

PSYCHOSOCIAL PROBLEMS FACED BY THALASSEMIA PATIENTS AND THEIR PARENTS. A SYSTEMATIC REVIEW.

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Introduction

Thalassemia is one of the most highly prevalent autosomal recessive diseases worldwide [23]. The prevalence of the disease in the Mediterranean, Middle East and Central Asia ranges from 2% to 25% [24]. Pakistan is considered as one of the highest thalassemia burden countries in the world. In Pakistan, the estimated carrier rate of thalassemia is 5-8% with 9.8 million carriers in the whole population and every year 5000 thalassemia major children are born [25].

Thalassemia major patients require repeated transfusion of blood and iron chelation therapy for their survival which is continuous source of distress for thalassemia major patients and their parents [28,29]. Up to 80% of thalassemia children are likely to have psychosocial problems [30,31]. Increased anxiety, depression, social withdrawal, aggression, poor relationships and poor school performance are among common psychosocial burden experienced by thalassemia patients [32,22].

Treatment of this disease puts a lot of psychosocial and financial burden on affected patients and their parents [34,35]. Patient and their parents have to face many challenges at the physical, social and psychological levels [36]. Psychological pressure is increased by fear of future complications and low life expectancy [37]. The purpose of this systematic review is to summarize the existing body of literature that serves to identify the psychosocial problems faced by thalassemia major patients and their parents so that programs would be aimed to provide psychosocial support to these thalassemia patients from an early stage of disease management.

Objectives

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



Methods and Materials

The present systematic review used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology.

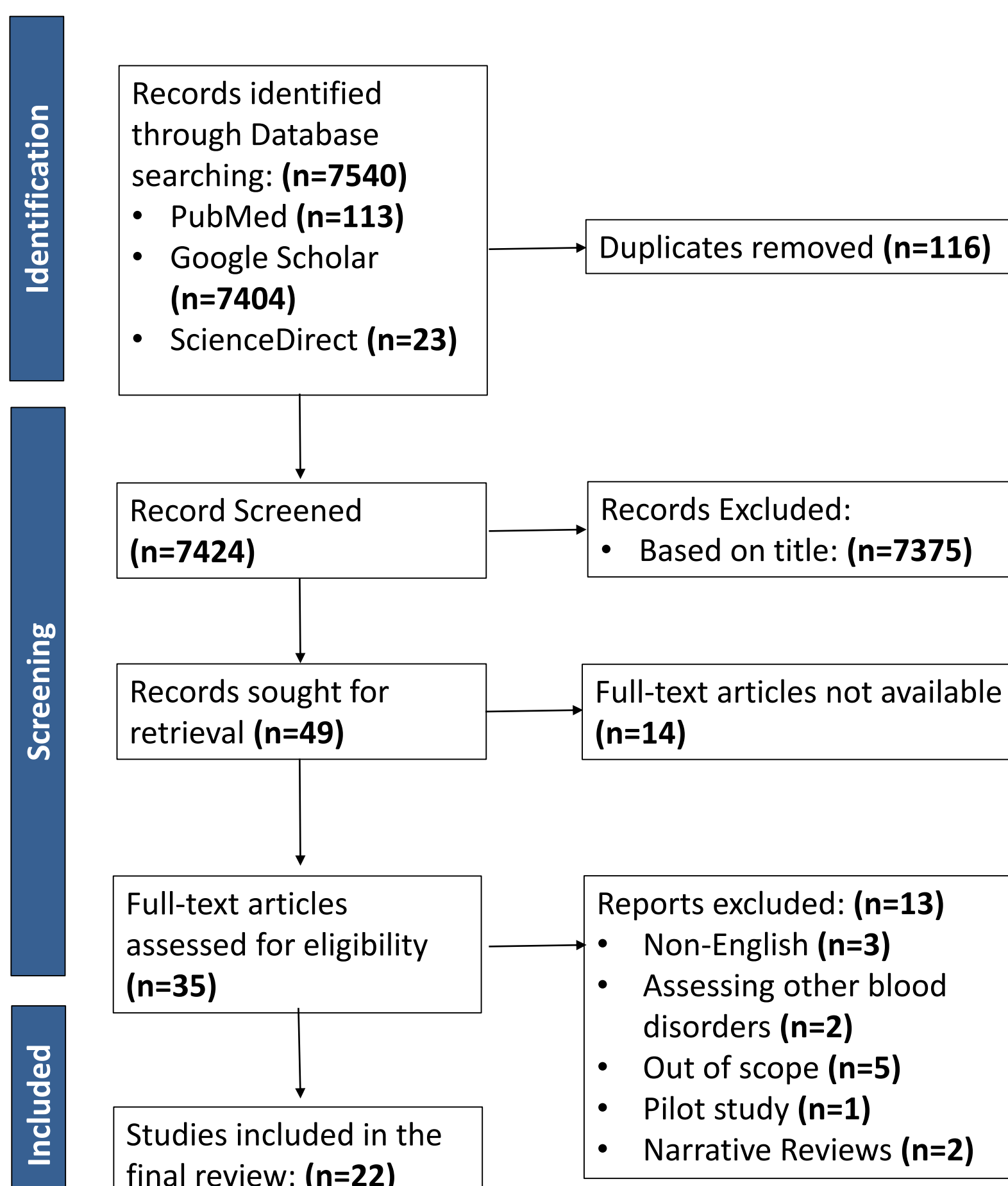
Literature Search Strategy:

