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Sickle cell disease management in Nigeria: Understanding the challenges from the physicians' perspectives

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Abstract

Introduction: Nigeria has the greatest burden of sickle cell disease (SCD) in sub-Saharan Africa. The disorder is usually associated with a huge psychological and financial toll on families and individuals in developing countries. However, SCD diagnosis and management are still largely rudimentary especially in Africa. This study therefore aims to explore the views of physicians about challenges facing SCD management in Nigeria as well as the health system responses to these challenges.

Methods: This qualitative cross-sectional study was conducted in 2015. A total of ten in-depth interviews (IDIs) were conducted among purposively selected resident doctors at the Hematology Department of the University College Hospital (UCH), Ibadan, Southwest Nigeria. Data from the IDIs were transcribed and analyzed with the aid of the NVIVO (version 10) software using the thematic framework approach to qualitative data analysis.

Results: In the opinion of the study participants, many of the SCD patients, cannot access up-to-date medical care because of poor health financing and poverty, inadequate health infrastructures and medical facilities including obsolete blood transfusion services and medical equipment. There were myriads of medical challenges facing individuals with SCD in Nigeria: frequent illnesses and crises which may comprise bone pains, recurrent anemia, malaria, chronic leg ulcer and even risk of HIV and Hepatitis B from frequent blood transfusion. Similarly, SCD patients may experience psychological challenges, according to the respondents, due to the frequent illnesses, discrimination suffered as well as stigmatization. Some respondents submitted that there is still significant ignorance about the disease and its pathophysiology among the patients themselves, their caregivers and the general population thereby feeding a lot of superstitious beliefs. Some health systems challenges highlighted in SCD management include inadequate financial support as well as poor infrastructures for diagnosis and treatment.

Conclusion: The knowledge gap in the community about sickle cell disease should be bridged through constant health education in order to alleviate stigma. There is also a need for an effective policy to protect persons living with SCD from discrimination in the labor market as well as the workplace. Better funding for research as well as the strengthening of the social health insurance will go a long way to promote the management of SCD and reduce catastrophic expenditure and poverty among SCD patients and their families.

Keywords: *Sickle cell disease, Health systems management, Physicians' perspective, Out-of-pocket health expenditure*

Résumé

Introduction: Le Nigéria a le plus grand fardeau de drépanocytose en Afrique subsaharienne. Le trouble est généralement associé à une lourde charge psychologique et financière sur les familles et les individus, en particulier dans les pays en voie de développement. Cependant, le diagnostic et la prise en charge de la drépanocytose sont encore largement rudimentaires surtout en Afrique. Cette étude vise donc à explorer les points de vue des médecins sur les défis de la prise en charge de la drépanocytose au Nigeria ainsi que les réponses du système de santé à ces défis.

Méthodes : Cette étude transversale qualitative a été menée en 2015. Au total, neuf entretiens approfondis ont été menés parmi des médecins résidents sélectionnés au sein du département d'hématologie du Collège Hospitalier Universitaire (UCH) à Ibadan, Sud - Ouest du Nigeria. Les données des entretiens approfondis ont été transcrites et analysées à l'aide du logiciel NVIVO (version 10) en utilisant l'approche du cadre thématique pour l'analyse qualitative des données.

Résultats: De l'avis des participants à l'étude, beaucoup de patients drépanocytaires ne peuvent pas accéder à des soins médicaux à jour en raison du mauvais financement de la santé et de la pauvreté, des infrastructures sanitaires et des installations médicales inadéquates, notamment des services de transfusion sanguine et du matériel médical

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obsolètes. Il y avait une myriade de défis médicaux auxquels sont confrontés les personnes atteintes de la drépanocytose au Nigeria: maladies fréquentes et crises qui peuvent comprendre des douleurs osseuses, anémie récurrente, paludisme, ulcère de jambe chronique et même risque de VIH et d'hépatite B provenant de transfusions sanguines fréquentes. De même, les patients drépanocytaires peuvent rencontrer des difficultés psychologiques, selon les répondants, en raison des maladies fréquentes, de la discrimination subie ainsi que de la stigmatisation. Certains répondants ont fait valoir que la maladie et sa physiopathologie demeurent ignorantes chez les patients eux-mêmes, chez leurs soignants et dans la population en général, alimentant ainsi de nombreuses croyances superstitieuses. Certains défis liés aux systèmes de santé mis en évidence dans la gestion de la drépanocytose comprennent un soutien financier inadéquat ainsi que des infrastructures médiocres pour le diagnostic et le traitement.

