Original Article

Psychological impact of β-Thalassemia major in young patients

Ayesha Irshad[1], Abdul Sannan[2], Farhan Hassan[3], Ayesha Imran[4], Fatima Ehsan[5], Ghamza Gul[6], Janita Mushtaq[7], Laraib Sajawal[8], Madiha Qamar[9], Maham Ahmad[10]

[1,2,4-10] Final year MBBS student, Rawalpindi Medical University, Rawalpindi.

[3] Senior Demonstrator of Community Medicine, Rawalpindi Medical University, Rawalpindi.

Author's Contribution

[1,3] *Conception of study*
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Corresponding Author

Ms. Ayesha Irshad,
Final year MBBS Student,
Rawalpindi Medical University,
Rawalpindi
Email: ayeshairshad7899@gmail.com

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Abstract

Background: ß-Thalassemia is an inherited blood disorder that shows a marked psychological burden in affected individuals.

Objective: To explore the psychological implications of ß-Thalassemia major in young patients living in Rawalpindi and Islamabad.

Materials and Methods: A study was conducted between March to November 2021 at the Thalassemia center of Holy Family Hospital, Rawalpindi. 306 voluntary patients suffering from ß-Thalassemia major on regular blood transfusion between the age of 10-30 years were included in the study through consecutive sampling. DASS-42 questionnaire was used. Semi-structured in-depth interviews were taken by the researchers to know the perception of patients about Thalassemia. Data were analyzed using SPSS version 21. Age, gender, and the effects of depression, anxiety, and stress on routine activities, school performance, and personalities were recorded.

Results: Among the study participants 62% of β-Thalassemia patients were suffering from anxiety, 40% from depression, and 41% individuals were facing moderate stress as per the DASS score. Mean scores ±SD of participants were 9.25(6.77) for depression, 9.32(4.02) for anxiety, and 18.46(8.90) for stress. Mean depression, anxiety, and stress scores were higher among 10-20 years old males; however, the difference was not statistically significant.

Conclusion: β-Thalassemia has major psychological impacts on the life of patients causing stress, anxiety, and depression affecting them physically, mentally, and socially.

Keywords: Quality of Life, depression, anxiety, Thalassemia major.

Introduction

ß-Thalassemia is a congenital hemoglobinopathy that has an autosomal recessive pattern of inheritance. It causes severe iron deficiency anemia for which regular blood transfusions are often required.[1]

Statistics indicate that about 1.5% of the world population is a carrier of ß-Thalassemia, and about 60,000 symptomatic individuals are born yearly. Third-world countries have higher annual rates. Incidence of symptomatic persons born each year is approximately 1 in 100,000 worldwide and 1 in 10,000 in the European Union.[2] As per 2015 Systematic statistics, 280 million people are suffering from ß-Thalassemia, with around 439,000 suffering from the severe type of disease.[3] Statistics indicate the highest frequency of carriers is in Cyprus (14%), Sardinia (10.3%), and Southeast Asia. It is most probably due to the selective pressure from Plasmodium falciparum malaria.[4] Thalassemia type ß is more common among Mediterranean people.[5] The islands having major disease burdens include Sicily, Malta, Corsica, and Crete.[6]

The commonest variant of Thalassemia with an abnormal Hb is Hb E/ß-Thalassemia, found mostly in Southeast Asia, having a carrier frequency of about 50%.[7] More or less 5000 Thalassemia major patients are born each year in Pakistan.[8] The number of Thalassemia patients in Pakistan is about 100,000, but the number of registered individuals in the Pakistan Thalassemia Federation is far less (25000). The major reason is the inability of the cases from large rural populations to get registered. The main reason for this large number of cases is the lack of prenatal diagnosis and a lack of knowledge about the disease. Prenatal diagnosis was introduced in 1994 but these facilities are present in selective big cities such as Rawalpindi, Lahore, Karachi, and Multan.[9]