Data Base	Searched Date	Keywords	Articles
PubMed	Sep 5, 2022	"Thalassemia"/ "Thalassaemic" & "Psychosocial"	113
ScienceDirect	Sep 5, 2022	"Thalassemia" & "Psychosocial"	23
Google Scholar	Sep 5, 2022	"Thalassemia"& "Psychosocial"	7404

- Inclusion Criteria:** We included articles that investigated thalassemia patients and the psychosocial aspects of life; articles that were in English language; articles published between 2002-2022; articles published in peer-reviewed journals and the terms "Thalassemia" and "Psychosocial" were included in the title.

- Exclusion Criteria:** We excluded studies assessing patients with diseases other than thalassemia; studies that are out of scope (assessing psychosocial effects of thalassemia screening procedures; studies comparing effects of various treatment regimens on psychosocial health of thalassemia patients; studies regarding development of bio-psychosocial scale for thalassemia patients); those with no accessible full text; published abstracts in congress, seminar, or conference-booklets; letter to the editors; and, short reports, case reports, pilot studies, meta-analysis and reviews.

Figure 1: Prisma Flow Diagram:



Quality Assessment of the included Articles by JBI Critical Appraisal Checklists:

High Medium



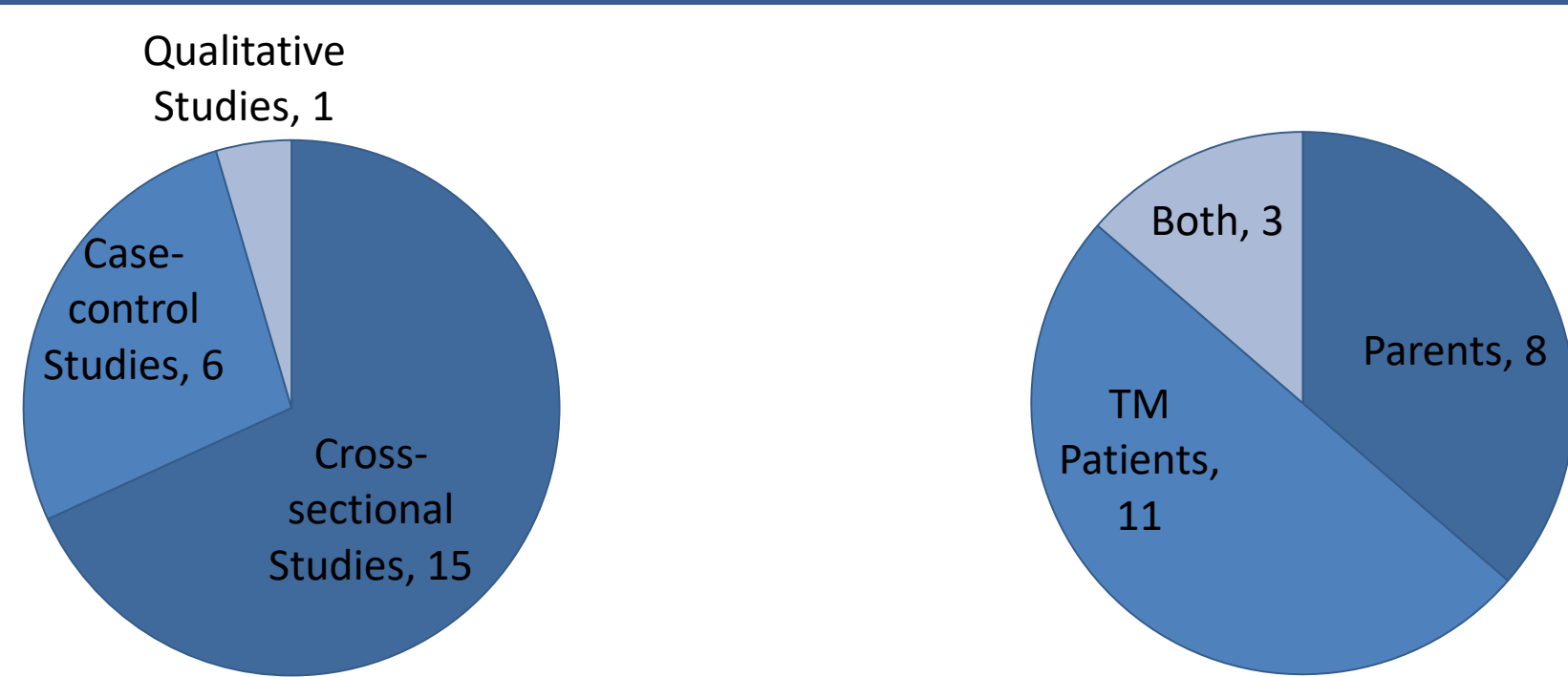
Data Extraction:

Tabulation on the basis of First Author, Year of Publication, Study Design, Objectives, Country, Study Subjects (Parents/Patients/Both), Number of Study Subjects, Questionnaire, Results, Limitations

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Results



Psychosocial Problems Faced by Thalassemia Major Patients	N	Articles (4,6,8,9,10,12,13,14,16,18,19,20,21,22)
Psychosocial problems	2	4 (15.3%), 14 (80%)
