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Original Research Article

Health related quality of life among adults living with sickle cell disease in Lagos, Nigeria

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ABSTRACT

Background: Sickle cell disease (SCD) is an inherited haemoglobinopathy which involves the inheritance of haemoglobin S with any other abnormal haemoglobin from both parents. Health related quality of life (HRQOL) provides the patient's view of his/her own wellbeing. This study was aimed at determining health related quality of life in SCD patients attending Lagos State University Teaching Hospital, Ikeja, Nigeria using the World Health organization quality of life-BREF (WHOQOL-BREF) questionnaire.
Methods: This was a descriptive, cross sectional study in which an interviewer-administered WHOQOL-BREF questionnaire was used to assess health related quality of life of 250 SCD participants and 50 HbAA controls. The questionnaire assessment was based on physical, psychological, social and environmental domains. Data were analyzed using SPSS statistical software version 23.0. P value was considered to be statistically significant at<0.05.
Results: Respondents mean age was 31.67±12.07 years. SCD participants scored generally lower than controls, regarding domains on physical, psychological and social health, however scores were at par on environmental domain. Physical health score was better in females with SCD than males, while males with SCD had a better social relationship than females. Psychological health and environment scores were almost equal in both males and females with SCD.
Conclusions: Health related quality of care is generally poor in SCD participants compared with HbAA controls, physical health is poorer in males with SCD than in females, however, psychological, social and environmental domains are similar in both genders.

Keywords: Health related quality of life, WHOQOL-BREF, Sickle cell disease

INTRODUCTION

Sickle cell disease (SCD) is an inherited disease which involves an abnormal haemoglobin gene inheritance from both parents. It is essentially a disease of blacks and those of mediterranean descent with an estimate of about 5% of the world's population.[1]

This genetic disorder is a single point mutation at position six of the beta globin gene subunit with a consequent substitution of glutamic acid a negatively charged with a neutral amino acid valine causing decrease solubility of the hemoglobin in low oxygen tension and sickling of the red blood cell. Over seventy-five (75%) of burden of SCD globally occurs in Sub-Sahara Africa where healthcare infrastructure and poverty constitute a great health challenge.[2] The prevalence of sickle cell anaemia (SCA) in Nigeria is between 1-3% while about 20-30%% have SCD.[3,4]

Quality of life (QOL) is defined by WHO as the “individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and their interests”.[5] Health related quality of life provides the patient’s view of his/her own wellbeing rather than that of the health care provider.[6]

In people who live with SCD, repeated hospitalizations due to pain crises, disease complications, and associated organ failure impact significantly on quality of life.[7-10]

SCD is reported to be associated with increased depression, poor coping ability and quality of life.[10-12]

WHO considered WHOQOL-100 (which consists of 100 questions) too detailed in the assessment of individual facets relating to quality of life and lengthy to administer when large epidemiological studies are involved hence the development of the WHOQOL-BREF (which consists of 26 questions. Appendix) to look at domain level profiles, which equally assesses quality of life. In order to maintain comprehensiveness in the abbreviated version of WHOQOL-100, one question from each of the 24 facets relating to quality of life was selected. The decision on what question to pick was based on the following criteria 1) items selected representing a particular domain must explain a large proportion of variance within that domain 2) items selected must explain a substantial proportion of variance within the general facet relating to overall quality of life and general wellbeing 3) the final version should explain structural integrity in terms of confirmatory factor analysis 4) the final version should be discriminatory between identified groups of subjects (i.e. ill vs well subjects)

Unlike most evaluations in Medicine which rely on physical examinations and laboratory assessment of patients, WHOQOL-BREF relies on the patients’ view of their own well-being and provides a new perspective on their diseases.

The 26 questions of WHOQOL-BREF were obtained from one item from each of the 24 facets contained in the WHOQOL-100 and two items from the overall quality of life.

Intended uses of the WHOQOL-BREF

The uses of WHOQOL-BREF amongst others are to allow detailed generation of quality-of-life data on a population with chronic disease like SCD. This enhances better understanding of the disease and treatment methods development. Secondly, it is found useful in clinical trials, creating baseline scores in a range of areas. It is also valuable in determining changes in quality of life over the course of interventions. It is effective where the disease prognosis involves partial remission and treatment may be more of palliative than curative.

