Original Article

Determinants of Psychosocial Health-related Quality of Life of Adults with Sickle Cell Disease in a Nigerian Setting

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Abstract

Background: With improved understanding of disease mechanism in sickle cell disorder, many persons living with sickle cell disease (SCD) are surviving unto adulthood. There is a growing concern that SCD may impair the psychosocial health-related quality of life (HRQoL), with a resultant lack of psychosocial stability and integration. The objective of this study was to assess the determinants of psychosocial quality of life (QoL) among adults with SCD. **Materials and Methods:** This was a cross-sectional study of adults with SCD. A multidimensional self-administered instrument, prevalidated for use in adults with chronic disease, was used. It consisted of 31 items that assessed physical function, physical and emotional role function, bodily pain, vitality, social function, mental health, and general health within 2 weeks prior to the time of survey. Questionnaires were administered to adults with sickle cell anemia who presented for their routine visit to the Sickle Cell Clinic at the Hematology Clinic in University of Nigeria Teaching Hospital, Ituku-Ozalla Enugu, or during sickle cell support group meetings. Psychosocial HRQoL was the primary outcome measured. Sociodemographic features such as marital status, gender, educational qualification, and SCD were the primary independent variables of interest. **Results:** A total of I16 adults with SCD were participated in the study. After adjusting for marital status, gender, and educational qualification of adults with SCD, gender and marital status did not significantly affect psychosocial HRQoL ($P = 0.619$ and $P = 0.146$), respectively, while educational status significantly affected their HRQoL ($P = 0.013$). **Conclusions:** Adults with SCD have impaired psychosocial HRQoL. There is a need to upscale patient-focused interventions to improve self-esteem and overall QoL.

Keywords: Determinants, Nigeria, psychosocial quality of life, sickle cell disease

Introduction

Sickle cell diseases (SCDs) are characterized by chronic painful episodes, multiple systemic involvement with increased morbidity and mortality rates. With improved health systems, childhood survivals, and absence of a cure, the aging SCD population is facing multifaceted effects from acute-on-chronic vascular, inflammatory, and thrombotic injury. Life expectancy for adults with sickle cell anemia remains stubbornly stagnant in the fifth decade of life.[1] Adults with SCD encounter significant disease-related complications which may include stroke, pulmonary hypertension, nephropathy, congestive heart failure, sickle leg ulcers, and avascular necrosis (AVN) of the femoral or humeral heads.[2]

Quality of life (QoL) is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life.[3] Health, emotional well-being, social dysfunction, chronic pain, and fatigability form the domains of overall complex QoL.[4] The severity of the disease is, in general, inversely proportional to the QoL.[5] Health-related QoL (HRQoL) refers to the physical, psychological, and social domains of health seen in areas influenced by a person's experiences, beliefs, expectations, and perceptions.[6,7] The closer a person's life is to the standard of normalcy, the better the HRQoL.[8] There are numerous reports of the impact of SCD on the psychosocial health, with a resultant lack of psychological stability and social integration.[8,9]

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Studies in both children and adolescents with SCD have reported poor HRQoL in qualitative studies using focus groups[10,11] and comparatively fare worse in their HRQoL than those of controls on health surveys.[12] Despite the considerable evidence in children for reduced HRQoL in SCD, there are few reports from evaluation of the impact of this disease on HRQoL in adults.[10,13]

The impact of this disease on psychosocial HRQoL for adults may be even greater than for children. Reports from a recent study showed depression and anxiety accounted for more of the variance in all domains of QoL than hemoglobin (Hb) type.[14] A similar study also reported that underlying stress and coping mechanism accounted for 44%–50% of dissimilarity in psychological adjustment to the disease.[15] HRQoL, in general, can be further worsened by poor socioeconomic conditions, lack of social support, episodic, debilitating pain associated with substantial analgesic use, frequent hospitalization for pain episodes, and ultimately organ failure.[16,17]

Despite the fact that SCD has been largely studied in terms of population frequency clinical variations and pathogenetic mechanisms,[17-20] research that addresses aspects related to HRQoL of persons living with SCD are relatively few in both the Nigerian and international literature. In this study, an in-depth assessment of the determinants of the psychosocial HRQoL among adult SCD population in Nigeria was undertaken to gain an understanding of factors that modify psychosocial impact of the disease. It may also provide health-care practitioners who care for these patients a more objective perspective on the impact and severity of this disease.

