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Challenges and Counselling Needs of Sickle Cell Patients Attending University of Ilorin Teaching Hospital

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Abstract · This study investigated the challenges and counselling needs of sickle cell patients attending the University of Ilorin Teaching Hospital (UITH) Kwara State, Nigeria. Purposive sampling was used to select 120 literate regular and non-regular patients of the hospital. A researcher developed instrument titled "Challenges and Counselling Needs of Sickle Cell Patients Questionnaire" (CCNSPQ) was used to elicit information from these participants. Five research questions raised in the study were answered using frequency counts, means and ranking and Analysis of Variance was used to test the hypotheses formulated at the .05 level of confidence. The findings showed that excessive bone, abdominal and chest pains are the major challenges confronting the respondents while occasional embarrassment due to unexpected sickness accompanying sickle cell disorder and stigma are the most serious counselling needs. There was no significant difference in the challenges of sickle cell patients based on age but the respondents had significantly different counselling needs. Therefore, it is recommended that guidance and public health education be put in place to reduce the stigmatisation of sickle cell patients. In addition, well-equipped clinics should be provided to facilitate early treatment. Genetic Counselling should also be provided both in the school and the community to prevent future occurrence of sickle cell disorder.

Keywords • Sickle cell disorder • Genetic Counselling • Higher Education

Introduction

Sickle-cell disease (SCD) is an inherited disorder of haemoglobin which occurs in any child that inherited sickle haemoglobin from each of the two parents (e.g. Hb SS). It is a genetic blood disorder that affects the haemoglobin within the red blood cells and the recurrent pains and complications caused by the disease can interfere with many aspects of the patient's life, including education, employment and psychosocial development. Sickle-cell disease is the most common inherited blood disorder in Africa although it affects millions of people worldwide (Ogungbemi, 2008). According to Boureima (2012), SCD is

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a major genetic disease in most countries in Sub-Saharan Africa. The blood disorder is passed on from parents to their children and is present at birth and remains the same for life like the colour of the eyes or skin or shape of the ears, nose or legs. Akinyanju and Olujohungbe (2009) stated that it is not an infection, a malignant condition or a cancer. The molecule in the red blood cell that delivers oxygen to the cell throughout the body, i.e. the haemoglobin is affected. A sufferer carries a typical haemoglobin molecule called haemoglobin S which can change the shape of the normal red blood cell into a sickle or crescent shape. Ogungbemi (2008) indicated that the disorder occurs because of the mutation in the haemoglobin genes and this shortens life expectancy with studies reporting an average of life expectancy of 48 years in females and 42 years in males in Nigeria.

Signs and symptoms of sickle cell disorders usually begin in early childhood. This is characterized by a low number of red blood cells (anaemia, repeated infections and reoccurring episodes of pain). Anaemia can cause shortness of breath, fatigue and delayed growth and development in children. The rapid breakdown of the red blood cell may also cause yellowing of the eyes and skin which are signs of jaundice. Painful episode/crises occur when sickle red blood cells, which are stiff and inflexible are stuck in small blood vessels; thus, preventing oxygen from getting to the vital organs like the lungs, the kidneys, the spleens or even the brain. These could lead to organ damage and death (Ogungbemi, 2008).

In the traditional African society, children were and are still highly valued because they represent the continuation of the lineage and they are considered important by all families in general and in Nigeria in particular (Ipaye, 1983). African culture exhibits a strong desire for possession of children both as assets, heritage and pride, and lack of children among couples is looked at as a curse from the gods or spirits. Having children that are sickly or dying is also viewed as another form of punishment from the gods. Among the Yoruba in the Western part of Nigeria, the name "Abiku" meaning "born-to-die" is a derogatory name often given to children born with sickle cell anaemia because they die before attaining the age of 2 or 3 years (Durosaro, 2010). Largely due to ignorance, most couples in Nigeria, before the last two or three decades married without checking their genotype and since the haemoglobin *S* is a common feature, many carriers come together in marriage and the resultant effect is procreation of children with haemoglobin sickle-cell. Babajide (1992) investigated the attitude of people towards sickle cell disorder children in Nigeria and the study revealed a negative attitude towards them. Another study conducted by Odu (1998) assessed the prevalence of positive, neutral and negative attitude towards sickle cell disorder patients and identified the correlates of different attitude in the population. The findings of the study revealed that about ninety percent of women disagreed with prescriptive norm that favours not having children to having sickle cell positive children.

