

PSYCHOSOCIAL RAMIFICATIONS OF PARENTS OF CHILDREN WITH THALASSEMIA IN LOWER- AND MIDDLE-INCOME COUNTRIES OF ASIA- A SYSTEMATIC REVIEW

Ms. Anna Hima Thomas^{1*}, Dr. Ponchitra R²

1.Ph. D Scholar, MGM New Bombay College of Nursing, MGMIHS, Navi Mumbai

2.Professor, MGM New Bombay College of Nursing, MGMIHS, Navi Mumbai.

*Corresponding Author

ABSTRACT

Background: Thalassemia is an autosomal recessive disorder which is affecting the synthesis of hemoglobin. The children with thalassemia need lifelong blood transfusion and hospitalizations to manage the complications. Due to the continuity in care of children with thalassemia, the parents experiences various levels of psychosocial issues. Financial burden is also very common specially in lower- and middle-income countries. Multiple studies reported that around 23,000 as thalassemia major and 90% of these children are born in low or middle-income countries (LMICs) **Materials and Methods:** The PICO framework was used to operationalize the review question into key concepts. The entire review process followed PRISMA guidelines 2020. Study selection was done through various electronic databases like PubMed, PsychINFO, CINAHL, Scopus and Cochrane library. The studies included in the systematic review were also searched from various websites, organizations like Thalassemia International Federation and from citation searches through ancestry and descendancy approaches. The studies were selected according to the set inclusion and exclusion criteria. The inclusion and exclusion criteria was set with PICo format (Population, phenomena of interest and context). The quality assessment for the studies selected for the review was done with Joanna Briggs Institute tools (JBI) and QUADAS-2 tool. There was minimal risk of bias in the studies were noted. 13 studies were finally selected for the review. **Results:** To synthesize the findings, results were qualitatively summarized. No statistical analysis were done. The various results were categorized under the headings, Psychological issues, social issues, financial issues and care giver burden. Majority of the parents have stress, anxiety, guilty, depression and also psychosomatic symptoms. A multidisciplinary approach to managing the disease and psychosocial support is required for the management of thalassemia and to minimize the burdens on both patients and families.

Key words: Psychosocial ramifications, Parents, Children with thalassemia, Lower and middle income countries , systematic review.

INTRODUCTION

Thalassemia is a group of inherited autosomal recessive disorder which results in ineffective hemoglobin synthesis. In beta thalassemia, there will be reduced or absent synthesis of beta chain in HbA molecule which makes this HbA molecule unstable which

results in hemolysis of red blood cells and ineffective erythropoiesis.² Approximately 1.5% of the global population are heterozygotes (carriers) of the β -thalassemias; there is a high incidence in populations from the Mediterranean basin, throughout the Middle East, the Indian subcontinent, Southeast Asia, and Melanesia to the Pacific Islands. Recent surveys suggest that between 300,000 and 400,000 babies are born with a serious hemoglobin disorder each year (23,000 with β -thalassemia major) and that up to 90% of these births occur in low- or middle-income countries.¹ In India, β -Thalassemia is prevalent across the country, with an average frequency of carriers being 3-4%.⁸ It is estimated that about 10000-15000 babies with Thalassemia Major (TM) are born every year. The prevalence of thalassemia trait in Maharashtra is about 2.7%. A child with thalassemia major requires lifelong blood transfusions unless the child undergoes bone marrow transplantation. There is a wide range of clinical manifestations seen in the case of thalassemia which comprises of moderate to severe anemia, fatigue, typical thalassemia facies, delayed growth and development, delayed sexual maturation in adolescents, psychosocial disturbances and behavioural disorders.²¹ The complications related to the disease and blood transfusion is also a matter of concern. As thalassemia is a chronic disease, this will have an overall deterioration in the quality of life of a child. The quality of life of child is directly proportional to the quality of life the parents as well.²³ Most chronic diseases have similar effects on family members including psychological and emotional functioning, disruption of leisure activities, effect on interpersonal relationships, and financial resources. Multiple studies reported that around 23,000 as thalassemia major and 90% of these children are born in low or middle-income countries (LMICs)¹⁹

