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The Health Workers Perspectives in the Management of Sickle Cell Disease in an Urban Health Centre in Ile-Ife, Nigeria

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Abstract

Management of sickle cell disease is key to improved quality of life of people living with the disease in Nigeria. This paper examined management strategies utilized by health workers in managing sickle cell patients in Obafemi Awolowo University health centre, in Ile-Ife, Nigeria. The specific objectives were to explore health workers definition of the disease, the observed symptoms by the health workers, drugs and non-drug strategies employed by these health workers in the management of the patients and the adequacy of health facilities for managing sickle cell patients. With structured in-depth interview schedule, fifteen health workers including nurses and doctors were interviewed. It was indicated that unanimously, health workers defined the disease as an inherited blood disorder which is highly symptomatic with a lot pains all over the body especially in joints and chest and that the sufferers are often admitted in the hospital. Also, the health workers use antibiotics, folic acid, analgesics, anti-malaria drugs, intravenous fluids and blood transfusion as drug regimens for managing the sufferers. The non- drug strategies employed by the health workers were counselling, education for self-care and psychotherapy. Furthermore, the health workers indicated that inadequate health facilities hamper their capacity to deliver effective management to people living with the disease. The paper concludes that health workers employ both drug and non-drug management strategies that promise improved quality of life for sickle cell patients in Nigeria but are constrained by inadequate health facilities and consumables.

Keywords: Sickle cell disease; Health workers; Management and political economy

Introduction

Sickle cell disease is a genetic disorder inherited from one's parents. It is estimated that 200,000 children are born with this disease in Africa annually (Ansong et al.) [1]. In corroboration of this, Alege [2] posited that Nigeria has the largest population of people with sickle cell disease in the world with over 150,000 babies born with serious condition every year. Nigeria bears the greatest burden of sickle cell in Sub-Saharan Africa (Adewoyin) [3] with forty million people carrying the gene for sickle cell disease in the country (Alhassan) [4]. Sickle cell disease can be in several forms which include sickle cell anaemia (when inherited in homozygous state), sickle cell beta plus thalassemia, sickle beta zero thalassemia and others (Adewoyin). Due to the symptomatic nature of the disease, people living with sickle cell disease are always in and out of hospitals. As such, health workers are confronted with daily routine care and management of people with the disease. The health workers see to the right drugs and how it can be taken and also give instructions on how to live their lives and other health education matters in order to minimize their chances of having crises. In the process of doing this, the health workers face a lot of challenges which may be in form of inadequate facilities and lack of training in the management of this special type of patients. As noted by Ansong et al. [1], health workers manage different symptoms and complications arising from the disease such as pains, infections, severe anaemia, acute chest syndrome, stroke and hip nectrosis. In managing these symptoms, health workers encounter enormous challenges such as gastric erosion and ulcers, lack of good microbiology laboratory, lack of functional radiological facilities, inadequate provision of safe and reliable blood and limited availability of hydroxyurea (Ansong et al.) [1]. The other therapeutic options such as pneumococcal and haemophilus vaccines and hip replacement may not be readily available in West Africa (Ansong et al.) [1]. These are the challenges pertaining to hospital facilities. The health workers further face the problem of daily routine care and even education. Adewoyin [3] noted that there is gross absence of dedicated sickle cell centres and the disease forms a small part of clinical practice of general duty doctors. As such, health workers bear the burden of knowing what to do sometimes but there are no facilities to carry out that action which can be very frustrating. As noted by Adewoyin [3], there have been appreciation in the quality of life of sickle cell disease sufferers in developed nations but in Nigeria and other West African States, treatment and control of the disease are largely suboptimal. This is partly the motivation for this study. The management of the disease therefore becomes very important as the quality of management can have implications for the quality of life of people living with sickle cell disease. The motivation for this study stems from the fact that on a daily basis, many health workers are seen grappling with health emergencies associated with sickle cell disease and I felt it is important to examine the health workers perspective of this disease in Nigeria. This is with a view to establishing what the health workers actually do for people with sickle cell disease in managing the disease. Examining health workers perspective will take into consideration the health workers definition of the disease, the symptoms of the disease, the Nigerian health care facilities and the routine care, the type of drugs given to them, and non-drug strategies employed by the health workers in the management of sickle cell disease.

