Quality of life of individuals with sickle cell disease followed at referral centers in Alagoas, Brazil

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Background: *Sickle cell disease is a genetic, hereditary and chronic disease that affects the health of its carriers and might impair their health-related quality of life.*

Objective: *The aim of the current study was to assess the health-related quality of life of individuals with sickle cell disease followed at referral centers in Alagoas, Brazil.*

Methods: *A total of 40 individuals with sickle cell disease aged 12 to 43 years old were evaluated by means of sociodemographic and clinical questionnaires, the Medical Outcomes Study 36-Item Short Form Health Survey and the Beck Depression Inventory. The latter was applied only to adults.*

Results: *Most participants were adults (62.5%) with a predominance of the SS genotype (85%) with pain being the commonest complication (95%). Mood disorder was found in 40% of the adults. The patients exhibited overall impairment of quality of life, which was more pronounced among the adults and under 15-year-old adolescents. Married adults exhibited less impairment of most quality of life domains compared to unmarried adults, and the adults with mood disorder exhibited greater impairment of all quality of life domains.*

Conclusions: *These results suggest that interventions that aim to improve vitality, pain, and mental health might contribute to maintaining high levels of quality of life in patients with sickle cell disease, especially among adults and under 15-year-old adolescents.*

Keywords: *Quality of life; Anemia, sickle cell/diagnosis; Electrophoresis; Questionnaire; Depression/diagnosis; Socioeconomic factors; Adolescents; Adults*

Introduction

Sickle cell disease (SCD) is the most common monogenic hereditary disease in Brazil with the prevalence of heterozygous cases being particularly high in the state of Alagoas (3%) [1,2]. SCD is a chronic, incurable disease that requires prolonged treatment. The wide clinical variability of the disease may negatively impact the quality of life (QOL) of patients[3]. Due to its clinical and epidemiological importance, SCD is considered a public health problem[4].

Within the field of biomedical sciences, the concept of health-related QOL (HR-QOL) is understood as the individual's own subjective perception of aspects of life directly related to the state of health. Therefore, this concept represents the satisfaction and well-being of an individual as concerns the physical, psychological, social, economic, and spiritual domains of his/her state of health[5], i.e., a combination of the state of health and the affective response to it[5,6].

The HR-QOL of children/adolescents and adults with SCD has been studied by means of generic instruments[7-10], which have shown that this disease significantly affects the physical and psychosocial domains of the HR-QOL in affected children, adolescents[7-10] and adults[7,9].

The present study sought to determine the correlation between HR-QOL, sociodemographic and clinical variables in patients with SCD followed at referral centers in Alagoas, Brazil. To this end, we assessed the QOL using the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) and measured its correlations with sociodemographic and clinical variables, as well as with depressive symptoms as measured by the Beck Depression Inventory (BDI), in adolescents and adults with SCD who were treated at the Hospital Universitário Prof. Alberto Antunes - HUPAA and the Hemocentro de Alagoas – HEMOAL.

Methods

Participants and procedures

The present study employed quantitative techniques allowing a descriptive, exploratory and cross-sectional study. Fifteen adolescents (10-20 years old) and 25 adults (older than 20 years) registered at the Hematology Service of HUPAA and at HEMOAL were interviewed. The participants of both genders had the diagnosis of SCD confirmed by laboratory tests (hemoglobin electrophoresis) and were asymptomatic at the time of the interview. The present sample corresponded to approximately 10% of the total number of individuals with SCD registered at the referral centers in Alagoas.

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The sample was selected randomly at routine consultations during the study period. Over 18-year-old patients and the guardians of minors signed informed consent forms before entering the study complying with Resolution no. 196/96 of the Brazilian National Health Council.

Instruments

All participants exhibited the level of understanding needed to fill out the questionnaires, which were applied by a trained interviewer between March and June 2011.

a. Sociodemographic data and clinical status

Sociodemographic information (age, gender, skin color, marital status, origin, educational level, number of siblings, occupation, employment, monthly family income) regarding the adolescents and adults with SCD was collected by means of structured interviews.

The clinical status of each subject was assessed (diagnosis, date of diagnosis, relevant personal history, age at first symptom, number of hospital admissions, number of blood transfusions, presence of complications and health problems related to the disease, use of medications).

b. The 36-Item Short Form Health Survey Questionnaire

SF-36 is a generic instrument to assess the HR-QOL, which was previously translated and validated in Portuguese and cross-culturally adapted for the Brazilian population[11]. SF-36 contains 36 questions corresponding to eight domains, which, in turn, represent two major components, i.e., physical and mental[12]. The questionnaire addresses general health notions that are not specific in regard to age, disease or treatment group. The questionnaire can be self-administered or administered by a trained interviewer[13].

c. Beck Depression Inventory

The BDI[14] is a self-assessment measure of depression widely used in the clinical practice and for research purposes. This inventory has been translated and validated in several countries, including Brazil[15], for individuals with or without clinical diagnosis of depression. Individuals scoring above 15 are considered as having mood or affective disorders (dysphoria), whereas the term "depression" is applied when the score is over 20. This instrument was applied to the 24 adults in the sample.