Psychological problems	4	13 (10%), 16 (50% in adults), 19 (54%), 21 (24%)
Internalization		
Mood Disorders	4	6, 14, 16 (26%), 12 (31.3%)
Anxiety (nervousness, feeling tense, fear of life)	6	9 (40.5%), 16 (20%), 19, 20 (66.67%), 21 (5%), 22 (84%)
Depression	4	6, 8 (10%), 19, 21 (13%)
Mood Disorders	4	6, 14, 16 (26%), 12 (31.3%)
low self-esteem/dissatisfied with body image	3	10 (76.9%), 18 (80%), 20 (68%)
Feelings of difference	2	10 (78%), 22 (50%)
Confusion	1	22 (14%)
Denial	1	22 (25%)
Helplessness	1	13 (37%)
Externalization		
Hyperkinetic activity	2	6, 12 (15.6%)
Conduct disorder (stubbornness, disobedience, aggression, argumentativeness)	3	6, 19, 12 (9.4%)
Behavioural Disturbances	2	12 (81.2%), 16 (31.4%)
Somatization	2	12 (46.9%), 18 (30%), 19
Physical symptoms due to stress		
Low general well being	2	13 (17%), 16 (20%)
Sleep Disturbance	1	16 (26%)
Eating Disturbance	1	16 (16.67%)
Sexual Problems	1	16 (15%)
Nocturnal enuresis	2	19 (31%), 21 (3%)
Tic Disorder	1	21 (3%)
Poor stamina	1	10 (58.2%)
Delayed development	1	12 (9.4%)
Mental retardation/Learning Disorders	2	12 (53.1%), 16
Daily Life		
Education affected	8	9 (63%), 10 (54.9%), 13 (56.66%), 14, 16 (100%), 19, 20 (70%), 22 (60%)
Changed ambitions	1	13 (70%)
Extracurricular activities	1	9 (53.5%)
Outdoor play	1	10 (84.6%)
Sports affected	2	10 (12.1%), 20 (72%)
Below average daily living skills	1	8 (24%)
Social Life		
Peer-relationship Problems	1	6
Below average communication skills	1	8 (38%)
Below average social skills	3	8 (8%), 18, 22 (47%)
Family adjustment affected	1	22 (3%)
Limited social life	4	9 (44.5%), 10 (60.4%), 14, 22 (25%)
Unable to discuss illness with friends	3	9 (85.4%), 10 (60.4%), 20 (80%)
Marginalized by relatives	3	2 (40%), 9 (30.5%), 17 (56%)