Conclusion: Le manque de connaissances sur la drépanocytose dans la communauté devrait être comblé par une éducation sanitaire constante afin de réduire la stigmatisation. Il est également nécessaire de mettre en place une politique efficace pour protéger les personnes vivant avec la drépanocytose contre la discrimination sur le marché du travail et sur le lieu de travail. Un meilleur financement pour la recherche ainsi que le renforcement de l'assurance de santé sociale contribueront grandement à promouvoir la prise en charge de la drépanocytose et à réduire les dépenses catastrophiques et la pauvreté parmi les patients atteints de drépanocytose et leurs familles.

Mots-clés: *Drépanocytose, Gestion des systèmes de santé, Point de vue des médecins, Dépenses de santé directes*

Introduction

Nigeria bears the greatest burden of sickle cell disease (SCD) in sub-Saharan Africa. [4]About 25% of Nigerians have the sickle cell trait.[6, 7]The disorder is usually associated with a huge psychological and financial burden on families and individuals especially in developing countries with limited social security.[1, 5]

Furthermore, despite being one of the most common monogenic disorders globally, SCD diagnosis and management are still largely rudimentary especially in Africa where the clinical course of the disease is more aggressive and there exists a wide knowledge gap with lack of novel therapies. [3, 12]Many studies have examined the pathophysiology and molecular nature of the disease but studies exploring the views of physicians, who are primary care givers, about the disease, the management modalities and health systems response are sparse. It is thus imperative to understand the views and perspectives of the doctors primarily involved in their management. This information will promote our understanding of the sickle cell disease process and how the health system may better respond to these challenges.

The findings of this study will have implications for patient education and policy formulation in healthcare delivery. This study therefore aims to explore the views of physicians at the University College Hospital about challenges facing SCD management in Nigeria as well as the health system responses to these challenges.

Methods

This cross-sectional study was conducted in 2015 and it is part of a larger study on management of sickle cell disease in Nigeria. A total of ten in-depth interviews (IDIs) were conducted at the University College Hospital (UCH), Ibadan, Southwest Nigeria. The University College Hospital Ibadan is a flagship referral center for Nigeria and many parts of the West African sub-region. The hospital has a department of haematology that provides clinical care for patients with sickle cell disease.

The study population consisted of resident doctors who had worked in the Department of Hematology for at least a year. A total of 10 resident doctors in Hematology were interviewed. All were men with ages ranging from 25 to 40 years(Median=30.5 years). However, nationality, gender or religions were not prerequisites for the selection of participants for the IDIs. The authors facilitated some of the interviews while the others were facilitated by research assistants who were also doctors in community medicine/health management. Each interview was recorded, with the participant's consent, using a digital voice recorder. The interviewer also took note of non-verbal expressions of participants. All the interviews were conducted in English.

Participants in this study were recruited through a purposive sampling method based on their ability to provide relevant information on the subject of interest and availability. An in-depth interview guide was used to facilitate the interviews. Issues explored in the interviews included views and opinions of participants presentation of SCD patients in this environment, causes of crises in SCD, challenges faced by people living with SCD in Nigeria as well as the challenges with the management of SCD in Nigeria. [14]

Data from the IDIs were transcribed and analyzed with the aid of the NVIVO (version 10)

software using the thematic framework approach to qualitative data analysis [15].This was an iterative process of analysis which started right after the first interview and continued throughout the research. A thematic framework was developed from emerging themes in the interviews. As themes emerged, these were indexed and compared with themes from subsequent interviews until a sense of attainment of saturation was achieved [15].

Ethical considerations

Ethical approval was obtained from the University of Ibadan/University College Hospital Ethical Review Board. Written informed consent was also gotten from participants before the interviews.

Results

The results of the qualitative enquiry into the subject of the perception of physicians about the challenges of individuals living with SCD in Nigeria as well as the physicians' view of SCD management in Nigeria:

Challenges faced by SCD patients in Nigeria

The interviewed physicians thought that SCD patients in Nigeria are confronted by a number of challenges. Some participants described some general/background challenges which include ignorance and superstitious beliefs on the part of parents/caregivers of SCD and the patients themselves on what causes the disease, the symptoms and management options. The ignorance and superstition may affect their compliance with medical management. As stated by some of the respondents:

"...it starts from the ignorance of the parents. Let us start from a child being born, if the parents do not have idea what sickle cell is, that is a challenge on its own. Now when the child begins to have problem ... the quality of medical care from the childhood is substandard" (IDI 10).

"...other challenge we find in this environment is poor education, some people still believe some myths that sickle cell disease is a punishment from some gods whatever... There is this dangerous belief people have, that when they attain a particular age they are immune from sickle cell crisis - that is another challenge. You will see people will not come for follow up in a long time" (IDI 6).

These challenges were described as "...lifelong ...and enormous" (IDI 3). According to the respondents these challenges include medical, psychological, social and financial challenges. These challenges are highlighted below and summarized in Figure 1.