There are some problems that are associated with sickle cell disorder amongst which are bone crisis, abdominal pain crisis, swelling of the feet and hands, acute chest syndrome, priapism, life threatening events of anaemia crises, stroke, etc. These and many more challenges always affect any person with sickle cell disorder (Akinyanju & Olujohungbe, 2009).

Statement of the Problem

Sickle-cell anaemia is a major source of concern among parents in Nigeria in particular and Africa in general. Boureima (2012) noted that in Africa, the highest prevalence of

sickle-cell trait occurs between latitudes 15° North and 20° South, ranging between 10% and 40% of the population in some areas. Prevalence levels decrease to between 1% and 2% in North Africa and to less than 1% in Southern Africa. In countries such as Cameroon, Republic of Congo, Gabon, Ghana and Nigeria, the prevalence is between 20% and 30% while in some parts of Uganda it is as high as 45%. In countries where the trait prevalence is above 20% the disease affects about 2% of the population.

Several studies indicate that sickle cell disorder is very common in Africa (Akinyanju & Olujohungbe 2009; Ogbe, 2004) and that episodes of crisis resulting in death produce negative consequences for women in Africa. Regardless of medical explanation, Ogungbemi (2008) reported that children born with sickle cell disorder are regarded as wicked and callous children who have intentionally cause grief for their parents before going back to meet their colleagues in the spirit world. This issue is not a new phenomenon in the African society, but the lack of understanding of the scientific reasons for having children with sickle-cell anaemia and the counselling needs of sufferers on the continent call for concern among social researchers especially counsellors. According to Boureima (2012), counselling and prevention of causes and infections are simple measures not readily accessible to most patients in Africa. As a result, the majority of children with the most severe form of the disease die before the age of five, usually from an infection or severe anaemia. He stressed further that the survivors remain vulnerable to exacerbations of the disease and different forms of complication. As at the time of this study, the researchers are unaware of any comprehensive research work on sickle cell using the variables of interest to this study. Although, some earlier studies (Odu, 1998; Ogbe, 2004) were carried out on the coping strategies adopted by patients suffering from sickle cell anaemia, the focus of this study, as it is, is designed to investigate the challenges and counselling needs of patients with sickle cell disorder.

Research Questions

For the purpose of this study, the following research questions have been raised:

- What are the challenges and counselling needs of sickle cell disorder patients attending the University of Ilorin Teaching Hospital?
- Is there any difference in the challenges of sickle cell disorder patients attending the University of Ilorin Teaching Hospital on the basis of age?
- Is there any difference in the counselling needs of sickle cell disorder patients attending the University of Ilorin Teaching Hospital on the basis of age?

Research Hypotheses

Based on the research questions, the following research hypotheses have been formulated:

- There are no significant differences in the challenges of sickle cell disorder patients attending University of Ilorin Teaching Hospital on the basis of age.
- There no significant difference in the counselling needs of sickle cell disorder patients attending University of Ilorin Teaching Hospital on the basis of age.

