

Research Article

Psychosocial Problems Faced by Thalassemia Patients and their Parents

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Abstract:

Background: Thalassemia is a highly prevalent autosomal recessive illness worldwide. Patients and their caregivers must bear many psychosocial pressures. The goal of this study is to provide a summary of the body of literature that identifies the psychological issues that people diagnosed with thalassemia and their parent encounter.

Methodology: This systematic review investigates articles explaining psychosocial problems faced by thalassemia patients and their families. English articles, published from 2002 to 2022, were sourced via PubMed, Science Direct, and Google Scholar. The Mesh-based search terms were "thalassemia" and "psychosocial".

Results: The electronic search yielded 7540 articles. A total of 22 articles were found to be appropriate for further analysis after the inclusion and exclusion criteria were applied. 8 articles revealed adverse effects on the education of the patients. Moreover, the study revealed that patients suffered from psychosocial problems like mood disorders, behavior disorders, and low self-esteem. The major issues faced by parents were financial expenditure, affected mutual relationships, and loss of interest.

Conclusion: According to the results, thalassaemic children faced extreme psychosocial issues. Psychotic problems and sexual problems were common among teenagers. Parents also faced issues like financial expenditure and their mutual relationship even marriage breakup. All this poses a major need to carry out strategies and interventions to help the patients and their parents cope with these psychosocial problems.

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INTRODUCTION:

Thalassemia is an autosomal recessive disease with a significant global prevalence, particularly in the Middle East, Mediterranean, and Central Asia [1,2]. The thalassemia carrier rate in Pakistan is 5-8%, with 9.8 million carriers and 5,000 thalassemia major births each year [3]. While recent advances in healthcare have improved patients' life expectancy and survival rate, the psychological and social functioning of thalassemia major patients is equally important for their well-being [4,5].

Thalassemia major patients demand repeated blood transfusions and the use of iron chelating treatment, which can be a source of distress for both patients and their parents [6]. Additionally, thalassemia affects patients' normal developmental tasks and can lead to psychosocial problems, including depression and anxiety, reported in up to 80% of thalassemia children [7]. Patients and their caregivers must manage numerous pressures, including psychosocial and economic burdens. As thalassemia prevalence increases worldwide, it has become a major factor causing psychosocial issues, including anxiety, despair, hostility, social disengagement, bad relationships, and subpar academic achievement [8].

The beta thalassemia gene is present in about 3% of the world's population and patients and their parents bear a heavy psychological and financial burden because of the disease's treatment [9,10]. Thalassemia affects patients and their parents at the bodily, emotional, and cognitive levels, which can directly impact their quality of life [11]. The anxiety about potential problems and poor quality of life

further exacerbates psychological pressure on patients and their parents. Worsening physical conditions, inability to afford treatment, and hospitalization can also contribute to the psychosocial burden [12].

While numerous studies have examined the psychosocial aspects of thalassemia major in patients, there is currently no systematic review that focuses on mental health issues that patients and their parents are dealing with. This systematic review aims to summarize existing literature to identify psychosocial problems and provide programs that aim to provide early psychosocial support to thalassemia patients.

OBJECTIVES:

To assess the psychosocial problems faced by thalassemia patients and their family members.

METHODS AND METHOD:

The PRISMA approach was used in the current systematic review to source articles published in the English language between 2002 and 2022, detailing the psychosocial difficulties encountered by both thalassemia patients and their parents. PubMed, Science Direct, and Google Scholar were searched using the Mesh-based terms "thalassemia" and "psychosocial" (**Table 1**). Central databases were accessed between September 3 and 6, 2022. Identified studies were uploaded onto EndNote, and duplicates were eliminated. The articles were initially screened based on their titles and abstracts, followed by a thorough review of the full-text articles. One author (SS) reviewed the abstracts, and a subset of complete articles was identified for data

extraction and analysis.

