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Research Paper

Assessment of The Quality of Life of Tribal Individuals With Sickle Cell Disease in a Selected District of Kerala

Nursing

KEYWORDS : Sickle cell disease, Sickle cell crisis, Quality of Life

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ABSTRACT

A descriptive survey was conducted to assess the quality of life (QOL) of tribal individuals with sickle cell disease (SCD) in Wyanad district of Kerala, India. The objectives of the study are to assess the QOL of tribal individuals between the age of 15-35 years with SCD and to find the association between the QOL of tribal individuals with SCD and the selected demographic variables. The tool used was SF-36® Health Survey. The major findings of the study showed that SCD affects the QOL of children, adolescents, and their families and there is no significant difference in the QOL of male and female individuals with SCD. The study also reveals a fact that the income of the family has a
significant impact on social functioning, physical functioning, physical health and general health of individuals with SCD.

INTRODUCTION

Sickle cell disease (SCD) is a genetic blood disorder caused by the presence of an abnormal form of hemoglobin. Normal red blood cells are disc-shaped and very flexible. In SCD, some red blood cells change their shape and they look like crescent moons. Because of their shape, they don't move well through the smallest blood vessels causing slow blood flow to the vital organs. About 300,000 children are born with a form of SCD every year, mostly in sub Saharan Africa, but also in other parts of the world such as the West Indies and in people of African origin . In 2013 it resulted in 176,000 deaths up from 113,000 deaths in 1990 (Global Burden of Disease Study 2013) Each year approximately 300,000 children are born with sickle cell anaemia, nearly 80 per cent of these births occur in poor socio-economic countries (Tewari, 2013). SCD is prevalent in many parts of India at a range of 9.4 to 22.2% in endemic areas (Shapiro B S (1989). Wayanad, a district of Tribal People in Kerala, about 5000 persons are suffering from SCD and there are twenty thousand carriers. The severity of the disease is, in general, inversely proportional to the quality of life (QOL). Epidemiologic data indicate 5.2 % of patients with sickle cell crisis have 3-10 episodes of severe pain crisis every year. In most patients a pain crisis resolves within 5-7 days. A severe crisis may cause pain that persists for weeks to months.

According to the World Health Organization (WHO), the QOL is defined as "the individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". It moves beyond direct manifestations of illness to the patient's personal morbidity. These assessments are an important aspect of chronic disease management. SCD is the most common genetic disorder. It is a chronic and potentially, debilitating disease which has impacts on physical, psychological, social and occupational wellbeing. The disease is severe and may result in significant morbidity, as well as a shortened life span.

NEED FOR THE STUDY

SCD is a genetic, hereditary and chronic disease that affects the health of its carriers and might impair their QOL (Vilela, 2012). Besides the medical consequences, most of the families with a child of SCD have to cope with financial and social crisis. Other than health; emotional well being, social dysfunction, chronic pain and fatigability are also important aspects of overall QOL. People with SCD present several signs and symptoms that can occur in different ways and at different severities; they occur jointly or separately. These complications have a physical, emotional and social impact on the carrier's life that can compromise their QOL. Although SCD has been largely studied in terms of population frequency and clinical variations, research that addresses aspects related to QOL of patients are relatively scarce. Despite the high prevalence, there are few studies describing the impact of the disease on QOL. Quality of life among adults with sickle cell disease has not been widely reported. In fact the tribal individuals with SCD and their family members are facing various physical, financial and psychosocial problems especially during the time of SCC. **STATEMENT OF THE PROBLEM**

A study to assess the quality of life of tribal individuals with Sickle cell disease in a selected District of Kerala.

OBJECTIVES

1. To assess the quality of life of tribal individuals (between the age of 15-35 years) with SCD in a selected district of Kerala.
2. To find the association between the QOL of tribal individuals with SCD and the selected demographic variables. **OPERATIONAL DEFINITION**

Quality of life - Quality of life refers to people's ability to function in the ordinary tasks of living.

WHO SF-36 questionnaire is a set of questions used for the assessment of QOL of individuals in their daily activities .

Sickle Cell Crisis (SCC) : It is phenomenon that occurs when the Sickled Red Blood Cells block small blood vessels and less blood flows to that part of the body damaging tissue and causing sudden pain and other serious complications.

Tribal individuals: Tribal individuals are those who reside in the interior areas of the selected districts of Kerala and to this day remain relatively isolated from the mainstream of the society.

RESEARCH METHODOLOGY

Design : Descriptive survey design

Setting : Tribal areas of Wayanad District in Kerala

Population & Sampling :-

Population : Tribal individuals with SCD from Wayanad District in Kerala

Sample : 25 Tribal individuals with SCD between the age of 15-35 years

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Sampling : Convenient sampling

Inclusion Criteria -

: Tribal Individuals with SCD between the age of 15-35 years

: Tribal individuals those who are able to read and understand Malayalam

: Tribal individuals those who were willing to participate in the study

TOOLS / INSTRUMENT
Questionnaire consists of 2 Sections

Demographic variables

The RAND 36-Item Health Survey (Version 1.0) which consists of eight health concepts:

ETHICAL CONSIDERATION
Permission obtained from Dist. Collector and Dist. Medical Officer of Wayanad District in Kerala. Ethical clearance obtained from the ethical committee of Govt. Medical College, Thrissur, Kerala. Consent was obtained from each individual before data collection.

DATA ANALYSIS – The data analyzed using descriptive and inferential statistics.