Researches on HRQOL in SCD in Nigeria are scarce despite many researches on clinical variations, profile, and management hence the need to use the World Health Organization quality of life questionnaire known as WHOQOL-BREF 17 to evaluate SCD patients.[13-16] This study was aimed at determining health related quality of life in SCD patients attending Lagos State University Teaching Hospital, Nigeria using the WHOQOL-BREF questionnaire.

METHODS

Study location

The adult Haematology clinic of Lagos State University Teaching Hospital (LASUTH) was used. The hospital was established as a cottage hospital in 1955, transformed into a secondary health centre in 1970 and later converted into a teaching hospital in July 2001 following establishment of Lagos State University College of Medicine on 9th February 1999.

Study population

The participants of the study were recruited from adult Sickle Cell Clinic (SCC) of LASUTH. Using a research assistant, they were all made to fill the WHOQOL-BREF questionnaire. The clinic runs three times a week, Mondays, Tuesdays and Thursdays. A total of over one thousand patients have ever registered in the clinic and include patients transitioning from the Pediatrics SCC. Control participants were recruited from among members of Staff of Lagos State University Teaching Hospital who are non-SCD patients and do not have any chronic illness.

Sampling technique

Participants were recruited consecutively as they consented to participate in the study.

Study instrument

The WHOQOL-BREF, a reliable and well validated WHO questionnaire contains a total of 26 questions on Likert scale of 1-5 and has four domains namely, physical component which assesses information on activities of daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, while the psychological component assesses information on bodily image and appearance, negative and positive feelings, self-esteem, and spirituality. The social component assesses information like personal relationship, social support and sexual activity and lastly the environmental component is about financial resources, freedom, physical safety and security, home environment etc.[18] WHOQOL-BREF was used to assess the quality of life of both the SCD patients and control group. It was an interviewer-administered questionnaire to all participants after signing the consent form.

Scoring the WHOQOL-BREF

There are 4 domain scores derivable from WHOQOL-BREF. Domain scores were calculated from the mean score of items within each domain. The mean scores were then multiplied by 4 in order to make it comparable with the scores used in WHOQOL-100.

Inclusion criteria

Inclusion criteria were 1) consenting adult SCD patients attending the clinic 2) volunteer controls non SCD patients.

Exclusion criteria

Exclusion criteria were 1) any other participants with other major chronic illness apart from SCD 2) participants younger than 18 years 3) non-consenting participants, either SCD or controls

Sample size calculation

WHOQOL-BREF has been field- tested in 20 field centers from 18 countries; it is recommended by the WHO [24] that countries not included in the initial 18 countries e.g., Nigeria, should be piloted on a minimum of 300 adults. This figure is based on the required numbers of participants needed for analysis of pilot data consisting of 250 with living with the disease and 50 apparently well persons.

Study design

This study was a descriptive, cross-sectional study involving 300 adult participants.

Participant's informed consent

The participants were informed about the study, as well as their rights and benefits. A written informed consent was obtained from each participant by means of voluntarily signed consent forms. No participant was coerced in any way to participate in this study, which was at no cost to them.

Ethics committee approval

Ethics committee approval was obtained before the commencement of the study from the ethics committee of Lagos State University Teaching Hospital. The approval number is LREC/06/10/1249

Statistical analysis

Data were analyzed using SPSS version 23.0 (statistical package for social sciences, Inc., Chicago, Ill). The continuous variables were given as means±standard deviation (SD). The Pearson chi square test was used to test for association between discrete variables. P value was considered to be statistically significant when at<0.05

RESULTS

This study recruited 300 participants comprising 250 SCD and 50 HbAA controls. The overall sex distribution of the respondents comprised 110 (36.7%) males and 190 (63.3%) females. Ninety- eight (39.2%) of the SCD participants were males while 152 (60.8%) were female while the controls comprised 12 (23.5%) males and 39 (76.5%) females. The mean age of SCD participants was 27.86±9.34 years and controls 49.20±6.17 years (p value 0.001). The overall mean age was 31.67±12.07 years. The age distribution of the SCD participants is shown in Table 1.