Financial challenges

The management of SCD is said to be financially tasking. Many of the SCD patients, in the opinion of this study participants, cannot access good medical care or keep up with prescribed line of management because of inadequate finances and poverty. In the word of one of the physicians, "...the greatest challenge is finance. It is a chronic disease that takes away the little earnings that they have and recurrent crises and recurrent need for medical treatment and their drugs. It tells more on them and most of them are mainly from low socioeconomic class" (IDI 6). While alluding to the importance of lack of finances among all other challenges facing SCD patients in Nigeria, a participant said: "...If I would arrange in descending order, I would first of all consider the financial challenge..." (IDI 9). Furthermore, another respondent corroborated: "...it requires a lot of resources in managing the crises so I think by and large the limitation to resources available to the patient is one of the most serious challenges that they face" (IDI 4).

Physicians' perception of medical challenges faced by patients

According to the participants, there are myriads of medical challenges facing individuals with SCD in Nigeria. These medical challenges include frequent illnesses and crises and slow growth. The illness may comprise bone pains, recurrent anemia, malaria, chronic leg ulcer and even risk of HIV and Hepatitis B from frequent blood transfusion. Also, the chronic nature of SCD and the need for constant medications sometimes affect patients' compliance with prescriptions. These issues, some participants opined, are challenging both for the patients and the primary caregivers. Some verbatim quotes from respondents are presented below:

"...most of them (SCD patients) when they come in, you think it is just bone pain; you cannot estimate when the patient is likely to be discharged...their disease has unpredictable pattern. I have seen a case that came in with pain and ended up with severe haemolytic crisis thereafter went into anemic heart failure, sequestration crises. She spent like almost a month before we could discharge her" (IDI 5).

"...when they are exposed to some conditions you and I ... are exposed to everyday because of their condition, they find it very difficult to manage it, for example: malaria" (IDI 3).

"...We have some patients who do not believe they have to be on medications (hematinics) perpetually.... That in itself is a challenge because it then becomes difficult for you to convince a patient

