

# Assessment of the Quality of Life of Children with Beta Thalassemia in Peshawar District: A Cross Sectional Study

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## Abstract

**Background:** Pakistan is considered as one of the highest thalassemia burden countries in the world. For chronic conditions like thalassemia, not only survival rate of the patient is significant but also their quality of life that includes both psychological and social functioning is important.

**Objective:** To assess the quality of life of the children with beta thalassemia major in district Peshawar.

**Study type, settings & duration:** A descriptive cross sectional study was conducted in four thalassemia centers of Peshawar from February to June 2018.

**Methodology:** A total of 100 thalassemia patients fulfilling the inclusion criteria were selected for the study by non-probability convenient sampling technique. The data were collected through the questionnaire modified from SF- Questionnaire. Data was analyzed on SPSS version 15.

**Results:** This study showed that 72% of the study participants were depressed, about 70% were afraid of performing any activity and 56% had trouble in sleeping, whereas 74% had a gloomy state of mind. We also found out that there was a significant limitation of activities of the participants as 48% of study participants complained of shortness of breath during physical activities and 66% of the participants were complaining of pain during physical activity.

**Conclusion:** The quality of life of the children suffering from thalassemia major is tremendously affected. They are vulnerable to physical, emotional and socio-psychosocial distress in very early stage of life that might impose hindrance to their way of growing into independent and functional adults in future.

**Key words:** Beta thalassemia, blood transfusion, quality of life, children.

## Introduction

Beta-thalassemia is one of the highly prevalent autosomal recessive disease worldwide.<sup>1</sup> The prevalence of the disease in the Mediterranean, Middle-East and Central Asia ranges from 2% to 25%.<sup>2</sup> Pakistan is considered as one of the highest thalassemia burden countries in the world. The usual estimated figure for the Pakistan is about

100,000 transfusion-dependent thalassemia patients.<sup>3</sup> The different studies on beta thalassemia in Pakistan has shown a prevalence rate of 5-7% in Pakistani population.<sup>4,5</sup> Due to recent advances and improvements in the health care, these patients have a longer life expectancies and survival rate.<sup>6</sup> For such chronic conditions like thalassemia, not only survival rate of the patient is significant but also their quality of life that include both psychological and social functioning is important.<sup>7</sup>

The consequences of thalassemia major are known to affect quality of life as limiting the physical, emotional, psychological and social performances of these patients.<sup>8,9</sup> The World Health Organization describes quality of life (QOL) as an individual's understanding of their attitude in life from their socio-cultural context and in relation to their expectations and desires.<sup>10</sup> The quality of life in thalassemia patients, being an important health care index can be defined as patient's self-evaluation and outlook of his/her disease and associated treatment on his/her daily life including the physical, mental,

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Received: 20 February 2021, Accepted: 27 April 2021,

Published: 25 October 2021

### Authors Contribution

AB conceptualized the project. SUK, MON & LA did the data collection. AB & MH did the literature search. Statistical analysis was performed by MH & SUK. Drafting, revision & writing of manuscript were done by AB, MH & SUK.

emotional and social performance, is often limited.<sup>11</sup> There have been significant improvements in the health related quality of life among B-thalassemia major children in developed countries but not in developing countries.<sup>12</sup> The influence of the diagnosis & treatment modalities for thalassemia, complications related to the disease, repeated hospital visits for transfusion & other treatment modalities and doubts regarding the treatment interventions affect the quality of life in these patients.<sup>13</sup> There are insufficient published studies on health related quality of life among B-thalassemia patients in developing countries despite the fact that the disease is most prevalent in developing countries.<sup>3</sup> Sufficient data is not available for policy making so that the disease can be fought at the root level accordingly.<sup>14</sup> To combat this problem, greater attention should be paid not only towards the medical treatment of the disease but also towards psychosocial understanding of the illness, thus providing compliance to chronic treatment regimen.<sup>15</sup> This study was planned to determine the physical, psychological and social life problems faced by thalassemia patients so that programs would be aimed to provide psychosocial support to these thalassemia patients from an early stage of disease management.

