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Health Related Quality of Life of Patients with Sickle Cell Disease attending a Secondary Healthcare Facility in Kano State, Nigeria

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Background: Sickle cell disease (SCD) has chronic symptoms that require daily care and sometimes intensive medication which may negatively impair the physical functioning, sleep, school performance, and overall quality of life (QOL) of patients. Certain socioeconomic and cultural factors of persons who live with SCD affect their quality of life. **Aim:** This study aimed to assess the quality of life of patients with sickle cell disease receiving care at a secondary health care setting in Kano State Nigeria. **Materials and Method:** Utilizing a descriptive cross-sectional design, data was collected from 273 eligible respondents with an adapted quality of Life tool. The data was analyzed using SPSS version 20 software and presented using frequency tables and percentages. Scores were assigned to individual responses of items of quality of life and were categorized based on the World Health Organization's quality of life index. **Results:** Findings revealed that more than two-thirds of the respondents(72.8%) have a moderate quality of life. **Conclusion:** The study finally recommended more social services be provided by relevant authorities for sickle cell disease victims at health care centres and the society in general.

Keywords: *Sickle cell disease, Patients, Quality of life, socio-economic factors, cultural factors.*

Introduction

Sickle cell disease (SCD), is a group of inherited genetic defect that results in abnormal structure of one of the globin chains of the hemoglobin molecules (Rees, Williams, & Gladwin, Sickle-cell disease, 2010) . The types of sickle cell diseases that are commonly known are; sickle cell anaemia (HbSS), hemoglobin SC disease and Beta-thalassemia (HbSB) minor and major (Hyacinth, Adekeye, & Yilgwan, 2013) . The most common is sickle cell anaemia (HbSS) which happens as a result of the exchange of amino acids within the sequence of the *beta*-globin chain of hemoglobin gene, creating another haemoglobin (S) gene (Jacob, 2011).

Sickle cell disease (SCD) affects many people throughout the world and it is highly common in sub-Saharan Africa, South America, Cuba, Central America, Saudi Arabia, India and the Mediterranean. In the US, the population affected by sickle cell disease each year is about 89,079 of which most are in the black race (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010).

In Africa, sickle cell disease contributes to about 50 to 90 percent of childhood mortality (Grosse, Odame, Atrash, Amendah, Piel & Williams, 2011). It conjointly has effect on over two hundred thousand children each year in Africa (Ansong, Osei-Akoto, Ocloo, & Ohene-Frempong, 2013) . The prevalence of sickle cell disease is highest in West Africa and other sub-Saharan African regions.

Sickle cell disease (SCD) is common in Nigeria (Emechebe, Onyire, Orji, & Achigbu, 2017) and was first observed in 1904 by Dr JB Herrick in the blood of an anaemic West Indian medical student (Umar, 2014) . About 130,000 children are born with the disease yearly (Hyacinth *et al.,* 2013).

Adeyemo, Ojewunmi, Diaku-Akinwumi, Ayinde and Akamu (2015), conducted a cross-sectional study on health-related quality of life and perception of stigmatization in adolescents living with sickle cell disease in Nigeria, found that participants with SCD have the lower health-related quality of life than those without the SCD.

It was reported in a cross-sectional study on Quality of life among caregivers of sickle cell disease patients by Madani, Raddadi Jaouni, Omer and Awa (2018), that caregivers of children with SCD have impaired sleep quality and unsatisfactory emotional and sexual life but relatively conserved social and professional achievements. In addition, emotional assessments showed a high incidence of anxiousness and feeling of exhaustion and negative trends regarding fitness and energetic feeling (Madani et al., 2018).

A higher incidence of depressive moods and feeling of unhappiness was found among caregivers in Netherland which was associated with marked guilt feeling and fear from having another sick child (Vanden Tweel, Haztman, Ensink, Vander lee, Peters & Fijnvandraat, 2008). Furthermore, the same study reported decreased motor and cognitive functioning in caregivers, which was attributed to the lack of sleep resulting from the frequently continuous caregiving, associated sometimes with interrupted sleep pattern, a lack of vigour and vitality.

Salih (2019) also reported in his study on "The impact of sickle cell anaemia on the quality of life of sickle cell disease victims at school age" that patients suffered from school absence, teasing, embarrassment due to bedwetting, embarrassment due to jaundice, failure to contribute to school activities such as sport, and depressive symptoms. In another study on"Poor health-related quality of life among patients of sickle cell disease", the overall health-related quality of life among SCD patients was observed significantly lower as compared with other chronically ill patients (Bhagat, Baviskar, Mudey, & Goyal, 2014).