Materials and Methods

Study area

This study was conducted between March and December 2017 among 116 patients in the Outpatient Sickle Cell Clinic of University of Nigeria Teaching Hospital (UNTH), Ituku-Ozalla, Enugu. UNTH is a tertiary health facility, and patients are referred from many states in Nigeria to the facility.

Study design and patients selection

This was a cross-sectional study of 116 adults with SCD. These cohort of patients were either approached by their hematologist during consultation in the Hematology Outpatient Sickle Cell Clinic of UNTH or during their sickle cell support group meetings. A total of 116 patients above 18 years were selected consecutively.

Diagnosis of sickle cell disease

The diagnosis of SCD was made by both clinical and laboratory.

Inclusion criteria

1. Diagnosis of SCD
2. Age ≥18 years at the time of the interview
3. No cognitive disturbances.

Exclusion criteria

1. Age <18 years
2. Patients with cognitive disturbances.

Measures

The WHO QoL 100 modified multidimensional self-administered instrument, prevalidated for use in adults with chronic disease, was used. It consisted of 31 items representing eight of the most important dimensions of HRQoL: physical function, physical role functions, emotional role functioning, bodily pain, vitality, general health, mental health, and social function, with a Cronbach's alpha of 0.82. Psychosocial variables and QoL were the primary outcome measured. Sociodemographic features such as marital status, gender, educational qualification, and type of SCD were the primary dependent variables of interest.

Sociodemographic characteristics and clinical variables

Sociodemographic and clinical information was obtained from the patients and records regarding sex, education, age, marital status, age at the first diagnosis, type of SCD, presence of complications, frequency of vaso-occlusive crisis (VOC), and history of blood transfusion.

Outcome variables

Quality of life

Health status perception was measured with questions that addressed both the physical and mental components of health. Each scale is converted directly into a 0–5 scale on the assumption that each question carries equal weight, in which 5 represents the highest level.

Subjective well-being

Subjective well-being was evaluated using questions on satisfaction with the level of life, health, personal achievement, personal relationships, social community connection, and future security. The score is the average of the items, varying from 0 to 5, in which higher values represent better subjective well-being.

Statistical analysis

Data collected was analyzed using SPSS version 22 (SPSS Inc., Chicago, Illinois, USA). Descriptive analysis of data was expressed as percentages. Binary logistic regression analysis was performed to determine sociodemographic characteristics of respondents associated with HRQoL. Variables which reached a statistical significance of ≤0.2 in the bivariable models were included in the multivariable analysis. The strength of association was measured using odds ratio and statistical significance assessed using *P* values and 95% confidence intervals (CIs) for odds ratio. We considered $P < 0.05$ statistically significant in the statistical analysis. Good QoL is defined by physical, mental, emotional, and social functioning: nil or limited painful crisis, nil depression, nil emotional stress, and able to function with the society.

Ethical clearance

The study was approved by the Health Research Ethics Committee of UNTH. Patients received information about the study and signed an informed consent form after acceptance.

Results

Sociodemographic characteristics of the respondents

A total of 116 respondents returned questionnaires giving a 100% response rate. Most of the patients were male (59.5%), and majority of them were below the age of 30 years with a mean age of 25.5 ± 6.4 years. In respect to education level, 62.9% had tertiary education, while only 15.5% were married [Table 1].

Clinical characteristics of the respondents

Most of the participants in the study had homozygous SS genotype (84.5%). The diagnosis was first made in childhood in majority of them (84.5%). Majority (69.8%) have been transfused in the past. All the participants experienced complications in the past, while 39.7% had VOC requiring admission between 1 and 3 times per year in the past [Table 2].

Assessment of psychosocial health-related quality of life of the respondents

More than half of the respondents were satisfied with sleep (67.2%), perform daily living activities (50.8%), personal relationship (56.9%), and conditions of living place (62.1%). Less than half of the respondents were satisfied with their sex life (46.6%) and capacity for work (44.8%) [Table 3].

Factors associated with overall quality of life of respondents

Table 4 shows factors associated with QoL of the respondents.

Of 22 married SCD patients, 18 (81.8%) had a good QoL, while 4 (18.2%) had a poor QoL. On the other hand, 52 (55.3%) of 94 unmarried participants had a good QoL, while 42 (44.7%) had the poor life quality.