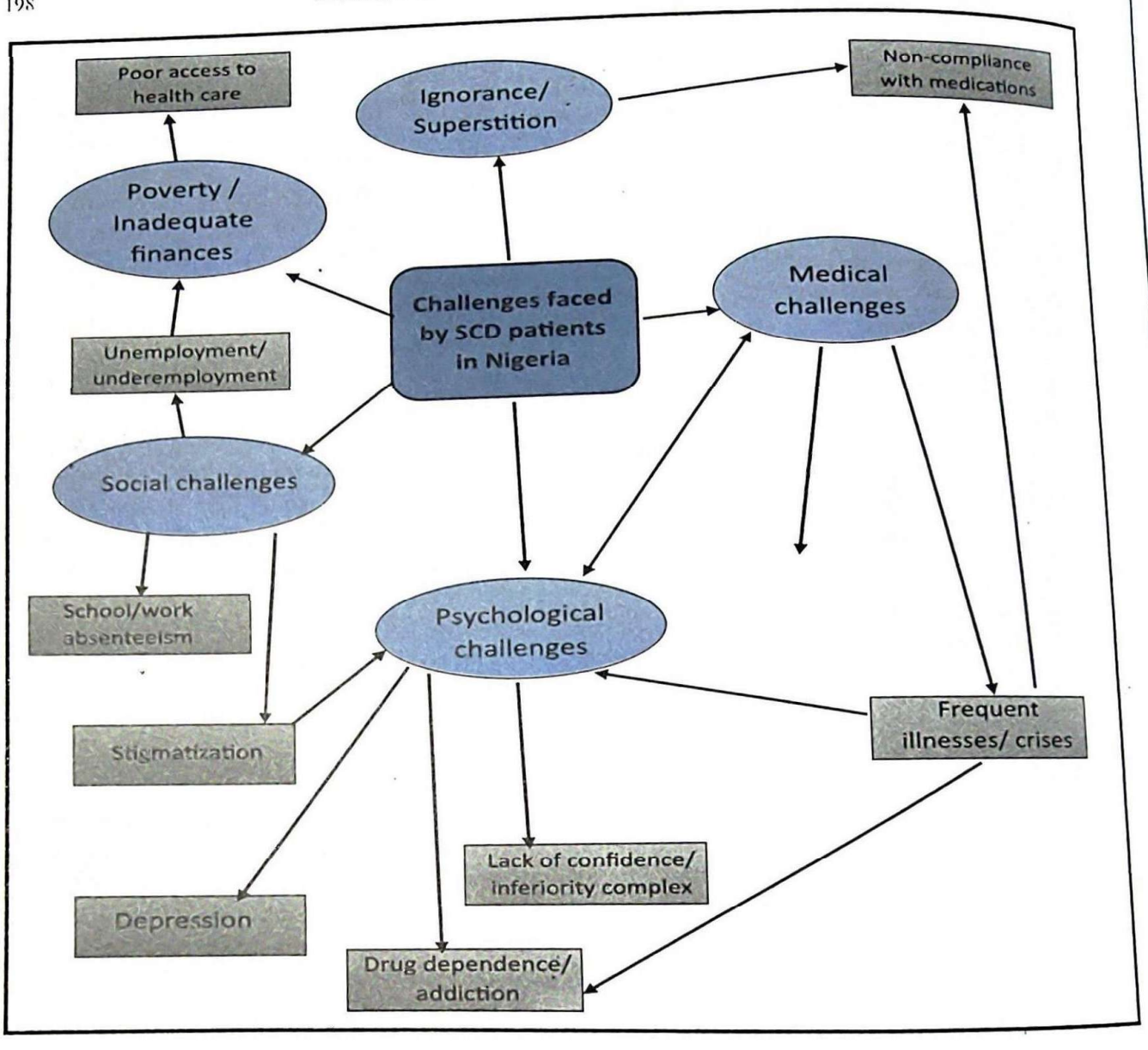

Fig. 1: Respondents' view on challenges facing sickle cell disease patients in Nigeria

to be adherent/compliant to the management when stable or there is no apparent sickness" (IDI 3).

""As a result of repeated transfusion, some SCD clients also come down with infections (like) HIV, Hepatitis B which could also lead to liver diseases and a host of others." (IDI 7)

Psychological challenges

There are a number of psychological issues SCD patients confront. Sometimes, these issues are intertwined with the medical challenges. Some respondents suggest that it is not only persons living with SCD that struggle with these psychological challenges but also the parents/ caregivers and families of SCD patients. Some of the issues that may bring psychological stress include the physique (which may be smaller than that of persons of the same age and gender), frequent illness and the attendant suffering.

"...in those days people just get married to each other without apparently checking their hemoglobin composites and eventually give birth to children with sickle cell disease and because of the chronic nature of the disorder and attendant manifestation, many a times you see family separated because the father will blame the mother for bringing the problem into the family." (IDI 4)

"...if you look at their physique, in fact it is enough to make them psychologically affected, because often times with their physique you can actually describe the classical sickle cell habitus even before patients are subjected to hemoglobin electrophoresis. (IDI 8)

Also some respondents opined that SCD patients often suffer from lack of confidence, doubtful marital prospects, stigmatization and drug dependency and addiction. One participant said:

"...when one is subjected to severe stress, there could be some form of depression. A few might come down