In Nigeria, a study on "Quality of life assessment among individuals with sickle cell disease attending haematology clinic of a Tertiary Hospital in Northwest Nigeria" whereby the study participants generally had significantly lower scores in all the domains compared to normal controls, thus indicating a lower QOL among participants of this study (Sufiyan, Tijjani, & Aminu, 2018) . Another study on "Health-related quality of life in sickle cell disease subjects in Benin City, Nigeria" found that the physical function, limitations due to physical health challenge, pain, and general health scores were significantly lower in the SCD population compared to the controlled populace (Ngowoh, Ofovwe, & Omoti, 2016)

Education and income are among the key socio-economic factors which determine the utilization of health services (Lawal, 2012) . Ballas (2009) mentioned that the management of SCD ranges from frequent acute pain episode requiring hospitalization, the use of intensive care units and facilities, surgical and nonsurgical treatment, and multidisciplinary method to management. Stigma, complications, and community attitudes toward SCD are the main causes of

psychosocial problems among individuals with SCD (Owotomo, 2016). This study was therefore embarked upon to assess the quality of life of patients with sickle cell disease in Waziri Shehu Gidado Hospital, Kano.

Materials and Methods

Research Design

The descriptive cross-sectional survey design was used for the study

Setting

The study was conducted at Waziri Shehu Gidado Memorial hospital in Kano Metropolis, Kano State. The hospital is a converted political office since the 28th of May, 2001. The zone covers three secondary health facilities which are Waziri Shehu Gidado, Maryam Sanusi Maternity hospital and Dawanau psychiatric hospital. Waziri Shehu Gidado provides Maternal and child health services including, Sickle cell services, Antenatal services, prevention of mother to child transmission (PMTCT), postnatal services, direct observational therapy short course, immunization, dental services, admission among others.

It has different sections such as administrative, nursing, pharmacy and accounting departments. It consists of the following wards which include labour ward, postnatal ward, accident and emergency ward, male and female ward, Emergency pediatric unit, sickle cell clinic, antenatal clinic, outpatient department, tuberculosis and DOT clinic.

Target Population

The research population were the sickle cell disease victims attending Waziri Shehu Gidado hospital.

Inclusion/Exclusion Criteria

All patients (inpatient and outpatient) attending the healthcare facility during the period of conducting the study were included in the study, excluding those absent or whose clinics did not fall within the period of data collection.

Sample Size and Sampling Technique

The sample size was calculated using Cochrane's formula as follows;

$$\mathbf{N= \frac{z^2pq}{d^2}}$$

Where

N= minimum sample size

z= standard normal deviation at 95%confidence interval on the normal distribution curve is given as 1.96

p= prevalence obtained from a similar study 21.6% (Olagunju, Faremi, & Olaifa, 2017) which is 0.216

q= complementary probability to p that is q=1-p= 0.784

d=the desired precision or margin of tolerance for the study. It will be 5%= 0.05

Therefore $n= \frac{(1.96)^2(0.216)(0.784)}{(0.05)^2} = \mathbf{260}$

Adding the risk of attrition, the sample size was taken to 273 respondents.

A convenience sampling technique was employed to select the respondents from each clinic day. About 60-70 victims attend the Sickle cell disease clinic on every clinic day, the data was therefore collected over 5weeks.

Data Collection Instrument

A modified quality of life assessment tool was adapted from Owotomo,(2016) on the Socioeconomic and Cultural Impact of Sickle cell disease in Nigeria. An interviewer-administered questionnaire was also used to collect relevant information regarding factors affecting the quality of life and other characteristics of the respondents.

Validity of instrument

The instrument was sent to five other experts to assess the relevance of content, clarity of statement, and logical accuracy of the instrument. Their inputs and possible corrections were used to modify the instrument.

Data Analysis Procedure

The data was analyzed using a statistical package for social sciences version 20. Completed instruments were checked for errors, consistency and completeness and cleaned. Data were entered into a computer and analyzed using Statistical Package for

Social Sciences (SPSS) software version 20. The data were summarized using frequency distribution tables and percentages and mean value

Ethical Approval

Ethical approval was sought and obtained from the Ministry of Health Kano State. Each potential participant was briefed about the purpose of the study and signed the consent form after a full understanding of its contents. Then the research instrument was administered through an interview to those that gave consent of participation.