Statistical analysis

Descriptive statistics were used for the demographic and clinical characterization of the participants. Epi Info 6.04 software was used for the statistical analysis. The Mann-Whitney U-test was used to compare the average scores of the SF-36 questionnaire according to the sociodemographic and clinical variables and the depressive symptoms as measured by the BDI. The significance level was set for a p-value < 0.05.

Results

Demographic characteristics of the study sample

Among the adolescents with SCD, most patients were male (73.3%) with an average age of 14.4 years and most were brown-skinned (54.5%). In regard to educational level, 60% had an incomplete elementary education and their family income was in general one to two minimum wages (Table 1).

Most of the adults with SCD were female (68%) and most had incomplete elementary education (40%). Most of the adults were married (45.8%) and only 12% reported being unemployed (Table 1).

Table 1 - Sociodemographic characteristics of the study sample

Characteristic	Adolescents (n = 15)	Adults (n = 25)
Gender - n (%)		
Male	11 (73.3)	8 (32)
Skin color - n (%)		
White	0 (0)	1 (4)
Brown	11 (73.3)	11 (44)
Black	4 (26.7)	13 (52)
Age (years)		
Mean (SD)	14.4 (2.89)	35.0 (8.2)
Median	14.0	35.0
Educational level - n (%)		
Illiterate	0 (0)	3 (12)
Incomplete elementary education	14 (93.3)	10 (40)
Complete elementary education	0 (0)	3 (12)
Incomplete secondary education	1 (6.7)	2 (8)
Complete secondary education	0 (0)	7 (28)
Existence of employment contract - n (%)	-	22 (88)
Family income in minimum wages - n (%)		
Less than 1	0 (0)	7 (28)
1 to 2	11 (73.3)	4 (16)
2 to 3	3 (20)	9 (36)
More than 3	1 (6.7)	5 (20)

Clinical characteristics of the study sample

In the study sample, the homozygous SS genotype predominated (85%). All patients exhibited complications and/or health problems associated with SCD, of which pain was the most common. It was observed that 40% of the interviewed adults exhibited BDI scores suggestive of mood disorders (Table 2).

Assessment of health-related quality of life

Health-related quality of life in all adolescents and adults with sickle cell disease

The adolescents and adults with SCD investigated in the current study had low HR-QOL scores. The comparison between these two groups showed that the adults exhibited significantly lower SF-36 scores in the functional capacity, mental health, social functioning and role-emotional domains (Table 3).

Health-related quality of life in adolescents with sickle cell disease according to age

The HR-QOL scores were significantly lower among the under 15-year-old adolescents compared to older adolescents regarding the functional capacity and social functioning domains (Table 4).

Table 2 - Clinical characteristics of the study sample

Variable	Adolescents (n = 15)	Adults (n = 25)
Hemoglobinopathy - n (%)		
SS	9 (60)	25 (100)
SC	3 (20)	0 (0)
S/β+ thalassemia	3 (20)	0 (0)
No. of hospital admissions in the previous year - n (%)		
0	6 (40)	7 (28)
1-5	9 (60)	18 (72)
No. of blood transfusions		
Mean (median)	2.6 (3.0)	1.3 (1.0)
Complications and/or health problems - n (%)		
Anxiety	5 (33.3)	12 (48)
Headache	8 (53.3)	22 (88)
Depressive mood	5 (33.3)	9 (36)
Pneumonia	6 (40.0)	7 (28)
Pain	14 (93.3)	24 (96)
Learning difficulties	4 (26.7)	15 (60)
Sleep disorders	2 (13.3)	9 (36)
Splenectomy	3 (20.0)	6 (24)
Cholecystectomy	2 (13.3)	11 (44)
Stroke	1 (6.7)	2 (8)
Kidney infection	2 (13.3)	6 (24)
Motor deficit	2 (13.3)	4 (16)
Epileptic crisis	2 (13.3)	3 (12)
taking hydroxyurea	8 (53.3)	6 (24)
BDI score		
Mean (median)	-	12.1 (10)
Dysthymia - n (%)	-	6 (24)
Depression - n (%)	-	4 (16)

