

Health Related Quality of Life of Adult Client Living with Sickle Cell Disease in a Hospital at Banke District, Nepal.

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Received Date 10 September 2022

Accepted Date 22 September 2022

Published Date 28 September 2022

ABSTRACT

Background: Sickle-cell disease is characterized by a modification in the shape of the red blood cell from a smooth shape into a crescent shape. The misshapen cells lack plasticity and can block small blood vessels, impairing blood flow. The purpose of the study was to find out the quality of life of client living with sickle cell disease.

Method: A descriptive cross sectional quantitative study design was used. Non probability convenient sampling technique was used for the selection of respondents after conforming hemoglobin electrophoresis report attending out-patient department of Bheri Hospital.

Results: A total 143 participants were studied who were at age range of 19 to 40 years with mean age of 30.26 ± 8.42 . Almost 81.8% perceived their health was only fair in comparison to past year. In comparison to other people 60.1% participants believe they get sick little easier. The overall quality of life was good in 56% participants. The health related quality of life scores for eight domains are as follows-physical functioning (77.25 ± 18.22), social functioning (58.39 ± 16.77), role limitation due to emotional problem (57.23 ± 33.99), pain (56.43 ± 22.84), role limitation due to physical problem (49.56 ± 29.76), emotional wellbeing (49.59 ± 14.5), Vitality (36.62 ± 16.85) and general health (36.78 ± 19.99).

Conclusion: Quality of life of adults with sickle cell disease is better in the domain of physical function in comparison to other domains. The aspect of energy scale indicates poor quality of life. Female and uneducated clients should be focused for improvement in all domains.

KEYWORDS

Adult, Quality of Life, Sickle Cell Disease

BACKGROUND

Sickle-cell disease is characterized by a modification in the shape of the red blood cell into a crescent or half-moon shape. The misshapen cells lack plasticity and can block small blood vessels, impairing blood flow. Sickle-cell disease can lead to chronic acute pain syndromes, severe bacterial infections, and necrosis. It is estimated that each year over 3, 00, 000 babies with severe forms of these diseases are born worldwide (Owolabi et al., 2011).

It is inherited as autosomal recessive (AR) disorders, where the abnormal genes are transmitted from carrier parents to the offspring (El-Hazmi, Al-Hazmi & Warsy, 2011). Heterozygotes are usually asymptomatic and homozygotes suffer from sickle cell anemia (Chavda, Goswami, & Goswami, 2015).

At least 5.2% of the world population (and over 7% of pregnant women) carry a significant variant. Hemoglobin S accounts for 40% of carriers but causes over 80% of disorders because of localized very high carrier prevalence (Modell, & Darlison, 2008).

Sickle cell disease puts patients in increased risk of central nervous system events such as silent and overt stroke and cerebral vasculopathy (Panepinto, & Bonner, 2012). Similar to other chronic illness, Sickle cell disease affects both physical and psychosocial areas of functioning (Jackson et al., 2014).

Currently available treatments are limited to transfusions and hydroxycarbamide, although stem cell transplantation might be a potentially curative therapy. Recent advances include systematic universal screening for stroke risk, improved management of iron overload using oral chelators and non-invasive MRI measurements, and point-of-care diagnostic devices (Ware et al., 2017).

In Africa and many other parts of the world have a common medical problem known as sickle cell anemia. But in Nepal this is rare hematological problem and only been described in the form of case reports (Lamsal, 2012).

METHODS

Non probability convenient sampling technique was used to collect data from client living with sickle cell disease. Enumerative sampling method, 143 clients were included in the study who visited outpatient department of Bheri Hospital Nepalgunj. Adult clients with confirmed diagnosis on hemoglobin electrophoresis. All clients having sickle cell anemia attending OPD of Bheri zonal hospital, Nepalgunj Banke and who are diagnosed since 1 year. Clients willing to participate in study are selected for study.

The instrument consists of the following parts: semi-structured questionnaire related to the socio-demographic details of the respondents developed by researcher herself through extensive literature review. Part II- structured questionnaire related to quality of life that was measured by standard tool SF-36 which was developed at RAND Health as part of the Medical Outcomes Study that includes physical function, physical role functions, emotional role functioning, bodily pain, vitality, general health, emotional wellbeing and social function.