Result

A total number of 273 questionnaires were issued while 272 were successfully retrieved representing a 99.6% response rate. The mean age and standard deviation of the subjects is 11.33 ± 6.47, half of the respondents (50.0%) are from the age group 1-10 years, followed by the age group 11-20 years with 41.2%. Out of the total 272 respondents, more than half (58.1%) are males. The majority of the respondents are Muslims (96.7%) and Hausa (91.2%) by tribe, They are predominantly single (89.7%). 33.8% of the respondents have no formal education, 36.8% attends primary school, and 26.5 % attends secondary school. Almost half (47.1%) of the respondents are not employed and less than half (42.6%) are students. The total number of household members has a mean and standard deviation of 2.07 ± 0.755. It showed that more than half (55.9%)of the respondents have 5-9 household members and three quarter (75.0%) of them have 45USD-110USD monthly income(Table1).

Table(2) showed that almost three quarter (72.8%)of the respondents have the moderate quality of life, less than one quarter (19.1%) of the respondents have a high quality of life while the minority (8.1%) have a low quality of life. A few of the respondent (11.8%) have low public awareness about the disease. Three quarter (75.0%) have perceived of actual lack of affordability of formal health care services. The majority of the respondent (82.4%) lack social support and three-quarter of them (75.0%) are not employed therefore not having challenges acquiring a career. All the respondents (100%) respond to spending a large quantity of income on medical care due to the disease and also experience financial costs of health care in terms of affordability and the utilization of health services while few of the respondents (5.9%) experienced stigmas toward the disease(Table3)

The majority of the respondents (95.6%) did not believe that sickle cell disease is possessed by an evil spirit and most of them (85.3%) did not believe that the disease is caused by supernatural or divine retribution. 94.5% of the respondents believed spirituality to be associated with the improvement in the health status of people affected with the disease. Very few of the respondents (4.4%) believed that sickle cell disease is as a result of reincarnation while 92.3% believed that praying and hoping is an effective coping strategy to the disease(Table4).

Table 1: *Distribution of the Respondents by Socio Demographic Data (N=272)*

Variables	Frequency (n)	Percentage (%)
AGE (in years)		
1-10	136	50.0
11-20	112	41.2
21-30	24	8.8
	11.38 ± 6.47	
GENDER		
Male	158	58.1

Variables	Frequency (n)	Percentage (%)
Female	114	41.9
RELIGION		
Islam	263	96.7
Christianity	9	3.3
ETHINICITY		
Hausa	248	91.2
Igbo	13	4.8
Yoruba	11	4.0
MARITAL STATUS		
Single	244	89.7
Married	24	8.8
Widow	4	1.5
EDUCATIONAL STATUS		
No formal education	92	33.8
Primary level	100	36.8
Secondary level	72	26.5
Tertiary level	8	2.9
EMPLOYMENT STATUS		
Not employed	128	47.1
Business	20	7.4
Civil servant	8	2.9
Others (student)	116	42.6
NUMBER OF HOUSEHOLD MEMBERS WITH SCD		
1-4	56	20.6
5-9	152	55.9
10-14	52	19.1
15 & above	12	4.4
	2.07 ± 0.755	
MONTHLY INCOME		
Less than ₦20,000	12	4.4
₦20,000 - ₦50,000	204	75.0
₦50,000 - ₦100,000	44	16.2
₦100,000 - ₦200,000	12	4.4

Table 2: *Distribution of Respondents by Quality of Life Relating to Sickle Cell Disease (N=272).*

ITEMS	D		P		MS		M		MD		UH		T		NR	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Financial security	0	0.0	16	5.9	97	35.7	135	49.6	24	8.8	0	0.0	0	0.0	0	0.0
Health-being physically fit	0	0.0	12	4.4	140	51.5	63	23.2	49	18.0	8	2.9	0	0.0	0	0.0
Relationship with parents, siblings and others	4	1.5	49	18.0	160	58.8	7	2.6	29	10.7	5	1.8	0	0.0	18	6.6
Having and raising children	2	0.7	0	0.0	13	4.8	0	0.0	10	3.7	0	0.0	2	0.7	245	90.1
Relationships with spouse or significant other	2	0.7	130	47.8	106	39.0	10	3.7	9	3.3	15	5.5	0	0.0	0	0.0
Relationship with friends	3	1.1	105	38.6	90	33.1	32	11.8	22	8.1	20	7.4	0	0.0	0	0.0
Helping or encouraging others in need	8	2.9	39	14.3	81	29.8	79	29.0	37	13.6	20	7.4	0	0.0	8	2.9
Participating in	6	2.2	52	18.8	121	44.5	32	11.8	39	14.3	15	5.5	1	0.4	7	2.6