Table 3 - SF-36 scores of adolescents and adults with SCD

Domain	Adolescents (n = 13)		Adults (n = 25)		p-value*
	Mean	SD	Mean	SD	
Functional capacity	62.6	21.4	47.8	17.9	0.021
Physical functioning	41.1	38.1	53.8	23.1	0.173
Bodily pain	49.3	22.1	51.4	25.5	0.797
General health perception	45.6	11.7	45.0	18.9	0.953
Vitality	49.2	15.3	47.5	18.6	0.902
Mental health	72.0	12.1	48.0	20.1	< 0.001
Social functioning	71.0	20.0	48.2	19.0	0.006
Role-emotional	77.3	38.8	44.6	21.5	0.003

SD: standard deviation; *Mann-Whitney U-test

Health-related quality of life in adults with sickle cell disease according to marital status

The married patients exhibited less impairment in all domains, except for pain, compared to unmarried participants (Table 5).

Health-related quality of life in adults with sickle cell disease according to the presence or absence of mood disorder

Comparisons of the average SF-36 scores between patients with and without mood disorder as assessed by BDI showed that patients with mood disorder had greater impairment in all HR-QOL domains (Table 6).

Discussion

Chronic diseases often promote the development of physical, social and emotional problems due to secondary organic dysfunctions associated with the underlying disease. SCD, as a chronic disease, also exhibits such characteristics[3,7,16]. Problems arise from the various complications that might appear during the natural course of the disease in addition to a reduction in the life expectancy of patients. The concerns and uncertainties stemming from these patients' medical complications and clinical prognoses provide fertile ground for feelings of anxiety and depression, which interfere directly in the patients' QOL[7,17].

The sample investigated in the current study comprised mostly female, brown-skinned, adult patients. The average age of the adults was 35 years old, which reflects the reduced life expectancy of the sample, which was composed almost exclusively of subjects with the SS genotype[18].

Patients with SCD should attend school continuously, even during their clinical setbacks. Patients need to learn how to cope with the disease and the limitations it imposes; this requires social and psychological support[11,19]. However, the present study shows that despite these recommendations, most of the patients lagged behind in school as other authors have previously reported[7,20,21]. This decreased level of education might be related to several factors, including school absenteeism due to clinical complications and bullying and/or discrimination at school in addition to early school dropout by adults due to the deterioration in their clinical condition[22].

A large proportion of the investigated sample (45.5%) reported a family income of two to three minimum wages, which agrees with the results of other local[23,24] and national studies[7,20,25], which also showed that the economic profile of families with SCD is one of extreme poverty. Without a doubt, the disease represents a further strain on the family budget.

Most of the interviewed adults (88%) reported being employed, which contrasts with previous studies[3,7,16,20]. The low educational level of many chronic disease patients does not enable them to obtain or hold well-paid jobs, which might give rise to the employment and financial difficulties they endure. This precarious financial situation becomes one of the main triggers of depressive symptoms in adults with SCD[26].

The SS genotype was the most common in this study (85%), which agrees with the findings of other studies conducted in the state of Alagoas[1,26,27]. All patients exhibited some complication or health problem associated with SCD, which points to the greater physical impairment in this type of hemoglobinopathy as other studies have already shown[2,3,16,18,21]. Pain is the most frequent complication and is a constant complaint among SCD patients. Pain interferes mainly with patients' work activities and QOL[22].

Mood disorder was identified in 40% of the adults with SCD in the present sample, 32% of whom exhibited manifestations suggestive of dysphoria and 16% of depression. According to the Diagnostic and Statistical Manual of Mental Disorders[28], these rates are higher than the rates in the general population, which are 10 to 25% among adult women and 5 to 12% among men. In addition to ethnic aspects, socioeconomic precariousness can be a significant risk factor for depression[29].

The group of under 15-year-old patients exhibited lower scores of functional capacity and social functioning compared to the older adolescents. To the best of our knowledge, no study has addressed this particular age range (10 to 14 years old). Although the sample size was small, these results suggest that younger adolescents exhibit poorer functional capacity, i.e., greater physical limitations in their activities (either vigorous or related to everyday life) compared to adolescents ≥ 15 years old. The homozygous condition (SS) is associated with greater impairment of HR-QOL because the clinical manifestations of disease are substantial in these patients[2,3,16,18,21].

A comparison of the HR-QOL scores between the adolescents and the adults showed that the latter exhibited lower scores in functional capacity, mental health, social functioning, and role-emotional domains. These results differ from those of Assis[7], who found lower scores only in the mental health domain among adolescents compared to adults with SCD, which might be explained by the psychological conflict typical in this phase of life.