After adjusting for age, sex, marital status, level of education, and Hb electrophoresis, the odds for a good QoL were about three times among females compared to males (adjusted odds ratio [AOR] =2.64, 95% CI = 0.87–8.00, P = 0.087). The odds for good QoL were about 1.3 times higher among married participants compared to those that were single/separated/divorce (AOR = 1.25, 95%CI = 0.27–5.79, P = 0.773) and about 11.8 times higher among those that had tertiary education compare to those that had only primary education (AOR = 11.87, 95% CI = 2.05–68.84, P = 0.006). However, the odds for QoL were 42% lower among participants with hemoglobin SC (HbSC) compared to those with hemoglobin SS (HbSS) (AOR = 0.58, 95%CI = 0.04–9.01, P = 0.701).

Table 1: Sociodemographic characteristics of the respondents (n=116)

Variables	Categories	Frequency (%)
Sex	Male	69 (59.5)
	Female	47 (40.5)
Age (years)	18-20	19 (16.4)
	21-30	60 (51.7)
	31-40	33 (28.4)
	41-50	4 (3.5)
Education level	Primary	11 (9.5)
	Secondary	32 (27.6)
	Tertiary	73 (62.9)
Marital status	Married	18 (15.5)
	Single	94 (81.0)
	Separated	1 (0.9)
	Divorced	2 (1.7)
	Widowed	1 (0.9)

Table 2: Clinical characteristics of the respondents (n=116)

Variables	Categories	Frequency (%)
Hb electrophoresis status	HbSS	98 (84.5)
	HbSC	15 (12.9)
	HbSβ	3 (2.6)
When diagnosis was first made	Childhood	98 (84.5)
	Adolescent	14 (12.1)
	Adult	4 (3.4)
Transfused blood before	No	35 (30.2)
	Yes	81 (69.8)
Complications experienced	Stroke	5 (4.3)
	Nephropathy	13 (11.2)
	Pulmonary HBP	1 (0.9)
	HBP	4 (3.4)
	AVN	24 (20.7)
	Ulcers	15 (12.9)
	None	54 (46.6)
Frequency of VOC requiring hospital admission (per year)	<1	32 (27.6)
	1-3	46 (39.7)
	>3	38 (32.7)

Hb – Haemoglobin; HBP – High blood pressure; HbSS – Haemoglobin SS; HbSC – Haemoglobin SC; HbSβ – Haemoglobin B Thal; AVN – Avascular necrosis; VOC – Vaso-occlusive crisis

Discussion

This study showed that SCD is associated with restrictions of different characteristics of HRQoL. The findings are similar to the studies conducted in the United Kingdom, the United States of America, Saudi Arabia, and Brazil.[10,16,21,22] These findings concerning gender are similar to the studies done in the Mecca region, Saudi Arabia, and Brazil[23,24] but were in contradictions to some other studies in the UK and India,[25,26] Majority of the participants were between the age of 18–30 years of age (68.1%) and had better QoL (64.3%) compared to those older than 30 years (35.7%). This is similar to the findings in the study conducted in Brazil and Saudi Arabia.[24,27] Surprisingly in this study, those who were single/separated/divorced had a better QoL than those who were married. This is contradictory to the findings reported in some studies.[11,24,26] Concerning educational level, majority of the participants 62.9% had tertiary education, while 8.5% had primary education. This high literacy level of the participants might have accounted for high satisfaction with living conditions in this study.

Table 3: Respondents satisfaction with various aspects of life (*n*=116)

Variables	Response		
	Never, *n* (%)	Sometimes, *n* (%)	Always, *n* (%)
Satisfaction with sleep	21 (18.1)	17 (14.7)	78 (67.2)
Satisfaction to perform daily living activities	17 (14.7)	40 (34.5)	59 (50.8)
Satisfaction with capacity for work	27 (23.3)	37 (31.9)	52 (44.8)
Satisfaction with yourself	18 (15.5)	19 (16.4)	79 (68.1)
Satisfaction with personal relationship	22 (19.0)	28 (24.1)	66 (56.9)
Satisfaction with support from friends	18 (15.5)	13 (11.2)	85 (73.3)
Satisfaction with sex life	27 (23.2)	35 (30.2)	54 (46.6)
Satisfaction with conditions of living place	29 (25.0)	15 (12.9)	72 (62.1)
Satisfaction with access to health services	24 (20.7)	24 (20.7)	68 (58.6)

Table 4: Factors associated with quality of life of respondents (*n*=116)