organizations and public Affairs																
Attending school, improving understanding, and getting additional knowledge	**4**	**1.5**	**59**	**21.7**	**102**	**37.5**	**33**	**12.1**	**14**	**5.1**	**22**	**8.1**	**0**	**0.0**	**38**	**14.0**
Personal understanding of self-knowing your limitations and assets	**4**	**1.5**	**111**	**40.8**	**87**	**31.0**	**32**	**11.8**	**26**	**9.6**	**12**	**4.4**	**0**	**0.0**	**0**	**0.0**
Occupational role job	**6**	**2.2**	**37**	**13.6**	**136**	**50.0**	**59**	**21.7**	**26**	**9.6**	**8**	**2.9**	**0**	**0.0**	**0**	**0.0**
Creativity/personal expression – ability to express yourself.	**6**	**2.2**	**130**	**47.8**	**77**	**28.3**	**23**	**8.5**	**22**	**8.1**	**14**	**5.1**	**0**	**0.0**	**0**	**0.0**
Socializing –meeting other people, doing things, parties,	**1**	**0.4**	**140**	**51.5**	**51**	**18.8**	**43**	**15.8**	**21**	**7.7**	**12**	**4.4**	**0**	**0.0**	**4**	**1.5**
Reading, listening to music, or observing Entertainment	**3**	**1.9**	**47**	**17.3**	**131**	**48.2**	**28**	**10.3**	**23**	**8.5**	**15**	**5.5**	**0**	**0.0**	**25**	**9.2**
Active participatory recreation	**3**	**1.1**	**89**	**32.7**	**109**	**40.1**	**24**	**8.8**	**25**	**9.2**	**22**	**8.1**	**0**	**0.0**	**0**	**0.0**
Independence – ability to do things for yourself.	**10**	**3.7**	**117**	**43.0**	**67**	**24.6**	**21**	**7.7**	**29**	**10.7**	**25**	**9.2**	**0**	**0.0**	**3**	**1.1**

Table 3: *Assessments of Quality of Life of the Respondents (N=272).*

CATEGORY	**HIGH QOL**		**MODERATE QOL**		**LOW QOL**	
	N	**%**	**n**	**%**	**n**	**%**
QUALITY OF SCORE	52	19.1	198	72.8	22	8.1

≥ 70 high quality of life 50 -69 moderate quality of life Score of < 50 low quality of life

Table 4: *Distribution of Respondents according to Socioeconomic Factors Affecting Sickle Cell Disease. (N=272)*

		Yes		**No**	
SN	**Items**	**n**	**%**	**n**	**%**
1	Low public awareness about the disease	32	11.8	240	88.2
2	Perceived or actual lack of affordability of formal health-care services	204	75.0	68	25.0
3	Lack of social support	224	82.4	48	17.6
4	Diminished ability to acquire new employment or even develop a career due to suffering Sickle cell disease	44	16.2	282	83.8
5	Spending large quantity of income on medical care due to Sickle cell disease	272	100.0	0	0.0
6	Financial costs of health care in terms of affordability and the utilization of health services	272	100.0	0	0.0
7	Stigma toward Sickle cell disease are main causes of psychosocial problems among individuals with Sickle cell disease	16	5.9	256	94.1

Table 5: *Distribution of Respondents by Cultural Factors affecting Quality of Life of Sickle Cell Disease (N=272).*

		Yes		No	
SN	**ITEMS**	**n**	**%**	**n**	**%**
1	Sickle cell disease is Possessed by evil spirits	12	4.4	260	95.6
2	Sickle cell disease is supernatural or a divine retribution	40	14.7	232	85.3
3	Spirituality (prayers and believing in the prayer) is associated with the improvement in the health status of people affected by Sickle cell disease	257	94.5	15	5.5
4	Sickle cell disease is a result of reincarnation	12	4.4	260	95.6
5	Praying and hoping is an effective coping strategy for sickle cell disease	251	92.3	21	7.7

Discussion of findings:

The result shows that children are the predominant of the respondents, with a slight increase in a number of male than female. The majority of the respondents are Muslims, Hausa and single due to the fact that Kano is an Islamic and predominantly Hausa state. Unlike in Owotomo (2016), where the respondents are participants were mostly single and Christian. Those without formal education predominate the study followed by those enrolled in primary school due to the age group of the majority of the respondents. Those without employment are more among the respondents because they are mostly children and the majority of them have ₦20,000-₦50,000 monthly income.