Data was collected after getting ethical clearance from IRC of National Health Research Council, Ramshahpath, and Kathmandu. One enumerator was selected and trained to use the instrument. Written informed consent was taken from clients diagnosed with sickle cell anemia. Data was collected from 2074/8/1 to 2074/11/30. Data was checked out thoroughly daily for its completeness, consistency and accuracy. Then data was edited and coded. Data was entered in excel sheet and exported and analyzed by using SPSS version-21 and analyzed by using appropriate statistics (descriptive or inferential).

RESULTS

Out of 143 respondents the mean \pm SD age was 30.26 \pm 8.42 years. Majority (88.1%) followed by Hindu religion and all (100%) were Janajati. Regarding family type, 51.7% were living in joint family, 67.8% were educated. Similarly, 60.8% had agriculture as their occupation whereas service was occupation of just only 1.4%. Maximum (68.5%) were married and only 0.7% were widow and divorce respectively. Maximum 71.3% are suffering from more than one year's whereas 87.4% were not suffered by other disease. Third fourth (74.8%) family were not affected by sickle cell anemia and 43.4% had heard about sickle cell anemia.

Health Condition of Respondents

All most general health condition was only fair (81.1%), 5.6% was perceiving poor and just 1.4% perceived their health condition is excellent. There was three quarters (75.5%) somewhat better in compare health in general whereas much worse were just (2.1%) as compare to one year ago.

Table 1: Quality of health during the illness

Statements	n=143		
	Yes, limited a lot	Limited a little	No, not limited at all
Moderate activities	7.0	51.7	41.3
Carrying groceries	3.5	28.0	68.5
Vigorous activities	17.5	65.7	16.8
Sever flights of stairs	9.8	45.5	44.8
Flight of stairs	1.4	11.9	86.7
Bending body	8.4	45.5	46.2
Walking on a mile	9.8	25.9	64.3
Walking several blocks	3.5	18.2	78.3
Walking one blocks	1.4	10.5	88.1
Dressing yourself	1.4	20.3	78.3

Table 1 shows that, the overall of vigorous activities were highest (17.5%) in yes limited a lot and(65.7%) in limited a little while 88.1% were no not limited at all in walking one blocks. The moderate activities just over a half (51.7%) which in limited a little whereas flights of stairs, walking one blocks and dressing were tiny fraction (1.4%) in yes limited a lot. Highest percentage in each response were in no not limited after that limited a little and least response were in yes limited a lot respectively.

Table 2: Physical health& emotional health among adult client living with sickle cell disease

Statement	Yes	No
Physical Health		
Time spent on work or other activities	30.8	69.2
Accomplish less than you would like	35.0	65.0
Limited in the kind of work or other activities	64.3	35.7
Difficulty performing the work or other activities	72.7	27.3
Emotional Health		
Amount of time spent on work or other activities two	30.1	69.9
Accomplish less than you would like to	35.0	65.0
Work or other activities	64.3	35.7

Table 2 shows that, the highest (72.2%) were difficulty performing the work or other activities while least (30.8%) were in time spent on work or other activities. Work or other activities were highest (64.3%) in yes whereas 69% amount of time spent on work or other activities were no.physical/emotional and pain interfere both are highest in slightly 39.9% and 40.6% respectively. The proportion of moderately were tiny fraction between them. Least percentage 0.7% and 7.7% were affected extremely by physical/emotional and pain interference respectively.

The highest percentage of (46.6) were mild, while very severe become least (5.6%). However, moderate (18.9%) come on second position and very mild (13.3%) were third whereas severe and none were same 7.7% in pain perception during the past 4 week among adult client living with sickle cell disease.

Table 3: Felling of quality of life among adult client living with sickle cell disease

Statement	n=143				
	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
Seem to get sick a little easier than other people	10.5	60.1	2.1	23.1	4.2
Am as healthy as anybody i knew	5.6	28.7	9.1	51.7	4.9
Expect my health to get worse	10.5	49.7	6.3	28.7	4.9
My health is excellent	4.9	21.0	5.6	32.2	36.4

Table 3 shows that, the felling of quality of life (60.1%) & (49.7) were mostly true at seem to get sick a little easier than other people and expect my health to get worse respectively whereas just over the half (51.7%) mentioned mostly false at am as healthy as anybody I knew. (36.4%) mentioned definitely false at statement my health is excellent.