### Methodology

This cross-sectional descriptive study was carried in the four major blood donation centers of Peshawar district namely Fatimid Foundation, Hamza Foundation, Frontier Foundation, and Hayatabad Medical complex; 25 participants from each center from February to June 2018 were included in the study to evaluate the general physical and psychological wellbeing of thalassemia major patient. A total of 100 patients (study participants) were selected by using WHO sample size calculator (where z is 1.96 & p value at 5%) from four blood donation centers of Peshawar through convenient sampling method. The participants included were patients under 15 years of age, coming to these centers for more than 1 year and were clinically stable. The data were collected through indigenously structured mixed questionnaire modified from SF-Questionnaire, which had both closed and open-ended questions. The questionnaire was validated and pre-tested. The questionnaire had four domains, the first dealing with the socio-demographic data, the second dealing with the general physical condition, the third dealing with the physical activity, and the fourth dealing with the mental health status. As most of the subjects were illiterate, so data were collected through direct interview in Pushto (local language)

based on translation of the questionnaire after the informed consent. Data were analyzed for descriptive analysis on SPSS version 15.

The Ethical approval was obtained from Institutional Research and Ethics Board, of Postgraduate Medical Institute (PGMI), Peshawar.

### Results

Out of a total 100 study participants, 44% were males and 56% were females. The mean age of participants was 9±2.5 years. About 88% of patients were taking regular blood transfusion (Table-1).

**Table 1: Demographic distribution of study participants.**

Gender	Age group (Years)	Frequency	%
Male	1-5	12	12
	6-10	20	20
	11-15	12	12
Total		44	44
Female	1-5	14	14
	6-10	26	26
	11-15	16	16
Total		56	56

About 54% of study participants were regularly being transfused blood while 46% were not on regular blood transfusions. Among those who transfused blood regularly were having good general physical condition; 23% responded that they were much better and 18% children responded to have somewhat better health than they had previously. The study provided a highly significant difference  $p = 0.001$  in the health status of the children who transfused blood regularly and those who did not (Table-2).

**Table 2: Comparisons of patient's response regarding general health condition and the regular blood transfusions.**

Blood transfusion on a regular basis	Much better	Somewhat better	same	Worse than one year ago	Total response
Yes	23	18	9	4	54
No	0	0	14	32	46

Regarding mental health, the study showed that 72% of the patients were anxious or depressed. About 70% of the participants were nervous/ afraid of performing any activity. About 56% had trouble in sleeping whereas 74% of the participants had a gloomy state of mind and felt like nothing could cheer them up. Out of these 75% participants 18%

had this feeling all the time, 24% had most of the times and 32% had some of the time whereas 26% did not experience any such feelings (Table-3).

**Table 3: Mental health assessment of thalassemia children.**

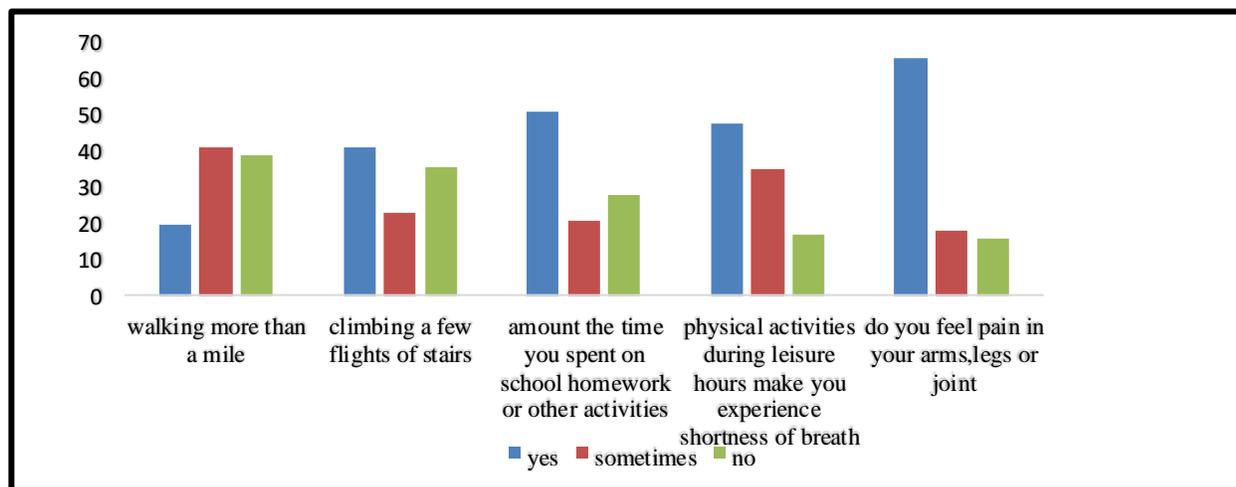
Mental status	All the time	Most of the time	Some of the time	Never
Anxious or depressed due to your illness	19	25	28	28
Nervous or are afraid before performing any activity	13	19	38	30
Trouble in sleeping	19	18	29	34
Gloomy state of mind	18	24	32	26