Framing the Study

In framing this study, the best approach that came to mind is the model of care in chronic disease which included the theory of nursing as proposed by Furtado and Lima da Nobrega [5] in which Wagner's chronic care model was the key element. Chronic care model was designed with a populational perspective and centred on the service users (Bacello et al.) as cited in Furtado and Lima da Nobrega [5,6]. As noted by Furtado and Lima da Nobrega, chronic care model is a multidimensional solution for a complex problem which relies on team work. This model entails the use of education for self-care, skills and attitudes. It also entails establishing relationship with clients, caregivers and communities, providing continuity of care, using technology to optimize the provision of care and supporting adherence to therapies in the long term (Furtado and Lima da Nobrega [5]. Applying this orientation to management of sickle cell disease from the perspective of health workers in the Obafemi Awolowo University health centre will enhance the explanation of the fact that the health workers (in this case nurses and doctors) work as a team in managing sickle cell patients. Effective management of this special kind of patients is critical for the survival and improved quality of life of people living with the disease in Nigeria. These health workers utilize drugs and non-drug strategies to manage these patients. The inclusion of non-drug strategies is necessary as it enhances the effectiveness of the drug therapy. This is especially important in this situation in which there are inadequate health facilities for the management of the disease in Nigeria as noted by Ansong et al. [1]. In the management of sickle cell disease, the health workers are hampered by this problem of inadequate facilities and the lack of government will to put necessary facilities in place pointing to the political economy of Nigeria. It is this same political economy – that is, lack of political will on the part of government that brought about few or no functional health facilities in rural areas which compounds the problem of management of sickle cell disease in Nigeria.

Methodology

The context

The study was carried out among health workers (nurses and doctors) in Obafemi Awolowo University health centre, Ile-Ife, Nigeria. This health centre is a large hospital that serves the entire university community (about thirty two thousand students and ten thousand workers) and its environs. The health workers in its employment are about twenty doctors and thirty three nurses. The health centre render a twenty four hour service and it is always a beehive of activities. The health workers attend to anybody with any health problem who presents at the hospital including sickle cell patients. The study lasted for two months – (between Octoberber 1st and November 30th, 2016).

Methods

The qualitative method of in-depth interview was employed in the collection of primary data. Fifteen health workers (seven doctors and eight nurses) were interviewed. The health workers were reached in their offices for the interviews. Each interview lasted between forty to sixty minutes. I used conversational interviews to capture the experiences of these health workers in the management of sickle cell disease in the health centre. The recording of the interview session was done by note taking which was aided by a tape recorder. The specific research questions were: what daily routine care do health workers give to people living with sickle cell anaemia, what drugs do health workers use in management of sickle cell disease sufferers? What are the other non-drug strategies employed by health workers in managing sickle cell disease?, Are the available facilities adequate for management of the patients? Each interview session lasted between forty-five (45) to sixty (60) minutes. Data were transcribed and categorized and were analysed in themes in which each objective formed a theme.

Participants

The target groups were doctors and nurses who have been working in the health for at least five years. Participants were fifteen health workers in the health centre including eight nurses and seven doctors. The doctors are mainly general practitioners who also care for people with other health problems in the health centre. The same thing applies to the nurses meaning that there are no doctors or nurses that have been specifically trained for the management of sickle cell disease in the health centre just as in most hospitals in Nigeria. Most of the participants have been working in Obafemi Awolowo University health Centre for five years or more. These fifteen were selected due to their having been in the service of the health centre for five and more years and have encountered and cared for people living with sickle cell disease.

Results

The conversational interviews yielded a lot of data which were transcribed and categorized in themes and each objective formed a theme around which the data were analyzed and discussed. Generally, the health workers discussed extensively on their own definition of sickle cell disease, the routine care which they give to people living with sickle cell disease, the type of drugs they give to them in order to manage the crises, the non-drug strategies and the problem of inadequate health facilities. Importantly, the descriptions of their views and experiences were over lapping in so many instances indicating the fact that their experience with sickle cell patients that present at the health centre and their experience in the management of sickle cell disease were basically the same.

The health workers definition of sickle cell disease and management of sufferers

The health workers defined sickle cell as a group of related red blood cell disorder; a group of inherited blood cells disorder, typically inherited from a person's parents; ; a haemological disease that causes abnormal sickling of the red blood cells; hemoglobinopathy- a defect in the red blood cells haemoglobin; a congenital form of anaemia occurring mostly in black race characterized by abnormal blood cells having a crescent shape (sickle shape); a hereditary blood disease from both parents characterized by production of abnormal type of haemoglobin which is sickle in shape; is a group of inherited red blood cell disorder, people with sickle cell disease have abnormal haemoglobin called haemoglobin S; a group of disorder in which the haemoglobin is distorted into a sickle shape; a group of disorders that affect haemoglobin, the molecule in red blood cells that delivers oxygen to cells throughout the body. From these definitions, it is clear that the health workers have adequate knowledge of what sickle cell disease is an indication that all the health workers have encountered sickle cell patients and have cared for them. These definitions are similar to Ansong et al. and Adewoyin [1,3].

