnerable groups, healthcare financing, maternal and child health, and health and safety management in organizations, among others.

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