Table 1:

Data Base	Searched Date	Keywords	Articles Retrieved
PubMed	Sep 5, 2022	“Thalassemia” OR “Thalassaemic” AND “Psychosocial”	113
Science Direct	Sep 5, 2022	“Thalassemia” AND “Psychosocial”	23
Google Scholar	Sep 5, 2022	“Thalassemia” AND “Psychosocial”	7404

In our study, we incorporated articles that examined the psychosocial implications of thalassemia in patients, published in English-language peer-reviewed journals between 2002-2022. We included articles that had the highest number of positive responses ($\geq 50\%$) on JBI checklists, and that had the terms "Thalassemia" and "Psychosocial" in their titles.

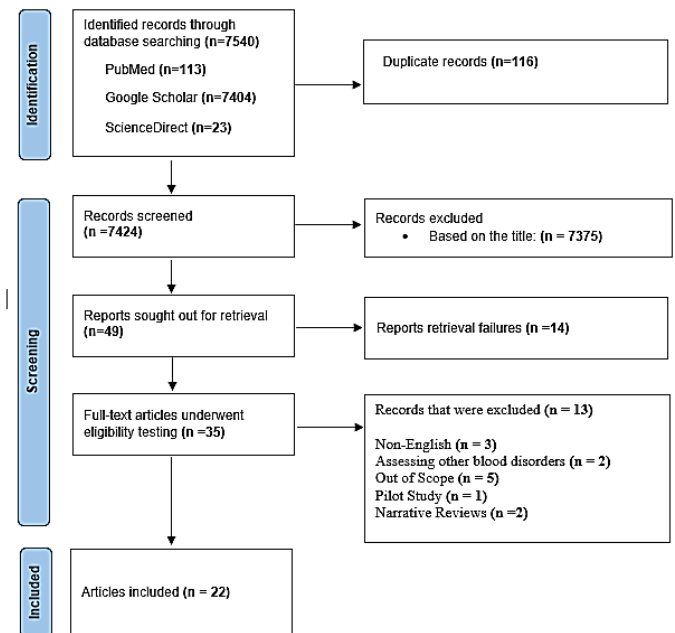
Conversely, we excluded research that evaluated individuals with illnesses besides thalassemia, those that were beyond the scope of our study (such as those assessing the psychosocial effects of thalassemia screening procedures or the development of bio-psychosocial scales for thalassemia patients), those without accessible full-text, as well as abstracts that have been published in conference, seminar, or congress proceedings, letters to the editor, case studies, short reports, and reviews.

Two reviewers screened all titles and abstracts. If the abstract didn't provide enough information to determine inclusion or exclusion criteria, the full text was obtained. Each selected paper was then independently assessed, and decisions were

discussed in consensus meetings. In case of disagreement, a third author was consulted. A subset of articles was identified for data extraction and analysis.

JBI critical appraisal checklists were employed to evaluate each article's quality, with separate checklists for qualitative, cross-sectional, analytical cross-sectional, and case-control studies [13]. Each checklist contained 8 to 10 questions with answer options of yes, no, unclear, and not applicable. The articles that had a high percentage of yes answers ($\geq 50\%$) were included in the study. Based on the scores, 15 studies were considered high quality and 7 were moderate quality.

Fig 1: PRISMA Flow Diagram



RESULTS

The study findings are reported following the guidelines of PRISMA. A search was conducted for relevant articles and a total of 7540 articles were identified from different sources including PubMed, Google Scholar, and Science Direct. After removing

116 duplicate articles, 7424 articles were screened based on their titles and abstracts. The articles that were related to psychosocial problems encountered by thalassemic patients and their parents were selected. Out of 49 articles, 35 were retrieved in full-text format. Finally, after applying certain criteria to include or exclude articles, 22 [14-35] articles were considered for the study. (Figure 1)

Out of 22, we found 15 cross-sectional, 6 case-control, and 1 qualitative study.

Out of 22, 8 publications examine the emotional problems that parents are only having, 11 articles examine the same concerns in patients, and 3 studies examine the psychosocial problems that both patients and their parents are facing.