Methodology

Descriptive research design was adopted for this study. The population of the study comprised sickle-cell anaemia patients of the University of Ilorin Teaching Hospital,

Nigeria. The target population consisted of literate sickle-cell anaemia patients of the University of Ilorin Teaching Hospital. Purposive sampling approach was adopted for the study. Thus, a total of one hundred and twenty literate sickle cell patients participated in the study. The instrument employed for the study is titled "Challenges and Counselling Needs of Sickle Cell Patients Questionnaire" (CCNSPQ). The instrument comprised three sections. Section A sought demographic data from the respondents; Section B contained items on challenges of sickle cell patients while section C contained items on the counselling needs of sickle cell patients. The content validity of the instrument was established by two professional Counsellors and a Physician while its reliability was determined using test re-test reliability procedure with a coefficient of 0.74 obtained. Respondents were required to respond to all the items on four-point Likert Type Scale of Strongly Agree, Agree, Disagree and Strongly Disagree. The questionnaire forms were administered by the researchers and five trained research assistants. Before the administration, the respondents were informed about the importance of the study, their consents were sought and the need to provide accurate information was emphasised. Data were analyzed using mean, percentage, ranking, t-test, and Analysis of Variance. All the hypotheses were tested at the level of confidence alpha = 0.05.

Results

The result of the findings are presented in tables 1-5

Table 1: Distribution of Respondents by Age, and Gender

Variation	Frequency	Percentage
Age		
18-30 years	26	21.7
31-40 years	83	69.2
41 years and above	11	9.2
Total	120	100
Gender		
Male	47	39
Female	73	61
Total	120	100

Table 1 shows that 26 (21.7%) respondents are between the ages of 10-20 years. The table also reveals that 83 (69.2%) respondents are within the age range of 20-30 years while 11 (9.2%) of the respondents are 31 years and above. A total of 47 (39%) respondents are males while 73 (61%) are females.

Table 2: Mean and Rank order of scores of respondents' challenges

The challenges of sickle-cell disorder are:	Mean score	Rank order
Excessive pain in the bone	3.49	1st
Excessive abdominal pains	3.25	2nd
Acute chest pain	3.21	3rd
Distorted growth	3.18	4th
Stroke	3.15	5th
Yellow coloration of the eyes	3.14	6th
Numbness of the lower part of the face (Jaw-numbness)	3.12	7th
Frequent hospitalization and anaemia crises	3.08	8th
Blood in the urine	3.04	9th
Priapism, painful leg ulcers	3.03	10th
Excessive painful hip joint	3.03	10th
Fits and cerebral seizures	2.88	12th
Frequent malaria pneumonia	2.71	13th
Inability to engage in physical exercise	2.66	14th
Frequent infections	2.43	15th

Table 2 reveals that majority of the respondents ranked excessive pains in the bone, excessive abdominal pains and acute chest pains as the major health challenges confronting them.

Table 3: Mean and Rank order of score of respondents on counselling needs

I need counselling to handle the following:	Mean score	Rank order
Occasional embarrassment caused by bone pains occurring at anytime and anywhere	3.36	1st
Emotional and physical effects of sickle-cell disorder	3.24	2nd
Preservation of life	3.23	3rd
Medical charges	3.22	4th
Occasional blood transfusion	3.20	5th
Stigma of having sickle cell disorder	3.01	6th
Stress of academic work	2.81	7th
Stress of choosing a life partner	2.77	8th
Career choice	2.59	9th
Reliance on others for assistance.	2.35	10th

Table 3 reveals that majority of the respondents indicated that they counselling mostly in the areas of embarrassment, emotional and physical effects of sickle-cell disorder and preservation of life.

Table 4: Analysis of variance in respondents' challenges by age

	Df	Sum of squares	Mean square	$F_{Calculated}$	$F_{Critical}$
Between group	2	109.77	54.5	2.91	3
Within groups	117	2192.82	18.74		
Total	119	2302.36			

Table 4 presents data on respondents' challenges with regards to their medical status. The table shows a calculated F-value of 2.91 and critical F-value of 3.00 at .05 alpha level.

Since the calculated F-value is less than the critical F-value, the null hypothesis was accepted.