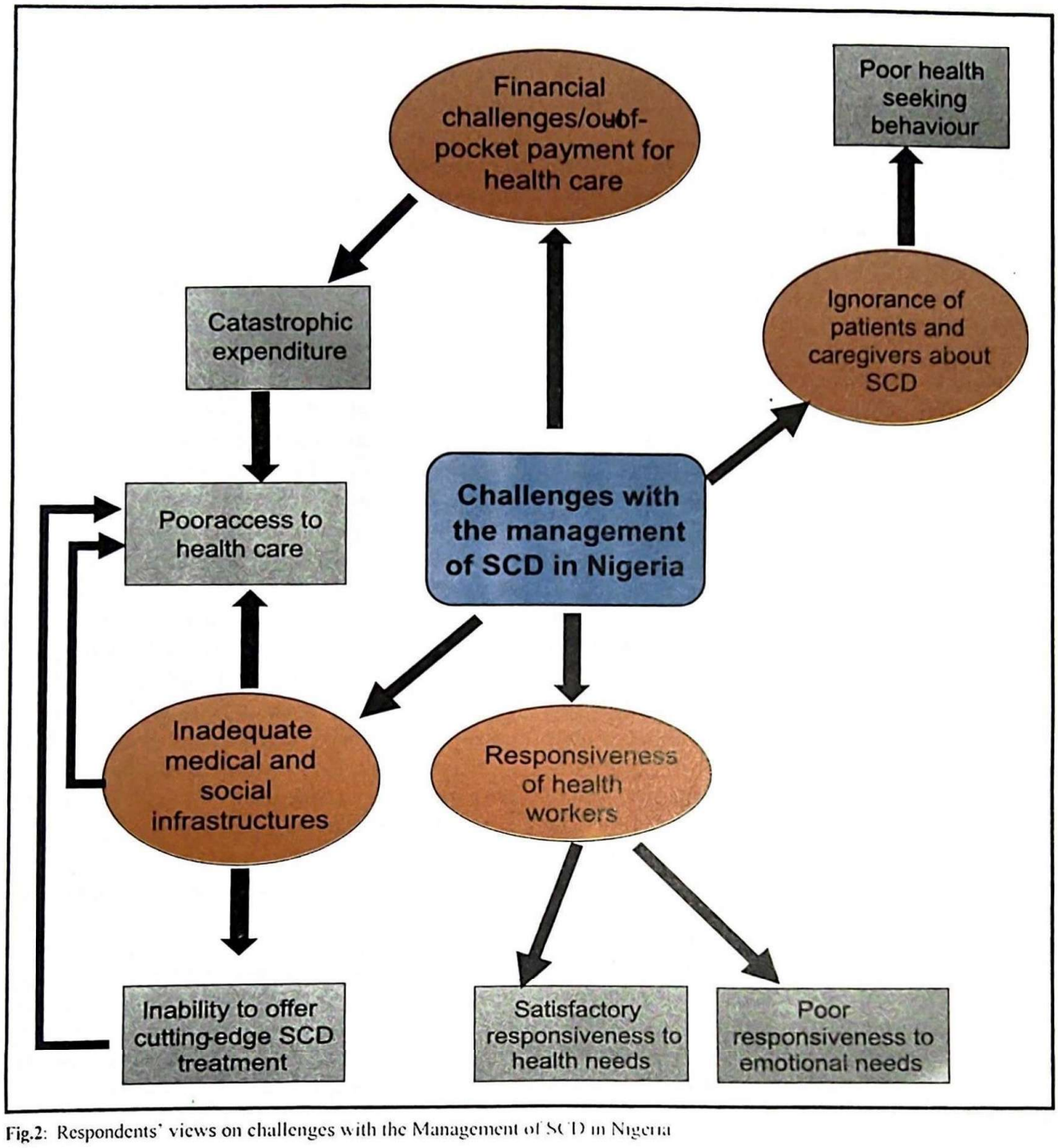

Fig.2: Respondents' views on challenges with the Management of SCD in Nigeria

with depression. In fact, some of them get addicted to things like morphine. In a bid to control the pain they develop that dependence."

According to another respondent, SCD patients tend "...to be less confident and they need a lot of support to improve their confidence" (IDI 10). In the opinion of another respondent, parent may stigmatise their children with SCD unknowingly: "Also a form of stigmatization - parents do not want other people to be aware of the child's condition..." (IDI 2). In addition, there could be regrets from the SCD patient (for being born with such an ailment) or the parent/caregiver (for entering the union that produced such suffering in an individual). To buttress this, a participant said: "...some of them have these feelings of wanting to blame their parents for not choosing rightly and having children with such an abnormality. So their parents have these ... feeling of regret to have married in such a way as to predispose them to producing an offspring with Sickle cell disease " (IDI 5).

Also there could be fear – of death and getting sick, feeling of guilt and inferiority complex and this could make the SCD patient withdraw from other people. A few quotes from participants to support this assertion include:

"You talk about ... fear of death. He/she may not be socially inclined, few friends, probably stays indoor most of the time, then fear of getting sick" (IDI 10)

"They feel guilty at times for not performing to expectation; they don't like the fact that people look at them as being "subnormal", sort of. Then even when they are present at work, those (SCD patients)

always want to perform in a way that people won't see them as being subnormal..." (IDI 5)

"...they withdraw from others - colleagues and activities" (IDI 5)

"...So the one (SCD patient) who goes in and out of the hospital, with time may begin to feel inferior and want to ask questions: what is really wrong with me? Am I normal?"(IDI 3)

Social challenges

Respondents alluded to the fact that there are numerous social challenges facing persons with SCD ranging from school or work absenteeism due to frequent illnesses, employability and hence income and ability to pay for healthcare, challenges with relationships, difficult pregnancy and delivery for women. "...It affects the child education; you could have poor attendance: when the child is sick, he/she misses exams. Now how is the child going to end up? How employable is this person? This now contributes to the person inability to pay for health care?" (IDI 10)

As par relationships, it becomes a little challenging as they seem to have a very narrow pool to choose from with regards to genotype compatibility. According to one respondent, "Some of the social issues they may see would include choice of marriage partner, because they have to be sure of the genotype of the person they likely to marry. They cannot just marry anybody." (IDI 8)

A respondent also reported that the stigma of being called a 'sickler' or being treated like an invalid is also a real challenge in the Nigerian context: "...people say 'you are a sickler', that is a stigma... She is a sickler; she can die. That stigma is there and then in the workplace, how fit is the person for the kind of work? (IDI 10). A more terrible kind of stigma however is to refer to children with SCD as *Ogbanje* – a mythical demonized child who would not stay on earth but would die after a while. A participant narrated his experience:

"...I remember as a child we used to hear what they call Ogbanje i.e. some little kids who come from the spirit world; they don't want to stay and they keep falling sick until they end up dying and that is the belief which hopefully education and enlightenment have come to clear but I can see that some people still believe their existence. There is that concept of bewitched children."