Table 1: Age distribution of SCD participants.

SCD age distribution (years)	Frequency	Percentage
<20	49	18.3
21-30	110	39.4
31-40	47	16.8
41-50	38	13.6
51-60	32	11.5
>61	1	0.4
Not known	21	7

Table 2: WHOQOL-100 domains in SCD and HbAA participants.

WHOQOL-100 Domains	SCD	HbAA	P value
Physical health	61.8±12.56	62.30±9.7	0.79
Psychological health	65.3±14.44	67.38±9.8	0.33
Social relationship	62.8±22.5	68.26±20.5	0.11
Environment	62.6±18.1	62.04±11.9	0.83

SCD participants' score regarding domain on physical health consisting of questions relating to pain and discomfort, sleep and rest, energy and fatigue, mobility, activities of daily living, dependence on medicinal substances, medical aids and work capacity though generally lower than in HBAA controls was not statistically significant (p=0.79) as shown in Table 2.

SCD participants also had lower scores regarding psychological health consisting of positive feeling, thinking, learning, concentration and memory, self-esteem, bodily image and appearance, spirituality, religion and personal belief compared with the HBAA controls.

Table 3: Gender specific SCD participants WHOQOL-100 domains.

SCD WHOQOL-100 Domains	Males	females	P value
Physical health	60.54±12.59	62.10 ±12.54	0.21
Psychological health	65.17±13.02	65.43±15.52	0.89
Social relationship	63.31±21.58	62.65±23.33	0.71
Environment	62.25±18.31	62.99 ±18.06	0.75

In addition, scores regarding social relationship related questions (personal relationship, social support and sexual activities) compared much lower in SCD participants compared with HBAA controls (p=0.11; Table 2)

However, the scores were almost equal for both groups of participants on questions regarding environment comprising freedom, physical safety and security, home environment, financial resources, health and social care, accessibility and quality, opportunities for acquiring new information and skills, participation in and opportunities for recreation and leisure activity, physical environment, pollution, noise and traffic and climate and transport.

Physical health score was better in females with SCD than in males, while males with SCD had a better social relationship than females. Psychological health and environment scores were almost equal in both males and females SCD (Table 3).

DISCUSSION

Nigeria being the most populous black nation in the world is a hub of sickle cell disease (SCD). SCD is a chronic debilitating disease recognized by World Health Organization (WHO) as a global public health problem in the year 2006. However, there has been a paucity of studies regarding the quality of life of the people who live with the disease especially in Nigeria.

Quality of life provides the patients' view on the burden of the disease rather than the physicians' report of morbidity and mortality of the disease.

This study used the WHO Quality of life–BREF (WHOQOL-BREF), a validated and tested WHO questionnaire to assess patients' view of his/her own wellbeing rather than that of the health care providers' assessments and was compared with HbAA controls.

Qualitative findings from focus groups were reported by Thomas et al 19 in which they evaluated experiences of SCD patients in order to gain an understanding of the psychosocial impact of the disease and compared their findings with the WHOQOL-BREF quantitative study. They concluded that as demonstrated by WHOQOL-BREF, SCD impacts on physical, psychological, social and occupational wellbeing as well as independence and environment.

Despite a much younger mean age of SCD participants of this study compared with HbAA controls (mean age 27.86±9.34 years vs 49.20±6.17 years controls) SCD patients scored generally lower than controls on domain regarding physical health. This is not unexpected because pain episodes are sine qua non in SCD population. SCD pain are of three types viz; acute recurrent painful crisis, chronic pain syndrome and neuropathic pain.20 Apart from pain episodes, SCD is a chronic disorder, and it requires continuous attention of myriad of acute complications associated with it, for example, acute chest syndrome, vaso-occlusive crisis, aplastic crisis, recurrent infections, priapism and chronic complications like pulmonary hypertension, chronic leg ulcer, and avascular necrosis of the head of femur. This impacts negatively on their score regarding pain and discomfort, sleep and rest, energy and fatigue, mobility, activities of daily living, dependence on medicinal substances and medical aids and work capacity which constitute physical domain of the WHOQOL-BREF questionnaire.