There as association between quality of life and sex (p-value 0.018), education (p-value 0.015). Finding shows that, male were better quality of life (68.5%) as compare to female (48.3%). Similarly educated person had better quality of life (62.9%) whereas uneducated were (41.3%). There was no statistically significant between quality of life and age group (p-value 0.184), level of education (p-value 0.367), occupation (p-value 0.765), marital status (p-value 0.453), Religion (p-value 0.191), Ethnicity (p-value 0.373) and family type (p-value 0.893).

DISCUSSION

In this study regarding the health condition of the respondents as compare to one year ago 5.6% respondents perceived their general health condition as poor than past year. The findings of the study is similar with the study conducted by (Tijani et al., 2018) which shows that 10.8% of the respondents perceived that their general health status is poor than past year.

Majority of respondents (40.6%) had slight bodily pains in last 4 weeks similarly, 46.9% of the respondent felt pain at mild intensity whereas 5.6% perceived pain as very severe that interfere performing normal work (including both work outside the home and housework). Similar study is conducted by (Evensen et al., 2008) which shows that nearly three quarters of respondents (67%) perceived that pain interfered with their normal lives. This difference in findings may be due the difference in tool used by Evensen et al., where quality of life of adults was measured by using Quality of care survey instead of SF 36.

Low proportion 16.8% of respondents believed that their health status did not limit at all from performing vigorous activities. The finding of the study is similar with the study conducted (Tijani et al., 2018) in which 21.0% believed that SCD don't interfere in performing vigorous activity. In contrast to this a study in the US shows that nearly half of respondents (46.7%) believed that their health status did not limit them from performing vigorous activities. This difference may be due to difference in age group of the respondents (adolescents)

Highest percentage of respondents (47.6%) felt full of pep none of the time, 37.8% respondents felt lots of energy a little of time, 37.1% felt worn out little time and most of the time 56.6% respondents felt tired during past 4 weeks and the vitality score was 36.62 ± 16.85 . Similarity was observed in study by (Tijani et al., 2018) in which a high proportion of the respondents had lot of energy worn out and tired and the vitality score was higher 53.8 ± 13.3 in males and 52.2 ± 12.9 in females. In this (77.25 ± 18.22) was better as compared to other domains because mean score was higher as compare to other domain. Regarding energy scale the transform mean and SD score was low (36.62 ± 16.85), was indicate poor quality of life among sickle cell diseases of adult. The reliability coefficient was higher in emotion problem (0.756) and least in pain (0.701). More than half (56%) had good quality of life while as 44% had poor quality of life. In contrast to this, in the study done by (Tijani et al., 2018) in Northwest Nigeria and (McClish et al., 2005)

in the US respondents had lower SF 36 scores in all domains that indicate a lower QOL among participants of this study.

CONCLUSIONS

Based in findings it can be concluded that respondents overall quality of life was good. On regard to each domain physical health domain was good than other and quality of life in aspect of emotional health was poor. Findings also concluded variables as being female and uneducated was statically significant and other variables as age, ethnicity, marital status, level of education, occupation were not significant with quality of life of clients.

FUNDING STATEMENT

This work was supported by Nepal Health Research Council, Ramshahpath, Kathmandu.

ACKNOWLEDGEMENTS

The authors would like to express gratitude to Nepal Health Research Council for providing the golden opportunity to carry out this study. The authors would like to offer heartfelt Thanks to Asst. Professor Kamala Uprety (Maharajgunj Nursing Campus), Mr Achyut Raj Pandey (Training officer at NHRC) and Mr Bijay Kumar Jha (Training Officer at NHRC) for untiring guidance, valuable suggestions, encouragement, cooperation and supervision during the study and Asst. Professor Govinda Prashad Dhungana for statistical support. The authors would like to express sincere gratitude to Hospital Director, Nursing Director and Focal person Dr. Rajan Pande of Bheri Hospital for providing the study area and cooperation.

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