Challenges with the management of SCD in Nigeria

There are a number of challenges with the effective treatment/management of SCD patients in Nigeria. In the opinion of respondents, some of these challenges have to do with how much patients and their caregivers know about the condition whereas some are as a result of health systems challenges in the country. The health systems challenges include out-of-pocket payment for healthcare, poor hospital infrastructures, inadequate blood transfusion facilities. These challenges are examined in greater depth below with verbatim quotes from participants. Figure 2 below also summarizes these challenges.

Limited knowledge of patients and caregivers about SCD

Many SCD patients as well as their parents/ caregivers are still said to be ill-informed about the disease and how to take care of themselves or provide support to a patient before coming to the hospital. According to a participant, "...some patients don't even know what is happening to them; most of them don't know how to take care of themselves; they don't know what to do and what not to do, things to avoid and things not to avoid. So having a good understanding of their own condition is also a problem for many of the patients." (IDI 8). About caregiver ignorance, a respondent remarked thus: "...it starts from the ignorance of the parents. ... if the parents do not have idea what sickle cell is, that is a challenge on its own." (IDI 10).

Financial challenges/out-of-pocket payment for health care

Due to the chronic nature of the disease and the need for relatively frequent consultations and hospitalization, with the predominant out-of-pocket-payment for healthcare, many SCD patients and their caregivers experience financial stress and catastrophic expenditure. In the words of a respondent, "...the fact that they (SCD patients) have to be hospitalized; pay for consultation; do investigations, so most of them have financial challenges" (IDI 5).The participant added that "When patient are asked to do test they can't afford: when they buy this drug, they may resort to begging and sourcing for funds... We have some of them that are homeless, most of them are jobless; owing to the fact that some have been made handicapped from the disease". In the opinion of another participant, "...the greatest challenge is finance. It is a chronic disease that takes away the little earnings that they have and recurrent crises and recurrent need for medical treatment and their drugs. It tells more of them and most of them are mainly from low socioeconomic class" (IDI 6).

Although the National Health Insurance Scheme (NHIS) is operational in Nigeria, many SCD

patients are not covered. One of the participants suggested: "...we still need more financial support in terms of NHIS, I mean Health Insurance Scheme to be available to almost all patients. Maybe we can have NGO, bodies that can really support them" (IDI 5).

Inadequate medical and social infrastructures

In the opinion of the interviewed doctors, challenges of SCD management in Nigeria span from diagnosis to actual treatment of patients. According to a respondent, "We have so many challenges in diagnosis. Though by and large, we are able to diagnose accurately with electrophoresis most of the time but there is this pocket of patients that have non typical usual hemoglobin variant" (IDI 4).In addition, a participant added: "I believe that with the recent advancement in management of this SCD, we should be able to offer them more than we do now. Precisely ...bone marrow transplant if they can afford it...I will not say we have got everything to take care of them" (IDI 6).

Furthermore, participants were of the opinion that many SCD patients cannot access good healthcare when they need it as a result of inadequate health infrastructures and medical facilities including blood transfusion services and medical equipment. According to a respondent, "Availability of blood for transfusion... is an issue" (IDI 10). The respondent added: "For instance we need a pulse oximeter which is very important, especially for our triage centerwhich we don't have...I think the problem is more about facilities and can be improved upon" (IDI 10). Some respondents believed that it is difficult for SCD patients to access good healthcare in the Nigerian context of weak health system. In the words of one of the respondents, "Health facilities in Nigeria generally, I will not say it is adequate, but we are just trying to offer the best we can offer with the little that is available to us" (IDI 5).In the opinion of another respondent, "I think in this center we have a comprehensive care... except for the sophisticated... bone marrow transplantation which is the gold standard therapy for people who are eligible at that age" (IDI 4).

However, a respondent proposed a special unit to take care of SCD patients in order to take care of their special needs; "I think special people like these should actually have special form of care...I would suggest ... a special unit in the hospital, maybe a special ward that will take of care of sickle cell patient..."(IDI 3).

Responsiveness of health workers

Generally, participants agree that health workers are very responsive to taking care of the health needs of SCD patients including their emotional needs. A respondent said: "...most of the time the management of SCD is an empathic kind of a relationship. In our own setting here, we have dedicated workers who empathize with people who have this disease ... to assist them in overcoming their distressing circumstance ..." (IDI 4). One of the participants buttressed the need for emotional responsiveness from the health workers with a personal story:

"...there is a medical student who was always coming down with pain. I just decided to be a friend to the guy and I think for some time now he has been doing well. I am just trying to say some of them need support. Some of them will just come to the hospital with crises and after their parents show them some level of love they get better and they go home" (IDI 6).