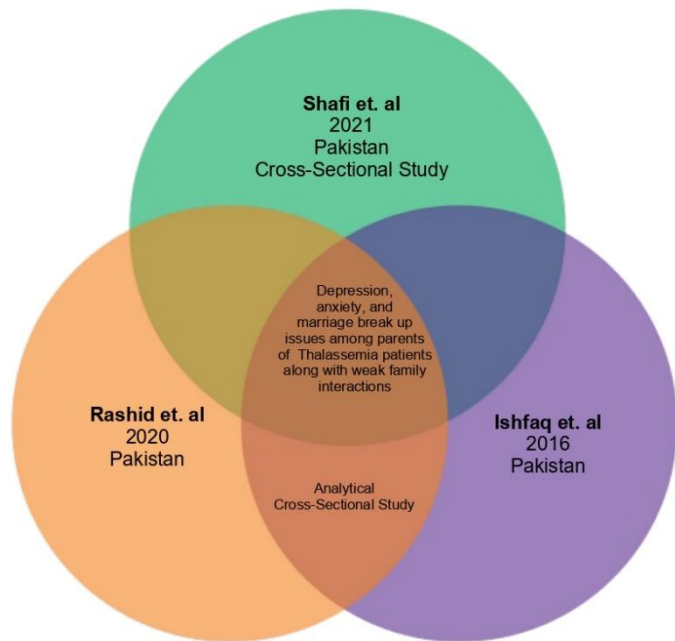


Figure 2: Psychosocial Problems Faced by Thalassemia Patients and their Parents.

Patients with thalassemia exhibit a significant incidence of psychosocial issues [14,15]. Patients suffered from low self-esteem [17-19], behavior problems (nervousness, aggression, temper tantrum,

and overactive) [23-26], mood disorders (somatization, depression, loneliness, panic, free-floating anxiety, worrying, sleep disturbances, obsessive-compulsive traits) [15-27], tic disorder, and enuresis nocturnal [25,27]. Psychotic problems (delusion, hallucination, thought disorder, lack of insight) and sexual problems (decreased libido, fear of impotence, decreased interest in the opposite sex) were popular among 20-25 years old [24].

Research revealed the adverse effects of disease on education [18-25] and sports of individuals [18,19]. Most of the patients reported that their disease limited their social life [15-18] [21-23]. Children with chronic illnesses are at great risk for the development of psychosocial disorders. Factors like frequent hospitalization, fear of death, excessive protection, and others increased such risks [25].

Almost 80% of parents admitted to having depression yet only 25% of them use antidepressants [29-31]. According to a study, most of the parents felt hopeless [31-35] and suffered from psychosomatic illnesses like body aches, diabetes, and heart disease [28,32]. The child's disease greatly affects the parents' mutual relationship [30-33]. A study showed that the degree of depression increased as the parent's educational level rose [31].

In a study, the major issues faced by most of the parents were a lack of concentration on daily work and loss of interest [28-32]. A majority (70%) of the parent face difficulties in meeting the financial expenditure of their thalassaemic children [28-33]. The effect of thalassemia major on parents' psychological and social well-being is significantly

influenced by inadequate knowledge of the disease [31-34], stigmatization [28-33], consanguineous marriages [30-34], and the frequency of marriage breakdowns [33] caused by the disease. Some parents admitted that the family size had been touched by the illness of their child [31,33]. According to a study, if the condition had been identified during pregnancy, 72% of the parents would have had an abortion [31]