Alpha and ß-Thalassemia are two main types of Thalassemia. Individuals may have mild to severe manifestations of the disease depending upon the type of Thalassemia. The most prominent symptom is anemia which usually causes pale skin and lethargy. Other complications associated with Thalassemia are stunted growth, delayed onset of puberty, splenomegaly, etc.[10] The typical way to diagnose these blood disorders is through blood tests which include complete blood count, hemoglobin electrophoresis, and genetic testing.[11] Electrophoresis is seldom used due to its unavailability. The Mentzer index is used to find out the possibility of the disease.[12]

Studies have shown that children with ß-Thalassemia bear marked psychological burdens.[13] The majority of the patients suffer from depression, anxiety, hopelessness, and stress. These patients also suffer from many physical and social limitations that affect their education and social activities.[1] These patients also face hurdles in their relationships, education, and finding suitable working opportunities. All these factors have a great influence on the quality of life of these patients.[14] The psychological burden associated with this disease affects many dimensions of an individual's life like education, functional capacity, as well as fertility.[1.] Studies show that factors such as the age of the patient, age at which anemia is first recorded, age at which transfusion is started and the effect of these factors on Hb levels could significantly affect the quality of life of children suffering from Thalassemia.[15] In another study, it was reported that 44% of ß-Thalassemia patients were suffering from psychological issues. Other main findings were anxiety-related symptoms (67%), depression (62%), and conduct problems (49%).[16]

The psychological burden has its toll on various dimensions of their life such as studies, sporting stamina, and social interactions. The psychological state of β-Thalassemic children must be well understood by medical professionals in order to treat them properly. Previous researchers have discussed the psychological implications of Thalassemia in different regions of the world but there are very few studies conducted in Pakistan to identify psychological implications. The objective of this study is to determine the extent of psychological, social, and emotional impact on young patients with B-Thalassemia. This will help to prevent various mental health issues.

Materials and Methods

It was an observational cross-sectional study. The study setting was the Thalassemia center Holy Family Hospital, Rawalpindi. The study duration was 09 months. Inclusion criteria were patients suffering from transfusion-dependent β-Thalassemia major and patients between the age of 10 to 30 years. Exclusion criteria were severely ill Thalassemic patients and patients with other comorbidities. The study population was β-Thalassemia Major patients of Rawalpindi and Islamabad. The sample size was 306, as calculated by the WHO sample size calculator with a 95% confidence interval and a previous prevalence

of 74%. The sampling technique was simple convenient sampling. The data collection tool used was DASS 42 (Depression, Anxiety & Stress scale). As per DASS-42, depression was scored as normal (0-9), mild (10-13), moderate (14-20), and severe (21-27). Regarding anxiety, the scoring used was normal (0-7), mild (8-9), moderate (10-14), severe (15-19), and extremely severe (20). The level of stress was scored as normal (0-14), mild (15-18), moderate (19-25), and severe (26-33). The questionnaires were translated into the local language and the data collection was done by the medical students of final year MBBS, RMU after permission from the Medical Superintendent of Holy Family Hospital and the Incharge Thalassemia House at Holy Family Hospital.

Data were analyzed using SPSS version 21. Means, frequencies, and percentages were calculated.

Results

A total of 306 patients suffering from ß-Thalassemia Major participated in the study. Table I shows the demographic details of the participants.

Table I: Demographic characteristics of the study population (n=306)

Variables		*n*	*%*
Gender	Male	164	53.6%
	Female	142	46.4%
Age	10 - 20 years	163	53.3%
	21 - 30 years	143	46.7%

Table II shows that the values (mean±SD) for depression, anxiety, and stress scores of participants were 9.25±6.77, 9.32±4.02, and 18.46±8.90 respectively.

Table II: Mean scores of DAS-42 (n=306)

Variables	*Mean± SD*	*Median*
Depression	9.25± 6.77	7
Anxiety	9.32±4.02	8
Stress	18.46± 8.90	19

Adapted from Parkitny L, McAuley J. The depression anxiety stress scale (DASS). Journal of physiotherapy. 2010 Jan 1;56(3):204.