However some respondents believe that health workers' responsiveness to SCD patients' emotional needs is poorer probably due to stress. As a participant puts it: "...the stress of work sometimes gets to some of us and we do not have empathy. I think many of us do try" (IDI 6). Furthermore, one of the participants interviewed believed that it takes training to be able to handle emotional needs of these patients better. "Yes it comes with the training, yes as a doctor you don't only look at the physical part but you consider the emotional part" (IDI 3).

Respondents' satisfaction with treatment received by SCD patients

Many of the respondents believe the care given to SCD patients in a tertiary hospital like theirs is much better than what obtains in other centers. Most respondents rated the SCD management in their center – the University College Hospital as fair although there is a consensus that the management can be better. According to a respondent, "...from what I have seen, I think our patients prefer our care because it is better than what they get from outside facilities" (IDI 5).

However, the respondent added that there are patients "...complaining about the kind of care they were given at referral centers that are not really into special care of sickle cell disease". Nonetheless, another doctor interviewed believed that patients are usually treated well especially because management has provision for indigent patients. His words: "...based on my experience, they (SCD patients) are well attended to...regardless of the financial aspect of the patient, you go to the management, talk with them and you are in for the treatment" (IDI 9).

Discussion

We present in this study physicians' views and opinions about the challenges with the management of sickle cell disease in Nigeria as well as the challenges facing individuals living with the disease in the country. As expected, participants have a good understanding about the etiology, distribution and presentation of the disease in line with what has been described in literature [1-3,5-7]. However, while making a case for better physician education on SCD, Adewoyin [4] submitted that Nigerian doctors need to know more on SCD phenotypes and comprehensive management of the disease in order for the quality of lives of persons living with the disease to improve.

Also, our study suggests that ignorance, poor education are still issues among persons living with SCD, their parents or caregivers in Ibadan. In a British study [16], researchers reported that ignorance about the natural course of SCD and the poor information about the disease's epidemiology hampered the effective management of the disease in Britain. Similarly, Burnes and colleagues [17] demonstrated through their Canadian study that the issue of SCD stigma is not limited to developing countries and that it has implications for health system responsiveness. Their study also showed that stigma can lead to social isolation for SCD patients and their families as well as reluctance to join a support group.

Also, our study highlighted other challenges facing SCD patients and their families including reported high out-of-pocket expenditure in paying for healthcare leading to poverty, stigma which leads to isolation in the immediate communities and in the labor market. Just like this study revealed, Abuosi and colleagues [18]in a study done in Ghana posited that there is a huge financial burden on families treating children with non-communicable diseases [NCDs] like SCD as a result of the ineffectiveness of the national health insurance system which offered no protection for children with NCDs from poor families and rural areas. This picture of high financial burden and poor insurance coverage among SCD patients and households was also demonstrated in Nigeria. [19]

In addition, studies have shown a vicious cycle between illnesses from SCD, poverty from low productivity as well as social stigma against SCD patients, their families [19,20]. Mubyazi and Njunwa [20] suggested that more resources need to be invested in research, public enlightenment and education in order to reduce the social stigma as well as in engaging policy makers in order to get these issues on the policy agenda.

Furthermore, apart from stigma, SCD patients and their families may also experience family disharmony, poor self-confidence and guilt. Good family support, reduced daily stress and conflicts have been suggested as essential for good psychological adjustment among SCD patients [21,22].

Physicians who participated in this study were of the opinion that the infrastructures for managing SCD were lacking or at best poor in Nigeria despite great advances in the management of the disease including hydroxyurea therapy, chronic blood transfusion and haemopoietic stem cell transplantation [4]. However, research has shown that SCD management requires a holistic approach which is mindful of the psychological, physical and financial needs of the affected individuals in a milieu of a responsive health system and good social support [23].

Conclusion

Physicians interviewed in this study were of the opinion that sickle cell disease patients and their families face myriads of challenges in Nigeria which range from medical, psychological, social and even that of poor health systems to address their needs. It is imperative that the knowledge gap in the community about the disease be bridged through constant health education and enlightenment in order in order to alleviate stigma about the disease. There is also a need for an effective policy to protect persons living with SCD from discrimination in the labor market as well as the workplace.