Table 2: Psychosocial Problems Faced by Thalassemia Major Patients

Psychosocial Problems Faced by Thalassemia Major Patients		Number of Articles	Articles ^[14-27]
Psychosocial problems		2	Ghassemi et al ^[14] (15.3%), Al Ebrahimi et al ^[15] (80%)
Psychological problems		4	Inamdar et al ^[20] (10%), Bagul et al ^[24] (50% in adults), Saini et al ^[25] (54%), Aydinok et al ^[27] (24%)
Internalization	Mood Disorders	4	Al Ebrahimi et al ^[15] , Raman et al ^[23] , Bagul et al ^[24] (26%), Kumaravel et al ^[26] (31.3%)
	Anxiety (nervousness, feeling tense, fear of life)	6	Khurana et al ^[19] (66.67%), Ishfaq et al ^[21] (40.5%), Canatan et al ^[22] (84%), Bagul et al ^[24] (20%), Saini et al ^[25] , Aydinok et al ^[27] (5%)
	Depression	4	Elzaree et al ^[16] (10%), Raman et al ^[23] , Saini et al ^[25] , Aydinok et al ^[27] (13%)
	Mood Disorders	4	Al Ebrahimi et al ^[15] , Raman et al ^[23] , Bagul et al ^[24] (26%), Kumaravel et al ^[26] (31.3%)
	low self-esteem/not satisfied with body image	3	Messina et al ^[17] (80%), Batool et al ^[18] (76.9%), Khurana et al ^[19] (68%)
	Feelings of difference	2	Batool et al ^[18] (78%), Canatan et al ^[22] (50%)
	Confusion	1	Canatan et al ^[22] (14%)
	Denial	1	Canatan et al ^[22] (25%)
	Helplessness	1	Inamdar et al ^[20] (37%)
Externalization	Hyperkinetic activity	2	Raman et al ^[23] , Kumaravel et al ^[26] (15.6%)
	Conduct disorder (stubbornness, disobedience, aggression, argumentativeness)	3	Raman et al ^[23] , Saini et al ^[25] , Kumaravel et al ^[26] (9.4%)
	Behavioral Disturbances	2	Bagul et al ^[24] (31.4%), Kumaravel et al ^[26] (81.2%)
	Somatization	3	Messina et al ^[17] (30%), Saini et al ^[25] , Kumaravel et al ^[26] (46.9%)
Physical symptoms due to stress	Low general well being	2	Inamdar et al ^[20] (17%), Bagul et al ^[24] (20%)
	Sleep Disturbance	1	Bagul et al ^[24] (26%)
	Eating Disturbance	1	Bagul et al ^[24] (16.67%)
	Sexual Problems	1	Bagul et al ^[24] (15%)
	Nocturnal enuresis	2	Saini et al ^[25] (31%), Aydinok et al ^[27] (3%)
	Tic Disorder	1	Aydinok et al ^[27] (3%)
	Poor stamina	1	Batool et al ^[18] (58.2%)
	Delayed development	1	Kumaravel et al ^[26] (9.4%)
Mental retardation/Learning Disorders	2	Bagul et al ^[24] , Kumaravel et al ^[26] (53.1%)	
Daily Life	Education affected	8	Al Ebrahimi et al ^[15] , Batool et al ^[18] (54.9%), Khurana et al ^[19] (70%), Inamdar et al ^[20] (56.66%), Ishfaq et al ^[21] (63%), Canatan et al ^[22] (60%), Bagul et al ^[24] (100%), Saini et al ^[25]
	Changed ambitions	1	Inamdar et al ^[20] (70%)
	Extracurricular activities	1	Ishfaq et al ^[21] (53.5%)

	Outdoor play	1	Batool et al ^[18] (84.6%)
	Sports affected	2	Batool et al ^[18] (12.1%), Khurana et al ^[19] (72%)
	Below-average daily living skills	1	Elzaree et al ^[16] (24%)
Social Life	Peer-relationship Problems	1	Raman et al ^[23]
	Below-average communication skills	1	Elzaree et al ^[16] (38%)
	Below-average social skills	3	Elzaree et al ^[16] (8%), Messina et al ^[17] , Canatan et al ^[22] (47%)
	Family adjustment affected	1	Canatan et al ^[22] (3%)
	Limited social life	4	Al Ebrahimy et al ^[15] , Batool et al ^[18] (60.4%), Ishfaq et al ^[21] (44.5%), Canatan et al ^[22] (25%)
	Unable to discuss the illness with friends/ lack of trust	3	Batool et al ^[18] (60.4%), Khurana et al ^[19] (80%), Ishfaq et al ^[21] (85.4%)
	Marginalized by relatives	3	Ishfaq et al ^[21] (30.5%), Shafi et al ^[30] (40%), Aziz et al ^[31] (56%)

Table 3: Psychosocial Problems Faced by The Parents of Thalassemia Patients

Psychosocial Problems Faced by Parents of Thalassemia Major Patients		Number of Articles	Articles ^[28-35,22,23,27]
Psychological Distress	Emotional Exhaustion	1	Nabavian et al ^[28]
	Mental Strain	3	Raman et al ^[23] , Nabavian et al ^[28] , Ishfaq et al ^[35]
	Depression	7	Canatan et al ^[22] , Raman et al ^[23] , Kaur et al ^[29] (28%), Shafi et al ^[30] (80%), Aziz et al ^[31] (29%), Deepak et al ^[32] , Rashid et al ^[34]
	Take Antidepressants	4	Kaur et al ^[29] (17%), Shafi et al ^[30] (25%), Aziz et al ^[31] (23%)
	Hopelessness	5	Shafi et al ^[30] (92%), Aziz et al ^[31] (9%), Deepak et al ^[32] , Rashid et al ^[34] , Ishfaq et al ^[35]
	Scared thinking about the grief of their child/ Anxiety	6	Canatan et al ^[22] (62%), Shafi et al ^[30] (96%), Aziz et al ^[31] , Deepak et al ^[32] , Rashid et al ^[33] , Rashid et al ^[34]
	Feeling Intolerant/Annoyed/ Aggression	4	Kaur et al ^[29] (38%), Shafi et al ^[30] (67%), Deepak et al ^[32] , Ishfaq et al ^[35]
	Unable to enjoy anything	4	Raman et al ^[23] , Kaur et al ^[29] (40%), Shafi et al ^[30] (92%), Aziz et al ^[31]
	Denial and Confusion	1	Canatan et al ^[22] (14%)
	Lack of concentration on daily work and loss of interest	4	Raman et al ^[23] , Kaur et al ^[29] (52%), Aziz et al ^[31] (21%), Deepak et al ^[32]
	Lack of confidence	2	Raman et al ^[23] , Kaur et al ^[29] (42%)
	Spent most of the time alone	1	Kaur et al ^[29] (43%)
	Blamed themselves	3	Raman et al ^[23] , Kaur et al ^[29] (22%), Rashid et al ^[33]
Bodily Burnout	Acute Psychosomatic Reactions (Headaches, Bone Pain, Stomach Aches)	2	Nabavian et al ^[28] , Deepak et al ^[32]
	Feeling Tired	3	Kaur et al ^[29] (50%), Aziz et al ^[31] , Deepak et al ^[32]
	Sleep Disturbances	3	Raman et al ^[23] , Kaur et al ^[29] (28%), Aziz et al ^[31] (16%)
	Affected Eating Habits	2	Kaur et al ^[29] , Aziz et al ^[31] (12%)
	Long-term Psychosomatic Consequences (Diabetes, Hypertension, Heart Disease)	1	Nabavian et al ^[28]
Financial Burden	-	5	Nabavian et al ^[28] , Kaur et al ^[29] (70%), Aziz et al ^[31] (56%), Rashid et al ^[33] , Ishfaq et al ^[35]
	Employment affected	1	Canatan et al ^[22] (47%)
Social Ramifications	Affected Relationship with Spouse	3	Shafi et al ^[30] (17%), Aziz et al ^[31] (12%), Deepak et al ^[32]
	Social Stigma	2	Nabavian et al ^[28] , Deepak et al ^[32]
	Child stigmatized by relatives	4	Kaur et al ^[29] (5%), Shafi et al ^[30] (40%), Aziz et al ^[31] (56%), Rashid et al ^[33]
	Decreased participation in family/social gatherings	4	Kaur et al ^[29] (37%), Aziz et al ^[31] (27%), Deepak et al ^[32] , Ishfaq et al ^[35]

	Lesser attention to other children	2	Shafi et al ^[30] (19%), Deepak et al ^[32]
	Weak Family Interactions due to thalassaemic child	3	Canatan et al ^[22] (6%), Deepak et al ^[32] , Rashid et al ^[33]
	Social Isolation	4	Canatan et al ^[22] (26%), Raman et al ^[23] , Kaur et al ^[29] (37%), Deepak et al ^[32]
	Insufficient/ Misdirected Social Support	1	Rashid et al ^[33]
	Marriage Breakups	2	Canatan et al ^[22] (1.8%), Rashid et al ^[33]
Parent's Need for Empathy and Support	The expectation of Family Support	2	Nabavian et al ^[28] , Rashid et al ^[34]
	Not Supported by Family Members	1	Kaur et al ^[29] (32%)
	Support Needs Outside Family	4	Nabavian et al ^[28] , Deepak et al ^[32] , Rashid et al ^[34] , Ishfaq et al ^[35]

DISCUSSION:

Based on the results of the review, there is a high prevalence of psychosocial problems suffered by patients of Thalassaemia and their parents, including but not limited to behavioral problems, according to Vijaya Raman MD et al [23], mood disorders, according to Manoj Jain et al [24], tics and psychosis, which are a likely result of low self-esteem, emotional instability, and self-doubt among patients. A symptom of this is low performance in educational activities and sporting endeavors, which leads to further deterioration of self-respect, confidence, and emotional stability, according to Kumaravel KS et al [26], which can form a vicious cycle of underachievement and stress. Nabavian M. et al [28] state that the disease results in the parents (of the afflicted) suffering from long-term effects of continued financial strain and stress leading to chronic illnesses like diabetes as well as heart disease, which can compound financial strain when the earning capacity of these individuals is reduced due to said diseases. This review includes 6 case-control studies, which are crucial in studying the evolution of these problems over a considerable period, as well as

assessing the persistence of most of the same problems over this period.

These problems are representative of a systemic issue in the allocation of resources and the development of adequate infrastructure to deal with and manage patients suffering from thalassaemia. The studies included, from 2002 to 2022, with the recurrence of the same problems such as mood disorders [17, 26] over different periods, is indicative of a lack of effort to address these problems effectively. Considering the scope of this issue, there is a failure to properly assess patients and their parents' psychosocial needs, stemming from a lack of prior research on this issue. The lack of relevant literature can be assessed by the fact that this systematic review is the first of its kind to be published on the issues of people suffering from thalassaemia. Trivialization of mental stresses suffered by patients with chronic diseases by society at large is one major factor in the lack of progress in taking relevant measures to improve the lives of these individuals. Contextualizing the scope of these issues is hopefully the first step towards addressing them on a macro scale.

LIMITATIONS:

However, only 3 databases (PubMed, Google Scholar, and Science Direct) were searched for this review, and the lack of generalizability in most articles and cultural limitations due to the scopes of the studies being limited to localized areas means that this review is not able to fully encapsulate all the issues that parents and their patients suffer from and thus, further efforts are needed to scrutinize completely and form a strategy to cope effectively.

CONCLUSION:

The findings reveal that children with thalassemia experience severe psychosocial challenges, such as poor self-image, mood disorders, and behavioral issues such as anxiety, isolation, worrying, sleep disturbances, and obsessive-compulsive traits. Teenagers frequently experience psychotic and sexual issues. Parents face difficulties, mainly related to financial burdens and strained relationships, including separation or divorce. Therefore, comprehending the psychosocial struggles encountered by individuals with beta-thalassemia major can aid healthcare providers and managers in devising effective interventions that enhance the coping skills of patients and their families, leading to better management of such challenges.

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