Figure 1 shows that 183(60%) of the study population had no depression while 123(40%) were suffering from mild to severe depression.

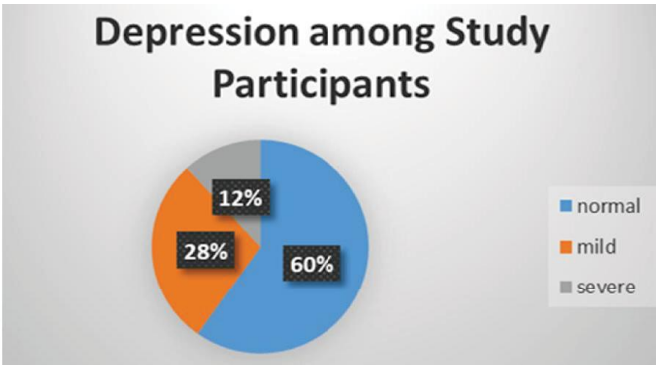

Figure 1: Depression among study participants (n=306)

Figure 2 shows the levels of anxiety among study participants. Out of 306 patients, 189(62%) were suffering from anxiety and 117 (38%) individuals were not suffering from anxiety, 95 (31%) participants had mild levels of anxiety, 58 (19%) participants had moderate anxiety, 23 (7.55) individuals had severe and 13 (4%) had extremely severe levels of anxiety.

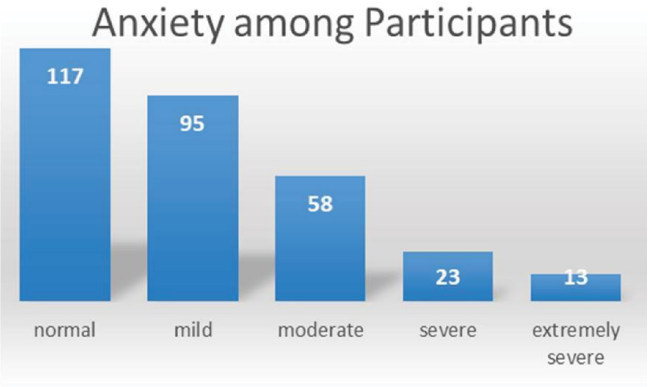

Figure 2: Anxiety among participants (n=306)

Figure 3 shows the levels of stress among study participants as per DASS 42 criterion. Majority of the study population(125/306) had moderate stress (41%).

Figure 3: Stress among study participants(n=306)

Table III: Comparison of DASS-42 scoring based on gender (n=306)

Study variables		*Male n(%)*	*Female n(%)*	*P-value*
Depression	Normal	99 (54.1%)	84 (45.9%)	
	Mild	47 (54.5%)	40 (46%)	0.899
	Severe	18 (50%)	18 (50%)	
Anxiety	Normal	64 (54.7%)	53 (45.3%)	
	Mild	49 (51.6%)	46 (48.4%)	
	Moderate	33 (56%)	25 (43.1%)	0.783
	Severe	10 (43.5%)	13 (56.6%)	
	Extremely severe	8 (61.5%)	5 (38.5%)	
Stress	Normal	56 (56%)	44 (44%)	
	Mild	9 (56.2%)	7 (43.8%)	0.855
	Moderate	67 (53.6%)	58 (46.4%)	
	Severe	32 (49.2%)	33 (50.8%)	

Table III shows the comparison of DASS-42 scoring based on gender. The condition of depression, anxiety and stress is higher among males as compared to females, although not statistically significant.