Poor physical health in SCD impacts on psychological wellbeing, and this accounted for the low score obtained in SCD participants in this study. Chronic and recurrent pain experienced by SCD participants, may contribute to school absenteeism and affects their faculty of thinking, learning, concentration and memory, they also have low self-esteem and negative feelings hence a low score on psychological domain. Psychological support is important for SCD patients, however, most clinics attending to SCD in Nigeria lack clinical psychologists to address this gap. Clinical psychologists are needed as part of multi-disciplinary team (MDT) to attend to psychological consequences of a lifetime with pain. They are also needed for the socioeconomic challenges faced by the patients in climes where patients pay out-of-pocket for numerous hospital admissions they are faced with.

The importance of cognitive behavioral therapy (CBT) in SCD cannot be over emphasized, in 2001, Broome et al in a study involving school age children and adolescent with SCD examined whether coping with pain changed immediately and one year after a self-care intervention. The outcome was a reduced healthcare utilization for all participants in the study.[21] Similarly, Thomas et al investigated the economic validity of using a Psychological Intervention in the management of SCD pain. They concluded that CBT is applicable in the management of SCD pain in terms of reducing psychological distress pain and improving coping.[22] That CBT should be a component of care in SCD and should be offered routinely to all SCD patients six monthly. Thus, improving on the psychological wellbeing of SCD patients will impact positively on their physical health and score.

The domain on social relationship i.e., personal relationship, social support and sexual activities also recorded a much lower score in SCD population compared with controls. Social relationship is hugely compromised in patients living with SCD as reflected in the low score compared with HbAA. This may be due to poor social supports from places of work, family members and friends. Health related stigmatization is largely responsible for poor social relationship score among SCD clients. Sources of health-related stigmatization are from family members, general public and health care providers.[23] SCD clients reported negative reactions from family/friends, co-workers, peers and community members regarding their SCD status.[24] Despite a defective physical development in SCD, sexual development is not different from HbAA controls, and they described sexual relations comparable to HbAA, however, SCD patients reported discrimination and feelings of inferiority stemming from chronicity and complications of the disease.[25]

Scores regarding environment were at par in both SCD and HbAA showing that the SCD clients were not at any particular disadvantage with regards to environmental issues. There was also no difference between males and females SCD clients, showing gender plays little or no role on the environmental impact.

Physical health score was observed to be lower in males than females in SCD, this may not be unrelated to more adventure undertaken by males than females and may be attributed to females paying more attention to health issues including their limits of their physical activity. While psychological, social and environmental health scores were similar in both males and females. This is similar to Amr et al study who reported a lower physical health score in males but similar psychological, social and environmental scores in both males and females.[26] However, Asani et al reported no association between health-related quality of care and gender.[27]

A major limitation of this study is the reliability on information provided by participants while filling the WHOQOL-BREF questionnaire. Secondly, generalizing conclusions based on hospital based and cross- sectional study rather than a population based and longitudinal study involving a larger sample size may also be a study limitation.

CONCLUSION

Health related quality of care is not optimal in SCD, and there is therefore a need for health providers and stakeholders to advocate for support systems to address the health-related care of our SCD population.

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APPENDIX

WHOQOL-BREF Questionnaire

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you pick is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask you that you think about your life in the last four weeks.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pains prevent you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you think life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask how completely you experience or were able to do certain things in the last four weeks?

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

Continued.

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

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____

[The following table should be completed after the interview is finished]

		Equation for computing domain scores	Raw Score	Transformed scores*	
				4-20	**0-100**
27.	**Domain 1**	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 ++☐+++ ☐ ☐ ☐ ☐ ☐ ☐	a.=	b:	c:
28.	**Domain 2**	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) ☐+ + ☐ ☐ ☐ ☐ ☐	a.=	b:	c:
29.	**Domain 3**	Q20 + Q21 + Q22 +☐ ☐ ☐	a.=	b:	c:
30.	**Domain 4**	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 ☐+ +☐+ + ☐ ☐ ☐ ☐ ☐ ☐	a.=	b:	c: