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Original Article

Assessment of Quality of Life and Satisfaction Level of Parents of the Thalassemia Major Malnourished Patients

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Abstract

Objective: To assess the quality of life & level of satisfaction among parents of the thalassemia major patients.
Study type, settings & duration: This cross-sectional study was conducted at Sandeman Provincial Hospital & Bolan Medical Hospital, Quetta from July to September 2017.
Methodology: A sample size of 100 participants was statistically calculated. Data was congregated by systematic random sampling via pre-designed structured questionnaire comprising of several portions. The satisfaction scale was "5-item Likert-type. Thalassemia major patients and their parents who didn't have any sort of mental or hearing concerns was our target population, while those who had problems other than mal-nourishment, or having haemoglobinopathies were excluded from the study. Ethical consideration was attained from participants by maintaining confidentiality & Internal Review Board of Health Services Academy prior to the study.
Results: Among the 100 respondents, 35 were females while 65 were males. Eight four percent parents having moderate degree of financial difficulties. About 62% of the parents said that they do not have enough money to fulfill their needs. About 60% of the attendants have adequate means of transport. Financially about 54% were poor and about 46% were in good financial condition. About 36 % of the attendants were not satisfied from the support they got and about 42% of them were less satisfied and about 22% of them were more satisfied from the support.
Conclusion: Parents of thalassemia major patients have financial & transportation difficulties in addition to support they got from the family and friends.
Key words: Level of satisfaction, quality of life, thalassemia major.

Introduction

World Health Organization (WHO) defined Quality of Life (QoL) as: "Individuals' perceptions of their position in life in context of value systems & culture in which they live, and with respect to their goals, standards, expectations and concerns. This broad-ranging concept incorporates in a multifaceted way, an individuals' physical health, personal beliefs, level of independence, psychological state, social relationships, and their relationships to salient features of atmosphere".[1]

The QoL aims to capture wellbeing, whether of an individual or populace, regarding both negative & positive elements within an entirety of their existence at a particular point in time. Such as, common facets of the QoL comprise personal health (mental, physical, and spiritual), relationships, work environment, education status, social status, sense of safety & security, freedom, wealth, autonomy in decision making, and physical surroundings. Concept of the quality of life remains pertinent to all the clinical settings.[2]

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MU & TN conceptualized the project. IK performed the statistical analysis. MU also did the data collection. RAS & MA did the literature search. Drafting, revision & writing of manuscript were done by MH & ABK.

This term is commonly used in field of public health-research. The QoL is a key goal of a contemporary health care. Multiple factors contribute to poor QoL, ranging from physical symptoms to the psychiatric co-morbidities, financial burden related with ailment, and sleep disturbance.[3]

Thalassemia major (TM) is an autosomal-recessive genetic ailment caused by absent or diminished β-globin chain production. Globally, it is most prevalent mono-genic malady, and its incidence is greater in Middle East.[4]

Acute mal-nutrition is the nutritional deficiency occurring due to either insufficient protein or energy intake. Kids with acute-malnutrition are common in emerging nations owing to inadequate food supply caused by economic, environmental, and social factors. Malnutrition raises healthcare costs, and causes shrinkage of economic development.[5] In Pakistan, roughly 5000 children born yearly with thalassemia, and then an expenditure that patients & their families have to endure is a lot.[6]

Satisfaction is a relative concept, influenced by one's expectations & evaluations of the health services' attributes, as each person has her/his perceptions.[7] Capacity of an individual to access health care is interceded by his/her socioeconomic status.[8-10]

Malnutrition is related to an increase in the morbidity, reduction in the functional capacity, as well as high number & duration of admissions in hospital, all of these may result in reduced health related quality of life (QOL) and also impact patients' emotional, psychosocial and physical health. It has also been delineated that the malnourished patients have worse QOL and hence, an early diagnosis & treatment of malnutrition is vital. It can cause difficulties in fulfilling the basic activities of daily living, & may decrease an individual's autonomy and strength, which ultimately can reduce QOL.[11] Nutrition and food intake are associated with social and cultural aspects of eating & life satisfaction, a component of quality of life.[12]

There is a significant research gap in Pakistan on this topic. So it is a need of hour to conduct a study on this matter in this region, so that recommendations can be given and public policies aiming to lessen social inequalities are obligatory for better QoL during the course of life. Objective of this study was to assess the quality of life & satisfaction level among parents of the thalassemia major children.

Methodology

This cross-sectional study was conducted at Sandeman Provincial Hospital & Bolan Medical Hospital, Quetta from July to September 2017. Sample size of 100 was estimated statistically.[13]

Inclusion Criteria was thalassemia major patients and their parents visiting the thalassemia ward who didn't have any sort of mental illness, without conversation or hearing concerns, who don't have any other systemic malady. While those parents who had problems other than mal-nourishment, or having haemoglobinopathies, were excluded from the study, after confirmation from the clinical notes written in patient's file. Ethical consideration was attained from participants by maintaining confidentiality.

Data was gathered by systematic random sampling by interval, k, obtained by dividing the total registered thalassemia population by target sample size via pre-formed structured questionnaire. Questionnaire was comprised of several portions; 1st part with the patient's & parents' demographic data, 2nd part describing financial burden on family, 3rd portion assessing quality of life in relation to financial domain & constraints, means of transportation and the final part level of satisfaction assessed by the support of family and friends. Availability of transportation is a main indicator of accessibility to health services, as transportation barriers are cited often as barriers to the healthcare access. Transportation barriers results in missed or rescheduled appointments, postponed care, and delayed or missed medication use. These consequences might lead to hapless management of chronic maladies and hence poorer health outcomes.[14]

Scoring for the level of satisfaction from the transport by means of the economic burden was analyzed. Mean score for transport domain was 7.3 Score less than 7.3 was considered as not satisfied, while score more than 7.3 was considered as satisfied. Similarly, Scoring was done by determining the means of the different variables related to financial domain. Calculated mean was 10.5, score less than 10.5 was considered as poor, while > 10.5 as good. Likewise, mean score for support domain was 11.5. Score less than 11.5 indicates dissatisfaction, score equal to 11.5 showed less satisfaction of respondents, whereas score greater than 11.5 revealed more satisfaction.
Quality of life was graded as **"**None at all" on Score 1 to 2, "A little" on 3 to 4, "Moderate" on 5 to 6, "Very much" on 7 to 8 and "Extreme" on score of 9 to 10. The satisfaction scale was "5-item Likert-type". Responses were scored as follows: (1) Extremely dissatisfied, (2) Dissatisfied, (3) Neither satisfied nor dissatisfied (Neutral), (4) Satisfied, (5) Extremely satisfied.[15] The higher the score, the higher a degree of satisfaction among the respondents.

Descriptive statistics were represented in the form of frequencies & percentages.

Data analysis was done after data was entered into SPSS version 20. Both the qualitative and quantitative variables were separately analyzed and their frequencies and percentages were written separately and section-wise. Their mean scores were mentioned and their elaboration was done according to the scales used in this study.

The ethical approval was obtained from the Internal Review Committee of Health Services Academy, Islamabad.

Results

Among the 100 respondents, 35 were females while 65 were males. Socio-demographic characteristics are shown in Table-1.

Table 1: Demographic characteristics of the study populace.

Demographic characteristic	*Number*
Age groups	
2-4 years	35
4-7 years	48
7-10 years	9
10-14 years	8
Patient accompanied with	
Father	47
Mother	25
Both	28
Level of education	
Educated	51
Un-educated	49

The section of quality of life of the respondents have different variables. On the question about the difficulty with sleeping among the parents of the thalassemia children, 84% parents having moderate degree of financial difficulties and almost the same amount (82%) of the parents were worried about the money. About 66% of the parents of the patients of thalassemia major said that they used to get help whenever they required from the others. About 62% of the parents said that they do not have enough money to full fill their needs. Financial constraints are summarized in Table-2.

About 60% of the attendants have adequate means of transport, about 24% have difficulty in finding adequate means of transport, while 15% of the attendants mostly have problem in finding the transport. As shown in Figure.

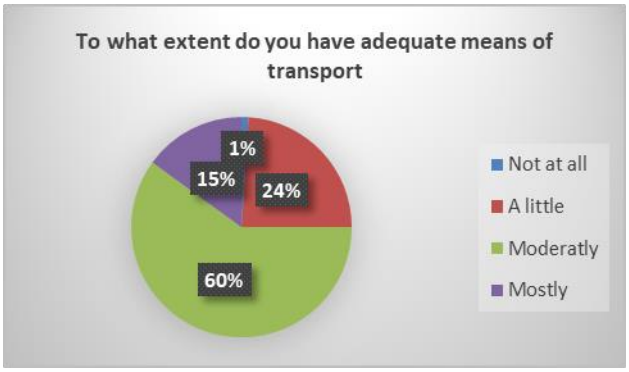

Figure: Adequate means of transportation.

About 61% of participants were not satisfied as they have to pay more for the transport, about 39% of them were satisfied from the transport expenditure. Similarly, mean score for support domain was 11.5. About 36 % of the attendants were not satisfied from the support they got and about 42% of them were less satisfied and about 22% of them were more satisfied from the support they got. Scoring with respect to financial domain indicates that financially about 54% were poor and about 46% were in good financial condition.

About 82% of the parents of the children were dissatisfied with the quality of life and about 59% were satisfied with their personal relationships this was asked in term of the husband and wife relation. The 77% of the attendants were dissatisfied from the support they got from the family, about 55% of the people were satisfied form the help they got from the friends (Table-3).

Discussion

Parents are worried about money, as the under-nutrition is often linked with poverty & high food prices. Parental socioeconomic status & literacy are imperative factors in this context.[16]

Table 2: Quality of life in relation to financial domain of study participants.

Quality of life questions	*Not at all N (%)*	*A Little N (%)*	*Moderate Amount N (%)*	*Very Much N (%)*	*Extreme N (%)*
Do you have any difficulty with sleeping	0 (0)	50 (50)	49 (49)	1 (1)	0 (0)
Do you have financial difficulties	0 (0)	12 (12)	84 (84)	4 (4)	0 (0)
How much do you worry about money	0 (0)	17 (17)	82 (82)	1 (1)	0 (0)
Do you get the kind of support from others that you need	0 (0)	27 (27)	66 (66)	7 (7)	0 (0)
Have you enough money to meet yours need	62 (62)	11 (11)	22 (22)	5 (5)	0 (0)

Table 3: Level of satisfaction assessed by the support of family and friends.

Level of satisfaction questions	*Extremely Dissatisfied N (%)*	*Dissatisfied N (%)*	*Neither Satisfied nor Dissatisfied (Neutral) N (%)*	*Satisfied N (%)*	*Extremely Satisfied N (%)*
How satisfied are you with the quality of life	0 (0)	82 (82)	9 (9)	9 (9)	0 (0)
How satisfied are you with your personal relationship	0 (0)	40 (40)	1 (1)	59 (59)	0 (0)
How satisfied are you from the support you get from the family	0 (0)	77 (77)	2 (2)	27 (27)	0 (0)
How satisfied are you from the support you get from the friends	0 (0)	45 (45)	0	55 (55)	0 (0)

In this study, 84% parents having moderate degree of financial difficulties, and almost the same amount (82%) of the parents were worried about the money, they feared the financial problems because they mostly worked on daily basis and their level of education is also very low as they all belong to the group of low socioeconomic status. Iranian study showed that level of education and then the employment status play very important role in stress levels, ultimately affecting the QOL.[17]

When talking more about domain of quality of life, about 62% of the parents responded that they do not have enough money to full fill their needs, and about 66% of the parents of the patients of thalassemia major said that they used to get help whenever they required from the others. Economic burden of thalassemia on the parents leads them to the stressful life lack of sleep, and financial problems most of the time as because of the one child the whole family and their needs to be suffered and that also impact on the social life of the parents and they required help most of the time by the others. A study from Malaysia also confirmed sleeping difficulty. Early recognition of stress among parents is imperative and these parents should be assessed, so that intercessions, for instance, social support & counseling may be given.[18]

Burden of care reduces as perceived social support by caregivers' surges. Social support is important in order to improve the quality of life.[19] In present study, 77% of the attendants were dissatisfied from the support they got from the family, about 55% of the people were satisfied from the help they got from the friends. A study conducted in Iran showed that the care givers have low level of social support generally.[20]

Social problem leads to the isolation of the parents from their friends and their families. A study from Peshawar showed that although the parents of the thalassemia major, at some stages face isolation but their interpersonal relationships are good.[21] About 60% of the attendants in this research have adequate means of transport, while 15% of the attendants mostly have problem in finding the transport. This is concomitant to another study, where 16.4% patients reported transportation problems.[22] In another survey, 31% respondents told that they have had hard time in finding transport.[23] Another study found that persons lacking transportation self-efficacy may still have trouble traveling to get healthcare even in situations where there are transportation options accessible.[24] Media coverage could do a substantial job.[25] Dissemination of information through caregivers, medical information systems and media would mobilize the social support for these parents.[17] Smaller sample size and shorter duration were the main limitations of study. Results were presented only in the form of descriptive statistics are few limitations of present study.

Parents of thalassemia major patients have financial & transportation difficulties in addition to support they got from the family & friends. These findings may lead to discussions and actions, which, in the short or medium term, may help to reduce the effects of burden on the caregivers of patients. Further studies with bigger sample sizes and advance statistical tests while exploring deeply about different aspects of lives of these parents are highly recommended. In depth interview & focus group discussion of these parents in future should be done for knowing more deeply about their lives.

Conflict of interest: None declared.

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