Table 5: Analysis of variance in respondents' counselling needs by age

	Df	Sum of squares	Mean square	$F_{Calculated}$	$F_{Critical}$
Between group	2	143.84	71.9	3.51	3
Within groups	117	2398.15	20.49		
Total	119	2541.99			

Significant at .05 alpha level

Table 5 presents data on respondents' counselling needs as related to their medical status. The table shows a calculated F-value of 3.51 and critical F-value of 3.00 at .05 alpha level. Since the calculated F-value is higher than the critical F-value and the null hypothesis was rejected.

Discussion

From the results of this study, it was discovered that sickle cell patients showed similarities in their expression of the challenges of sickle cell disorder especially in the areas of excessive bone pains, excessive abdominal pains and acute chest pains. The findings are in line with the submission of Ogungbemi (2008) that generally excessive bone pains, excessive abdominal pains and yellow colouration of the eyes are common among majority of sickle cell anaemia patients. Akinyanju and Olujohungbe (2009) also indicated that the best known type of crisis among sicklers is the pain crisis.

Another finding of the study revealed that majority of the respondents indentified their counselling needs as coping with occasional embarrassment of unexpected bone pains and its accompanying sicknesses that could lead to hospitalization. Ogbe (2004) noted that sickle cell disorder often makes sufferers sick when appropriate medication that can relieve pains is not used on a daily basis. Ogungbemi (2008) also stated that sickle cell patients constantly need emotional and psychological support as they experience anxiety, financial insecurity, fear of loss of relation, etc. According to the researcher, they also need supportive counselling which will help them on how to manage their problems.

It was also found that the respondents need counselling on how to cope with the stigmatization. This is not surprising since the sickle-cell patients are normally stigmatized especially when the clinical features of yellow eye colouration, enlarged spleen, anaemia, stunted growth, etc. are feasible. This finding supports Abdulraheem's (2004) assertion that clients need counselling and support activities to address feelings of fear, guilt, depression, anxiety, anger and suicide activity or thinking so as to reduce low self-esteem.

The study indicated no significant difference in the challenges of sickle-cell patients based on age. This finding is in tandem with the assertion of Akinyanju and Olujohungbe (2008) that age has no influence on the expression of challenges of sickle cell patients. The similarity in findings can be associated with the common nature of the effects of sickle-cell anaemia on all sufferers irrespective of age group.

The finding of the study showed that there was significant difference in the counselling needs of sickle-cell anaemia patients based on age. This indicated that age had significant influence on the counselling needs of the respondents. The finding may be due to the fact

that the older sickle cell anaemia patients might have acquired better coping strategies as a result of experience than the younger ones.

Conclusion and implications for counselling

Based on the findings of this study, it is important to note that one of the aims of counselling is to assist individual to overcome their challenges, become well-adjusted and live a better life. There is no doubt that the challenges of sickle cell disorder could cause psychological and emotional trauma, endanger interpersonal relationships, destabilize families and in some cases result in death of sufferers. Counsellors are known to perform a variety of specialized services due to the versatility of the profession. They are normally faced with the challenges of educating, sensitizing and convincing affected individuals and the general public on salient facts about their medical conditions. The causal and in-depth medical findings have shown that sickle cell disorder is a genetic problem that could be prevented. It is important therefore that students and young people especially those preparing for marriage be provided with adequate information on human reproduction and issues related to genotype and how parents can pass sickle cell disorder to their children. Government at all levels (federal, state and local) should also look for ways of organizing campaign programmes to educate the general public on the various ways (e.g. lectures, seminars and workshops) by which sickle cell disorder can be reduced or eradicated. Formation of sickle cell clubs in all local government areas is also necessary so as to find ways of helping people living with sickle cell disorder.

It is pertinent that sickle cell clinics be established by the governments as they complement the activities of support associations. These clinics could be run once or twice weekly with a multi-disciplinary team including paediatricians, physicians, nurses, genetic counsellors, haematologists, orthopaedic surgeons and a host of other professionals in allied disciplines.

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