Psychosocial Problems Faced by Parents of Thalassemia Major Patients	N	Articles (1,2,3,5,6,7,11,15,17,21,22)
Psychological stress		
Emotional Exhaustion	1	1
Mental Strain	3	1, 6, 15
Depression	7	2 (80%), 3, 6, 7 (28%), 11, 17 (29%), 22
Take Antidepressants	2	2 (25%), 7 (17%), 17 (23%)
Hopelessness	5	2 (92%), 3, 11, 15, 17 (9%)
Anxiety	6	2 (96%), 3, 5, 11, 17, 22 (82%)
Feeling Intolerant/Annoyed/Aggression	4	2 (67%), 7 (38%), 11, 15
Unable to enjoy anything	4	2 (92%), 6, 7 (40%), 17
Denial and Confusion	2	5, 22 (14%)
Lack of concentration on daily work and loss of interest	4	6, 7 (52%), 11, 17 (21%)
Lack of confidence	2	6, 7 (42%)
Spent most of the time alone	1	7 (43%)
Blamed themselves	3	5, 6, 7 (22%)
Bodily Burnout		
Acute Psychosomatic Reactions (Headaches, Stomach Aches)	2	1, 11
Feeling Tired	3	7 (50%), 11, 17
Sleep Disturbances	3	6, 7 (28%), 17 (16%)
Affected Eating Habits	2	7, 17 (12%)
Long-term Psychosomatic Consequences (Diabetes, Hypertension, Heart Disease)	1	1
Financial Burden		
-	5	1, 5, 7 (70%), 15, 17 (56%)
Employment affected	1	22 (47%)
Social Ramifications		
Affected Relationship with Spouse	3	2 (17%), 11, 17 (12%)
Social Stigma	1	1, 11
Child stigmatized by relatives	4	2 (40%), 5, 7 (5%), 17 (56%)
Decreased participation in family/social gatherings	4	7 (37%), 11, 15, 17 (27%)
Lesser attention to other children	2	2 (19%), 11
Weak Family Interactions due to thalassaemic child	3	5, 11, 22 (6%)
Social Isolation	4	5, 7 (37%), 11, 22 (26%)
Insufficient/ Misdirected Social Support	1	5
Marriage Breakups	2	5, 22 (1.8%)
Parent's Need for Empathy and Support		
Expectation of Family Support	2	1, 3
Not Supported by Family Members	1	7 (32%)
Support Needs Outside Family	4	1, 3, 11, 15

Discussion

- Based on the results of the review, there is a high prevalence of psychosocial problems suffered by patients of Thalassemia and their parents.
- The persistence of these problems over such a long period of time is a representative of a systemic issue in allocation of resources and development of adequate infrastructure to deal with and manage mental aspect of patients suffering from chronic illnesses.
- Trivialisation of mental stresses suffered by patients of chronic diseases by society at large is one major factor in lack of progress in taking relevant measures to improve the lives of these individuals.
- Limitations:**
Only 3 databases (PubMed, Google Scholar and ScienceDirect) were searched over the course of this review, and the lack of generalisability in most articles and cultural limitations due to the scopes of the studies being limited to localised 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 scrutinise completely, and form a strategy to cope effectively.

Conclusions

According to the results, thalassaemic children and their parents face extreme psychosocial issues. Hence, understanding the psychosocial problems in patients with beta-thalassemia major can help the health managers and health care providers in planning some effective interventions to increase the coping skills in thalassaemic patients and their families for improving their ability in dealing with such problems.