The result of the study revealed that the victims of sickle cell disease have a moderate quality of life. This is similar to the study by Adeyemo, Ojewunmi, Diaku-Akinwumi, Ayinde & Akamu (2015), where they found that participants with SCD have lower health-related quality of life than those without the SCD. This is also similar to another study where the study participants generally had significantly lower scores in all the domains compared to normal controls, thus indicating a lower QOL among participants of this study (Sufiyan, Tijjani, & Aminu, 2018) . It's also similar to another study by Bhagat, Baviskar, Mudey & Goyal (2014), that the overall health-related quality of life among SCD patients was observed significantly lower as compared with other chronically ill patients. These findings may be because sickle cell disease victims suffer limitations due to physical health challenge, pain, and other complications as a result of their disease conditions. The QOL of patients with SCD attending Waziri Shehu Gidado Hospital, Kano is poor and significantly lower than those of normal individuals. Therefore, in addition to measures taken to reduce SCD complications, other interventions should target improving their physical, mental, and emotional health.

According to Mubyazi and Njunwa (2011), the socioeconomic challenges associated with sickle cell disease are low public knowledge about the disease. This contradicts the findings from the study where the majority of the respondent have public awareness of the disease. This may be due to increased awareness of the disease by caregivers. They also reported perceived or actual lack of affordability of formal health-care services as another socioeconomic challenge which is similar to the findings from the study.

From the study, the majority of the respondents lack social support, spends a large quantity of income on sickle cell disease and also experience financial costs of health

care in terms of affordability and the utilization of health services. This is similar to the findings in Owotomo, (2016), which mentioned the loss of employment, lack of social support, diminished ability to acquire new employment or even develop a career due to suffering SCD, spending a large quantity of income on medical care due to SCD as the socio-economic factors affecting the QOL of patients living with SCD in Nigeria. Almost all the respondents reported not to experience stigma toward Sickle cell disease. This contradicts another study that mentioned stigma, complications, and community attitudes toward SCD are the main causes of psychosocial problems among individuals with SCD (Owotomo, 2016).

Almost all the respondents reported to disbelief that sickle cell disease is possessed by an evil spirit. This is similar to research conducted by Owotomo (2016), which showed that few participants believed they were possessed by evil spirits before being diagnosed with SCD, which led to having poor management of the disease prior to diagnosis. The majority of them also reported not believing that the disease is a result of supernatural or divine retribution. This is contrary to a study by Anie, Ogunjobi & Akinyaju (2010) which mentioned that religious healing such as prayer is one measure taken in addition to medical treatment to manage SCD based on the thought that SCD is supernatural or divine retribution. The majority believe that spirituality is associated with the improvement in the health status of people affected by Sickle cell disease. This is similar to the study by Cooper-Effa, Blown, Kaslow, Rothenberg & Eckman (2001), where the religious wellbeing and coping among individuals with SCD were studied, the results indicated that the spiritual (prayers and believing in the prayer) is associated with the improvement in the health status of people affected by SCD. The majority of them reported that sickle cell disease is not a result of reincarnation. This contradicts the study by Anie et al., (2010); Ohaeri & Sokunbi, (2001) which they reported that many Nigerians believe that SCD is a result of reincarnation or *Oghanje* in the Igbo language, and *Abiku* in the Yoruba language. This is because the study is among Hausa and they don't have such belief. The majority of the sickle cell disease victims believe praying and hoping as an effective coping strategy for sickle cell disease. This is similar to another study which revealed that people with SCD living in the UK and Nigeria commonly used praying and hoping as an effective coping strategy, which seems to be influenced by external factors such as religion, faith in God, superstition and stigma (Anie, Dasgupta, Ezenduka, Anarado, & Emodi, 2007).

Conclusion and Recommendation

The findings from this study showed that the sickle cell disease victims attending Waziri Shehu Gidado Hospital have the moderate quality of life, however, they have certain socioeconomic factors affecting their lives. Sickle cell disease (SCD) is partly or greatly neglected not because of being poorly known among many families, communities and national policy/decision-makers. It is therefore important to prioritize research on SCD that would provide evidence for decision and policymaking. Frontiers in family health affairs including those concerned with marriage matters should be sensitized on this problem and be well informed about appropriate marriage related decisions. This will, therefore, help them prepare psychologically and emotionally and take appropriate measures of medical care.

The need for a more expanded study cannot be overemphasized. Social supports are highly suggested for sickle cell disease victims in particular. Social workers are advised to revise families' circumstances financially and socially.In addition, there is a need for the government and other nongovernmental bodies to provide support particularly in the area of employment and occupation to reduce the scourge of the disease.It is recommended to improve the overall Health related quality

of life (HRQOL) among all the domains as a clinical end point.

Conflict of Interest
Nil

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