Furthermore, the government as well as the private sector need to invest more in research that promote better management of SCD including improved blood transfusion services and bone marrow transplantation. Special protection should also be given to SCD patients in the National Health Insurance Scheme in order to ameliorate catastrophic health expenditure and poverty among SCD patients and their families. A possible way of doing this is to ensure greater coverage of the people in the informal sector [where a greater proportion of the poor falls] through a greater spread of the community based health insurance. [24]

References

1. Brown B, Okereke J, Lagunju I, *et al.* Burden of health care of carers of children with sickle cell disease in Nigeria. Health & social care in the community. 2010;18(3):289-295.
2. World Health Organization. Fifty-Ninth World Health Assembly. Resolutions anddecisions

annexes. Resolution WHA59. 20. Sickle cell anemia(Internet). Geneva 2006.

3. Weatherall DJ. The inherited diseases of hemoglobin are an emerging global health burden. Blood. 2010;115(22):4331-4336.
4. Adewoyin AS. Management of sickle cell disease: a review for physician education in Nigeria (sub-saharan Africa). Anemia. 2015;2015.
5. Ohaeri JU and Shokunbi WA. Psychosocial burden of sickle cell disease on caregivers in a Nigerian setting. Journal of the National Medical Association. 2002; 94(12):1058.
6. Akinyanju OO. A profile of sickle cell disease in Nigeria. Annals of the New York Academy of Sciences. 1989;565(1):126-136.
7. Fleming A, Storey J, Molineaux L, Iroko E and Attai E. Abnormal hemoglobins in the Sudan savanna of Nigeria. I. Prevalence of hemoglobins and relationships between sickle cell trait, malaria and survival. Annals of tropical medicine and parasitology. 1979;73(2):161-172.
8. Ferster A, Tahriri P, Vermylen C, *et al.* Five years of experience with hydroxyurea in children and young adults with sickle cell disease. Blood. 2001;97(11): 3628-3632.
9. Hickman M, Modell B, Greengross P, *et al.* Mapping the prevalence of sickle cell and beta thalassaemia in England: estimating and validating ethnic‐specific rates. British journal of Hematology. 1999;104(4):860-867.
10. Platt OS, Brambilla DJ, Rosse WF, *et al.* Mortality in sickle cell disease—life expectancy and risk factors for early death. New England Journal of Medicine. 1994;330(23):1639-644.
11. Ohaeri JU, Shokunbi WA, Akinlade KS and Dare LO. The psychosocial problems of sickle cell disease sufferers and their methods of coping. Social science and medicine. 1995;40(7):955-960.
12. Rees DC, Williams TN and Gladwin MT. Sickle-cell disease. The Lancet. 2010;376(9757):2018-2031.
13. Guion LA, Diehl DC and McDonald D. Conducting an In-depth Interview2001. Available from: http://greenmedicine.ie/school/images/Library/ Conducting%20An%20 In%20 Depth%20Interview.pdf.
14. Pope C and Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. BMJ: British Medical Journal. 1995; 311 (6996) :42.
15. Temple B and Edwards R. Interpreters/translators and cross-language research: Reflexivity and border crossings. International Journal of Qualitative Methods. 2008;1(2):1-12.
16. Streetly A, Dick M and Layton M. Sickle cell disease: the case for coordinated information. British Medical Journal. 1993;306(6891):1491-1492.
17. Burnes DP, Antle BJ, Williams CC and Cook L. Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma. Health and social work. 2008;33(3): 211-220.
18. Abuosi AA, Adzei FA, Anarfi J, *et al.* Investigating parents/caregivers financial burden of care for children with non-communicable diseases in Ghana. BMC pediatrics. 2015;15(1):1.
19. Olatunya OS, Ogundare EO, Fadare JO, *et al.* The financial burden of sickle cell disease on households in Ekiti, Southwest Nigeria. ClinicoEconomics and outcomes research: CEOR. 2015;7:545.
20. Mubyazi GM and Njunwa KJ. Is sickle cell disease sufficiently prioritized in policy and socio- economic research on diseases in Tanzania? Lessons for the past 50 years. Tanzania journal of health research. 2012;13(5).
21. Thompson RJ, Gil KM, Burbach DJ, Keith BR and Kinney TR. Psychological adjustment of mothers of children and adolescents with sickle cell disease: The role of stress, coping methods, and family functioning. Journal of Pediatric Psychology. 1993;18(5):549-559.
22. Gil KM, Carson JW, Porter LS, *et al.* Daily stress and mood and their association with pain, health-care use, and school activity in adolescents with sickle cell disease. Journal of Pediatric Psychology. 2003;28(5):363-373.
23. Dennis-Antwi JA, Dyson S and Frempong KO. Healthcare provision for sickle cell disease in Ghana: challenges for the African context. Diversity and Equality in Health and Care. 2008.
24. Onwujekwe O, Onoka C, Uguru N, *et al.*. Preferences for benefit packages for community-based health insurance: an exploratory study in Nigeria. BMC health services research. 2010;10(1):162.