Importantly, the health workers indicated that sickle cell patients are often admitted in the health centre. According to one of the medical doctors, sickle cell patients are regularly admitted in the health centre especially during the rainy season, examination periods or temperature changes. This was also indicated by a senior nursing officer who said that; sickle cell patients are regularly admitted in hospital but the number of times they are admitted in the health centre in a year depends on the immune system of sufferers and how the sufferers care for themselves generally. If well cared for, they don't need hospitalization often but if not, they are often hospitalized. These results showed that sickle cell patients are often admitted in the hospital but there are ways to reduce the frequency of hospitalization which includes building the patient's immune system, compliance with the drug regimen being sensitive and avoiding stress and guarding against the effects of the weather. These ways of reducing sickle cell crises as indicated by health workers is an indication that successful management of sickle cell disease depends partly on the sufferers and their families because good nutrition that would strengthen the immune system depends on how the family of sickle cell patient is able to feed him/her. Also avoiding stress and complying to drug regimen are the responsibilities of the patient. This means that sickle cell disease is like any other chronic disease in which the patient ability to adopt correct life style is critical. Adopting the correct life style would improve the quality of life of sickle cell patients and would also reduce the severity of the symptoms as the disease is very symptomatic in nature.

In order to ascertain the symptoms of sickle cell disease in Nigeria, the health workers were asked to describe the symptoms as they encounter it on daily routine care for sickle cell patients. Majority of the health workers said that the major symptoms are pains in the various parts of the body especially in the bones with fever, anaemia, jaundice, wound, fatigue, painful swellings, dehydration, lethargy, vomiting, loss of appetite, stunted growth, protruding abdomen and infections. This showed that the sickle cell patients in Nigeria are having so many severe symptoms which are capable of disrupting their lives physically, socially and psychologically. This is because anybody that is having one or more of the above symptoms will not be comfortable to be involved in any meaningful activity. Importantly, these symptoms can be managed in such a way that sickle cell patients can live normal lives to some extent.

In Nigeria, sickle cell disease is managed with certain routine drugs. Most of the health workers indicated that they use analgesics, folic acid, anti-malaria, paludrine, vitamin B complex, intraveneous fluids, and antibiotics especially in suspected cases of sepsis and blood transfusion and topical balms. These drugs are available but the problem is that many families with sickle cell patients may not be able to afford them. The issue of poverty makes it difficult for such families to bring sickle cell patients to the hospital. Such delays can result in increased mortality of sickle cell patients.

Apart from drugs, the health workers also use non drug strategies to manage sickle cell patients. According to the health workers, counselling and psychotherapy are the major non drug strategies used in ensuring that sickle cell patients live comfortable lives. The patients are counselled and educated on the need for recognizing early detection of signs of crises and prevention. They are also encouraged to accept the situation and to take their medications as specified in order to stay healthy. Moreover, the sickle cell patients are sensitized on the importance of taking nutritious foods, how to avoid malaria and to avoid stress and undue exposure during the rainy season. They are also encouraged to take a lot of water and to dress up well during whether changes, for instance, to cover their bodies very well during cold periods. Furthermore, health workers indicated that they show sympathy and concern which tend to minimize the sufferings experienced by sickle cell patients. In a nut shell, the four major non drug strategies are counselling, education, diets, malaria prevention and stress management. This is an indication that the health workers are doing more than just prescribing drugs which implied that the health workers need special training in order to manage sickle cell patients efficiently.

Importantly, many of the health workers complained of inadequate health facilities and consumables and which makes it difficult to manage people living with sickle cell disease successfully. A female nursing officer in the health centre noted that the health facilities are inadequate in most health care facilities. Investigations needed are meant to be immediate and evaluated in order to give proper treatment but in most cases investigations will not be available until after twenty four hours. The implication of this is that a sickle cell patient in crises may have died before the result of the investigation comes out and this is how many sickle cell patients die avoidable deaths while the health workers watch helplessly. Also, as noted by a male doctor: some of our hospitals don't have adequate facilities or equipment to analyse the blood sample sent to them. Most treatments are blind spots and even the fluid intake and output charts are in shambles. There is no proper heart to heart management but God help some that survive each crises. In the same vein, another male doctor said: there are no special facilities for sickle cell patients. All hospitals in this environment takes care of general cases, hence sickle cell clients are only a proportion of every other patient and they receive little or no special attention and the limited health workers are compelled to serve every patient which is usually grossly inadequate. This has confirmed the fact that sickle cell patients are not adequately cared for and this could explain why the survival rate is low in Nigeria. Also, the fact that health workers are few and there is no special hospital or specially trained health personnel for sickle cell patient is an indication that both health facilities and personnel are not adequate which implies that sickle cell patients are in the hands of God. This is especially critical considering the fact that the disease is very symptomatic which makes it very devastating to sufferers.