The adults who reported being married scored higher in all HR-QOL domains except for pain. The literature characterizes marriage and other types of family and/or social support as protective factors against common mental disorders. This fact might be explained by the care provided by spouses, relatives, or social groups at difficult times, which reflects better family and social support with consequent improvement of the physical and mental condition[20].

The patients with mood disorder according to BDI exhibited greater impairment in all HR-QOL domains, possibly due to their inability to cope with the recurrent episodes of pain, resulting in feelings of despair, anguish and lack of control[17]; this impairs the physical, emotional, and social aspects of HR-QOL[29,30].

Our results indicate the importance of developing a multidisciplinary assistance strategy for the follow-up of the physical, mental and social health of adolescents and adults with SCD. It is worth emphasizing that there is a need to conduct further studies on their HR-QOL, especially by means of qualitative methods to complement the quantitative data, as SCD is a chronic condition that should be approached as a whole, instead of focusing only on its medical implications. Finally, the present study suggests the importance of public health measures and strategies at the local level to aid the SCD population in the process of adapting family activities to account for their debilitation and in the management of their home care.

The limitations of the present study are its cross-sectional design and the numerous unexamined variables that could have been measured. Future qualitative and longitudinal studies are needed to investigate the influence of clinical and psychosocial factors on the HR-QOL during the progression of SCD.

Table 4 - SF-36 scores of adolescents with sickle cell disease distributed according to age

Domain	Under 15 years old (n = 6)		15 to 20 years (n = 7)		p-value*
	Mean	SD	Mean	SD	
Functional capacity	46.6	19.6	76.4	11.0	0.012
Physical functioning	35.0	36.0	46.4	41.9	0.886
Bodily pain	48.6	29.3	49.8	16.0	0.384
General health perception	48.1	12.9	43.4	11.0	0.772
Vitality	44.1	9.7	53.5	18.6	0.093
Mental health	70.6	9.3	73.1	14.7	0.662
Social functioning	60.3	20.0	80.1	16.0	0.031
Role-emotional	67.6	41.1	85.7	37.7	0.254

SD: standard deviation; * Mann-Whitney U-test

Table 5 - SF-36 scores of adults with sickle cell disease according to marital status

Domain	Married (n = 12)		Unmarried (n = 13)		p-value*
	Mean	SD	Mean	SD	
Functional capacity	56.0	16.1	40.2	16.4	0.013
Physical functioning	63.3	23.4	45.0	19.7	0.042
Bodily pain	59.2	24.3	44.1	25.2	0.136
General health perception	54.3	16.1	36.3	17.6	0.015
Vitality	57.9	16.1	37.9	15.7	0.003
Mental health	58.0	17.7	38.6	18.2	0.003
Social functioning	56.5	18.7	40.6	16.2	0.012
Role-emotional	53.7	23.8	36.2	15.9	0.008

SD: standard deviation; * Mann-Whitney U-test

Table 6 - SF-36 scores of adults with SCD according to the presence of mood disorder

Domain	Without mood disorder (BDI ≤ 15) (n = 15)		With mood disorder (BDI > 15) (n = 10)		p-value*
	Mean	SD	Mean	SD	
Functional capacity	58.5	7.5	31.8	17.0	0.001
Physical functioning	68.8	15.2	31.4	11.4	< 0.001
Bodily pain	68.7	15.9	25.4	9.4	< 0.001
General health perception	54.8	15.0	30.3	14.3	0.001
Vitality	55.8	14.5	35.1	17.6	0.007
Mental health	60.3	10.5	29.5	16.7	< 0.001
Social functioning	59.3	10.9	31.5	16.1	< 0.001
Role-emotional	57.2	13.6	25.7	17.0	< 0.001

SD: standard deviation; * Mann-Whitney U-test

Conclusions

The results of the present study corroborate the hypothesis that, as a chronic disease with wide clinical variability, SCD limits the lives of patients and pain is most likely the major cause of the physical and emotional destabilization of patients.

Gender did not influence the HR-QOL of the patients in the present study.

The adult patients exhibited greater impairment in the functional capacity, mental health, social functioning, and role-emotional domains of HR-QOL compared to the adolescents.

Among the adults, being married had a positive influence on all the domains of HR-QOL, except for pain.

Among the adults, those who exhibited mood disorder (BDI > 15) exhibited greater impairment of HR-QOL compared to adults without mood disorder (BDI ≤ 15).

The current study suggests that interventions to improve vitality, pain and mental health might help maintain higher levels of HR-QOL in patients with SCD.

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