Regarding the impact of the disease on their physical activities, the study showed that 20% of the study participants were able to walk for more than a mile. When asked if they could climb a few flights of staircase, 41% responded positively about climbing few of stairs. About 51% of the participants responded positively for giving time to do their school homework or activities. Whereas 48% of study participants complained of shortness of breath during physical activities and 66% of the participants had pain in legs, arms and joints during physical activity (Figure).

## Discussion

Beta-thalassemia major is a serious and hypothetically life-threatening disease that causes considerable impact on the physical, mental, emotional and social performance of these patients.<sup>16</sup>

Our study results showed that participants having regular blood transfusions had better general physical condition as compared to those who did not transfuse blood regularly. Another study conducted in Pakistan using Transfusion-dependent QoL questionnaire showed consistent results in which the study participants who were undergoing regular blood transfusions had reported better general health conditions as compared to those who were not doing so.<sup>17</sup> Similar results were shown by a study conducted in Western India where thalassemia major patients receiving multiple blood transfusions at a transfusion center, in which 53% of participants have shown positive relationship between better general health conditions and regular blood transfusions.<sup>18</sup> A study conducted in Shahrekord (Iran), showed that the quality of life indicators of the thalassemia patients was not high (68.06±18.96). The general health status of the study subjects was 57.48±23.93. The mean score of mental health was 58.51±23.68 whereas that of social functioning was 68.94±23.37.<sup>8</sup> This lowered physical & psychosocial health values of thalassemia patients were consistent with our study findings too. Another study conducted in Iran, found that many of thalassemia patients felt lonely and depressed. These higher symptoms of anxiety and depression were associated to poorer perceived health related Quality of Life and sleep quality among thalassemia patients as consistent with our study.<sup>19</sup>



**Figure: Assessment of physical health and limitation of activities of thalassemia patients.**

The findings of a study published in the Journal of the college of physicians and surgeon Pakistan in 2014 about the quality of life in beta thalassemia patients in developing countries, were also consistent with our study results as this study also showed the limitation of physical activities and depression to be common in the study participants. Regarding the psychological functioning this study identified that 28.7% of the patients felt depression due to their illness, 26.7% often found the disease as a liability on them, while 20.8% felt irritable because of it. Forty five subjects (44.6%) felt lonely due to this life threatening disease. With respect to physical functioning, 25 (24.8%) of the patients confirmed that they sometimes feel weaker due to their disease. About one quarter of the patients often could not contribute to the extra-curricular activities and sports. Thirty six (35.6%) of the parents of these children did not permit their children to participate in different games and sports because of their illness.<sup>15</sup>

Another study, conducted in Islamic International University of Malaysia on thalassemia children revealed that most of them were not fully involved in sports or outdoor activities due to exhaustion and tiredness as consistent with our study results. It had also been observed that most of these subjects had poor self-respect, confidence and were psychologically affected.<sup>20</sup>

The study had certain limitations as only four blood donation centers were selected for the evaluation of physical, mental and emotional health of thalassemia patients from the Peshawar districts. At the same time convenient sampling technique was used, so the results of the analysis cannot be generalized. Further research across the whole province or the country is proposed, aimed to help policy makers for evidence based compliance towards overall management of this chronic condition.

This study signifies that blood transfusions had a positive effect on thalassemia patients' general health conditions but the disease itself has significantly affected the different dimensions of quality of life of these patients. These children are vulnerable to physical, mental & psychosocial distress very early in their lives. All of these strains in such an early life period impose hindrance to their way of growing into independent and functional adults in future.

### Acknowledgement

The authors are grateful to the staff of blood donation centers of Peshawar for cooperation and offering their valuable time for execution of research

work. I am extremely thankful to the attendants of participating children for their cooperation and time.

**Conflict of interest:** None declared.

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