Variable	QoL (*n*=116)		χ^2	*P*	AOR (95% CI)	*P*
	Good (70), *n* (%)	Poor (46), *n* (%)				
Sex						
Male	35 (50.0)	34 (73.9)	2.642	0.619	1.00	
Female	35 (50.0)	12 (26.1)			2.64 (0.87-8.00)	0.087
Age group (years)						
18-30	45 (64.3)	34 (73.9)	28.754	0.230	1.00	
31-60	25 (35.7)	12 (26.1)			1.44 (0.07-2.68)	0.376
Marital status						
Married	18 (25.7)	4 (8.7)	12.463	0.415	1.00	
Single/separated/widowed/divorced	52 (74.3)	42 (91.3)			1.25 (0.27-5.79)	0.773
Education level						
Primary	1 (1.4)	10 (21.7)	14.995	0.002*	1.00	
Secondary	19 (27.1)	13 (28.3)			10.17 (1.54-67.29)	0.016*
Tertiary	50 (71.5)	23 (50.0)			11.87 (2.05-68.84)	0.006*
Hb electrophoresis						
HbSS	56 (80.0)	42 (91.3)	3.507	0.744	1.00	
HbSC	12 (17.1)	3 (6.5)			0.58 (0.04-9.01)	0.701
HbSβ	2 (2.9)	1 (2.2)			2.02 (0.09-44.98)	0.658

*AOR – Adjusted odds ratio; 95% CI – 95% confidence interval; Reference category – 1; QoL – Quality of life; Hb – Haemoglobin; HbSS – Haemoglobin SS; HbSC – Haemoglobin SC; HbSβ – Haemoglobin B Thal

The study revealed that 84.5% of the participants had HbSS and 2.6% had Hamoglobin B thalassemia. This finding is similar to other studies that reported HbSS as the most common.[16,17,24] Despite the fact that HbSC trait is largely confined to the Yoruba people of Southwest Nigeria where it appears in about 6%, lower than 12.9% documented in this study.[28] The diagnosis of SCD was made during childhood in 84.5% of the participants, and this early diagnosis might have be as a result of the investigations of the features of the sickle cell crises experienced during the period at health facilities.

Majority of the participants 69.8% had been transfused with blood in the past. This confirmed constant hemolytic process reported among SCD patients. Many complications such as stroke, nephropathy, ulcers, and AVN were reported in the study. About 46.6% of the participants had not experienced any acute complications contrary to the findings in another study where all patients experienced some.[24,29]

This study showed that 18.1% of the participants never had satisfactory sleep. This could be responsible for other medical problems among the participants. This result is similar to the findings reported in some studies.[21,23] More than half of the participants (50.8%) always had satisfaction to perform daily living activities, lower than findings in another study where 70% satisfaction was reported.[23] Satisfaction with personal relationship in this study of 19% is higher than 5% reported in another study conducted in Saudi Arabia.[23] This aspect is very important in the QoL among the participants, as this can be related to the level of stigma in the society which has effects on living conditions of individuals. Only 46.6% of the participants had satisfaction with their sex life. The reasons for this poor satisfaction with sex life could be due to some complications experienced by the participants. Concerning access to health services, more than half 58.6% had satisfaction with their access to care. This might be due to a high literacy level of the participants, expected to have

better socioeconomic conditions, more so that the study was conducted in urban hospital settings.

This study assessed the factors that are associated with psychosocial HRQoL. The odds for good QoL were about three times higher among females compared to males similar to the findings in the study conducted in Saudi Arabia.[21] It however contradicted some studies that reported poorer QoL among females compared to their male counterparts.[9,30] The findings in this study could be due to the fact that females were not engaged in rigorous activities, and this might had affected their QoL. The study revealed that the odds for good QoL were about one and half times higher among those older than 30 years compared to those who were between 18 and 30. Surprisingly in this study, the odds for good QoL were about 1.3 times higher among participants who were single/separated/divorced/widowed compared to those who were married. The odds for good life were about 42% less among participants who were HbSS compared to those that were HbSC. Concerning education, the higher the literacy level, the better the QoL. The odds for good QoL were about 10 times better among participants who had secondary education compared to those who had primary education, while they were 12 times higher among those who had tertiary education. The differences could be due to possible higher socioeconomic status.

Conclusions

It is concluded from this study that adults with SCD have impaired psychosocial QoL. After adjusting for marital status, age, gender, and educational qualification of adults with SCD, only educational status significantly affected the psychosocial HRQoL. There is a need to upscale patient-focused interventions to improve self-esteem and overall QoL.

Ethical approval and consent to participate

Ethical approval was obtained from Health Research Ethics Committee of the University of Nigeria Teaching Hospital, Ituku-Ozalla, Enugu. Informed written consent was obtained from the participants.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patients have given their consent for their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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