Table IV: Comparison of DASS-42 scoring based on age groups (n=306)

Study variables		**10 - 20 years n(%)**	**21- 30 years n(%)**	***P*-value**
Depression	Normal	95 (52.5%)	87 (47.5%)	
	Mild	47 (54%)	40 (46.0%)	
	Severe	20 (55.6%)	16 (44.4%)	0.931
Anxiety	Normal	59 (50.4%)	58 (49.6%)	
	Mild	53 (55.3%)	42 (44.2%)	
	Moderate	31 (53.4%)	27 (46.6%)	0.694
	Severe	11 (47.8%)	12 (52.2%)	
	Extremely severe	9 (69.3%)	4 (30.8%)	
Stress	Normal	53 (53.0%)	47 (47%)	
	Mild	8 (50%)	8 (50%)	
	Moderate	65 (52%)	60 (48%)	0.919
	Severe	37 (56.9%)	28 (43.1%)	

Table IV shows the comparison of DASS-42 scoring based on age. The condition of depression, anxiety and stress is higher among 10-20 years group as compared to 21-30 years age group.

Discussion

In this study, 40% of the study population suffered from depression, almost 60% from anxiety, and approximately 70% were found to be under various levels of stress. Results also indicate that patients, due to their emotional and physical limitations, were lagging behind in achieving their maximum potential in the community. These results are in accordance with the findings of studies done by Haghpanah et al. in Shiraz, Safizadeh, et al. in Kerman, and Ansari et al. in Tehran.[17-19] The psychological complications and quality of life in children suffering from β-Thalassemia results are also in accordance with the outcome of the research done by Shaligram et al.[20] Similar results are also found in a study by Naderi et al. who conducted research regarding the psychological well-being of patients with β-Thalassemia Major in southeast Iran.[21] It seems that mental problems are common among individuals suffering from β-Thalassemia Major.

Research has illustrated that in comparison to normal individuals, patients suffering from β-Thalassemia Major endure higher degrees of depression, anxiety, and stress. They also bear a considerable decrease in

their psychological welfare and 80% of them experience at least one psychological disorder.[19,22] Naderi et al. have also reported an increased incidence of temper and anxiety impairments among thalassemic individuals.[21] In spite of development in the protocol of Thalassemia management, these individuals face hurdles in daily life situations 20 that consequently make them liable to depression, anxiety, and stress.

In this study, the condition of anxiety, stress, and depression was found to be more common among patients in the age group 10 to 20 years while it was less frequent in the age group of 20-30 years. This may be due to the uncertainty about their future or due to a lack of support from their family and friends circle. Thus, they are more liable to social prejudice and social injustice that may eventually exacerbate the individual's depression, anxiety, and stress. On the contrary, Naderi et al. reported no considerable association between age and psychological issues in patients suffering from β-Thalassemia Major.[21] The reason can be that in Naderi et al's study, all participants were at 25 years of age, however, in the current study, many patients were above the age of 19. It seems that older patients may get used to their daily life situations and finally learn to handle them with a relatively mature approach. The psychosocial approach toward society among thalassemic patients can also be gender-based.

In our study, the anxiety, depression, and stress scores were higher in males than females as compared to a study by Naderi et al. that did not report a significant association between gender and mental wellbeing.[21] It may be because males have a bigger role in our society and are more affected socially, economically, and logistically as compared to females.

It has been studied that thalassemic patients are also more prone to various disorders such as cardiac issues, diabetes, stunted growth, late onset of puberty, and mental issues like depression and anxiety.[22] It appears that such complications cause direct deterioration of the quality of life in patients, and increase their psychological disorders which eventually level up their requirement for repeated hospital visits and stays.

It has been seen that patients with lower educational standards suffer from higher degrees of depression, anxiety, and stress. Ansari et al have found a considerable association between educational standards and the psychological health of patients suffering from ß-Thalassemia major.[19]

Hence, it is a need of the hour to set a proper system that must include the organization of standard psychological counseling at Thalassemia centers.

Conclusion

β-Thalassemia Major has substantial psychological impacts on the life of young patients causing stress, anxiety, and depression. Counselling sessions arranged by psychologists may also help to adapt these patients to the associated anxiety and depression. Regular screening should be carried out to identify these complications early and treat them properly.

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