However, some health workers believe that the health facilities are adequate because there is standard haematology unit and competent haematologist and those drugs are available. These two health workers believe that sickle cell patients do not need any special treatment but they also said that there are no adequate facilities for serious sickle cell crises but that the patient can be referred to the teaching hospital and though the major problem is that the patients may die before finishing the procedure to admission in the teaching hospital. The implication of this is that the facilities are still not adequate because being referred to the teaching hospital involves some logistics that would take time and other resources and which may constitute a push factor in mortality rate of sickle cell patients. From the fore- going, it has become clear that health workers are ready to do extra activities in order to make life more comfortable for sickle cell disease patients. However, they experience a lot of frustration in the management of sickle cell disease patients due to non-availability of necessary facilities to work with.

Discussion

The study set out to examine the definition of the disease by health workers, the symptoms, the drugs used in managing the disease, the

health facilities and non-drug strategies employed by the health workers. The definition given by most health workers showed that they have adequate knowledge of the disease and this is not surprising considering the fact that they encounter sickle cell disease patients daily; an indication that sickle cell disease patients are many, indicating the magnitude of the problem. Also, many of them were unanimous in the types of symptoms associated with the disease. The symptoms they indicated showed that sickle cell disease is a serious health issue which could explain why the disease devastates the sufferers. These symptoms implies that the patients cannot participate effectively in any social and economic activities and which calls for the need to ensure proper effective management of the disease. This is especially important considering the fact that many Nigerians are living with the sickle cell disease.

The drugs that are used in managing the disease are the drugs that are available here and which may not be the best. The other therapeutic options such as pneumococcal and haemophilus vaccines and hip replacement indicated by Ansong et al., (2013) [1] were absent in the treatment options indicated by health workers in this study. This means that sickle cell patients are not getting the optimal care they deserve in Nigeria. This could be partly due to government not giving sickle cell disease the attention it deserves and partly due to lack of expertise in handling certain treatment option such as hip transplant [6].

A non-drug strategy which represents a diversification of sickle cell management strategies showed that the doctors are doing a lot for the patients [7,8]. This supports the nursing chronic disease care model as posited by Furtudo and Nobrega) [5], which called for multi-dimentional approach in the management of chronic diseases. It also implies that there is so much the patient can do for them to make their life more comfortable. Importantly it points to the fact that special training is needed for the health workers to make them more efficient in these non-drug strategies because many of them are just doing it as a matter of concern without adequate training in that area [9].

Arising from these findings, lack of drugs, the inadequate health facility, the patients non- compliance with non- drug strategies all make it difficult for health workers to perform optimally and which can be frustrating to the health workers. Much of these issues are issues in the Nigerian political economy. This is especially in the area of policy as there is no effective policy to take care of people with sickle cell disease [10]. For instance, lack of health facilities is an indication that the Nigerian government has not put any effective policy in place to cater for the health needs of people living with sickle cell disease in the country. Indeed, the Nigerian government has not given sickle cell disease the urgent and serious attention that it deserves and this is why the mortality rate of sickle cell patient is very high in Nigeria. This is even worse in the rural areas where there is hardly any standard health facility. The implication of all these for the health worker is that the health workers capacity and ability to help sickle cell patient is curtailed by factors beyond their control and which as a matter of fact, no health worker enjoys [11,12]. This could be a pointer to the issue of brain drain in which health workers travel out to other countries to practice without thinking of coming back. Furthermore, the implication of this for sickle cell patient is that they are under served; they are not getting adequate attention and which could increase morbidity and mortality among them.

Importantly, the issue of political economy still rears its ugly head in every aspect of management of the sickle cell disease in Nigeria and it is difficult to say when lasting effective solution will be in place. For instance, it is not yet clear whether government is ready to fund any research on sickle cell in Nigeria. Those of us who are interested in researching in the area do it with our meager salary and funding research this way can discourage many researchers.

Sociologically, the implication of these findings is that the Nigerian society is not yet ready to tackle the problem of sickle cell disease [12,13]. Also, the traditional society's view of anybody that is disabled or incapacitated as useless may be a factor in the neglect of people living with sickle cell disease in the country [14].

Conclusion

This paper explored the health workers perspective in the management of sickle cell disease in Nigeria and found that health workers had adequate knowledge of the disease and utilized both drugs and non- drug strategies in managing people living with the disease. However, inadequate health facilities curtail their capacity to give effective and adequate care to sickle cell patients. The paper concludes that health workers have not performed optimally due to inadequate facilities and lack of expertise [15-17]. Their employment of drug and non-drug strategies promises improved quality of life for sickle cell patients in Nigeria.

The paper recommends that local health authorities should make effective management of sickle cell disease a priority and should allocate more funds to provision of adequate health facilities to enable health workers to perform optimally [17]. Also, training of medical personnel in the management of sickle cell disease should be a priority of government.

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