Descriptive statistics were used for the demographic and clinical characterization of the participants. The Mann-Whitney U-test was used to compare the average scores of the SF-36 questionnaire according to the socio-demographic and clinical variables.

RESULTS
The major findings of the study

Table 1. Demographic profile of the subject N = 25

Characteristics	Category	Frequency	Per cent
Sex	Male	12	48.0
	Female	13	52.0
Age	16-20	4	16.0
	21-25	10	40.0
	26-30	5	20.0
	131-35	6	24.0
Education	B	1	4.0
	C	11	44.0
	D	13	52.0
Occupation	A	8	32.0
	B	6	24.0
	C	2	8.0
	D	9	36.0
Income	A	15	60.0
	B	5	20.0
	C	5	20.0

This table shows that among 25 subjects 12 subjects (48%) are male and 13 subjects (52%) are female and 10 subjects (40%) are between the age of 21-25 years. Out of 25 subjects 13 subjects (52%) are having above +2 education. Among 25 subjects 8 subjects are students, 6 subjects are doing household work, 2 subjects are coolie workers and 9 subjects are doing other works.

Table 2. Central Tendency, and Variability of Scales

Dimensions of QOL	Items	Mean	SD
Physical functioning	10	50.00	22.64
Role functioning/physical	4	64.00	21.75
Role functioning/emotional	3	49.33	29.06
Energy/fatigue	4	58.20	19.94
Emotional well-being	5	60.80	21.69
Social functioning	2	68.00	19.79
Pain	2	79.00	16.66
General health	5	38.97	17.74
Health change	1	82.00	18.43

The above table reveals that the mean score of health change is 82.00 with a standard Deviation of 18.43 and the mean score of pain is 79.00 with a standard deviation of 16.66.

Table 3. Comparison of QOL amon male and female
N = 25

Dimensions of QOL	Male		Female		t-value	p-value
	Mean	Std. Deviation	Mean	SD		
Physical functioning	45.83	23.73	53.85	21.81	0.880^{ns}	0.388
Physical health	62.50	19.94	65.39	24.02	0.325^{ns}	0.748
Emotional problems	47.22	33.21	51.28	25.88	0.343^{ns}	0.735
Energy	53.75	19.20	62.31	20.48	1.075^{ns}	0.293
Emotional wellbeing	57.67	21.81	63.69	22.06	0.686^{ns}	0.499
Social functioning	66.67	20.18	69.23	20.17	0.318^{ns}	0.754
pain	81.88	14.03	76.35	18.95	0.823^{ns}	0.419
General health	39.10	19.87	38.85	16.35	0.035^{ns}	0.972
Health change	87.50	16.86	76.92	18.99	1.468^{ns}	0.156

ns non significant at 0.05 level

This table shows that there is no significant difference in the QOL of male and female individuals with sickle cell disease at 0.05 level of significance.

Table 4. Association of QOL with age, education and income

Dimensions of QOL	Age	Education	Income
Physical functioning	0.138^{ns}	-0.198^{ns}	0.428*
Physical health	-0.172^{ns}	0.238^{ns}	0.484*
Emotional problems	0.155^{ns}	-0.228^{ns}	-0.014^{ns}
Energy	0.020^{ns}	-0.040^{ns}	0.270^{ns}
Emotional wellbeing	0.140^{ns}	-0.010^{ns}	0.270^{ns}
Social functioning	-0.100^{ns}	-0.070^{ns}	0.514**
pain	-0.158^{ns}	-0.273^{ns}	0.360^{ns}
General health	0.026^{ns}	-0.169^{ns}	0.438*
Health change	0.054^{ns}	-0.219^{ns}	0.083^{ns}

ns non significant at 0.05 level; * significant at 0.05 level; ** sig-

nificant at 0.01 level

The above table reveals that there is a significant association between the social functioning dimension of QOL and income of the subjects at 0.01 level of significance. The table also shows that there is a significant association between physical functioning dimension of QOL and income, between physical health dimension of QOL and income and between general health dimension of QOL and income at 0.05 level of significance.

DISCUSSION

In general, SCD patients experience a poor QOL. SCD affects the QOL of children, adolescents, and their families. Patients sense restrictions in the emotional, social, family and physical aspects, among others. SCD, as a chronic disease, exhibits physical, social and emotional problems due to secondary organic dysfunctions and reduce the life expectancy of patients. This study shows that there is no significant difference in the QOL of male and female individuals with sickle cell disease. A study conducted in Brazil supports this study by stating that gender did not influence the QOL of the patients with SCD. The findings of this study also reveal a fact that the income of the family has a significant impact on social functioning, physical functioning, physical health and general health of individuals with SCD. These findings are supported by another study conducted in Brazil which also showed that the economic profile of families with SCD is extreme poverty. Another study conducted in Saudi Arabia reported that socio-demographics including low family income and the occurrence of disease-related complications were associated mainly with deterioration of physical health of individuals with SCD. The socio-demographic profile including low family income and unemployed with SCD considered to be a significant impediment to find a job. Evaluation of QOL as a determining factor of health is essential for the creation of specific policies and measures, appropriate for the specific characteristics and social context of sickle cell disease.

CONCLUSION

SCD limits the lives of patients and pain is most likely the major cause of the physical and emotional destabilization of patients. The interventions to improve vitality, pain and mental health might help to maintain higher levels of QOL in patients with SCD. The findings of this study implicate the seriousness of poor QOL among SCD patients, necessitating a national level program and introduce restoration of overall QOL as mainstay of management of patients with SCD; besides merely symptom based pharmacotherapy.

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