Studies involving the families of children with chronic diseases including thalassemia have been conducted, but none have addressed the Psychosocial concerns of parents of children with thalassemia. This systematic review hopes to contribute to filling this gap in the literature, while also emphasizing the importance of preventing genetically inherited diseases^{3,5}. Also, findings can guide practices that can enhance the quality of care in thalassemia patients and increase the life satisfaction of parents who are the primary care givers of children. The findings of this systematic review will be a corner stone for the development of evidenced based and holistically designed parent empowerment programmes in various health care settings.

Objective of the study: To synthesize the psychosocial ramifications of parents of children with thalassemia

Research question- What are the various psychosocial concerns of parents of children with thalassemia?

Materials and Methods

The systematic review followed the guidelines of The Preferred Reporting Items for Systematic Reviews and Meta analysis 2020 (PRISMA)

Study identification

A systematic literature search was performed using PubMed, Web of Science, Embase, CINAHL, Psyc INFO, MEDLINE and Cochrane library to identify articles published between 2010 and 2024, in English. Studies on the population of interest were identified from electronic databases using search terms that included the combinations of free text and Medical Subject Headings (MeSH). The keywords used for searching the studies included ‘Psychological issues’, ‘Economic burden’, ‘care giver burden’, ‘Psychological distress’, ‘social problems/concern’, and ‘care givers/ parents of children with thalassemia. The studies included in the systematic review were also searched from various websites, organizations like Thalassemia International Federation and from citation searches through ancestry and descendancy approaches. All articles identified were reviewed against PICo (Population, Phenomena of interest and the Context of the study) Criteria (Table 1). The Table 1 shows the inclusion and exclusion criteria set for the systematic review. Screening 1 was done by the first reviewer and screening 2 by the second reviewer. The discrepancies noticed by both reviewers were discussed with third reviewer to achieve the consensus. The studies which met the inclusion and exclusion criteria were taken for data extraction and analysis. The quality assessment for the studies selected for the review was done with Joanna Briggs Institute tools (JBI) and QUADAS-2 tool. There was minimal risk of bias in the studies were noted. The Prisma flow diagram is depicted in Fig.1

Table 1

PICo study selection criteria

Domain	Inclusion Criteria	Exclusion criteria
Population	<ul style="list-style-type: none"> • Age of children less than 18 years • Father or mother as samples • Population from countries of Asian subcontinent • Studies conducted in Middle and low income countries 	<ul style="list-style-type: none"> • Care givers of adult patients • Studies which is only available as abstracts

Phenomena of interest	<ul style="list-style-type: none"> • Psychological issues of parents • Social issues faced by parents • Economic problems • Health related quality of life of parents 	<ul style="list-style-type: none"> • Publications which do not report the phenomena of interest and the study designs mentioned in inclusion criteria
Study Design	Phenomenological studies and cross sectional studies	
Others	<ul style="list-style-type: none"> • Studies Published in Peer reviewed journals and grey literature • Studies published in English Language • Articles published from Jan 2010 to Jan 2024 	<ul style="list-style-type: none"> • Systematic reviews and narrative reviews

Data extraction and analysis the studies selected after meeting the inclusion criteria were extracted and tabulated into Covidence software which is specially designed for Systematic reviews. The data tabulated were under following headings: Name of the author, year of study, title of the study, population, study design, sampling technique, tools and techniques of data collection and the results of the study. All the data was extracted by the first reviewer and the validation of data extracted was done by the second reviewer. There was no requirement for third reviewer as there was no discrepancies or contradictory findings between the first and the second reviewer. To synthesize the findings, results were qualitatively summarized. No statistical analysis were done.

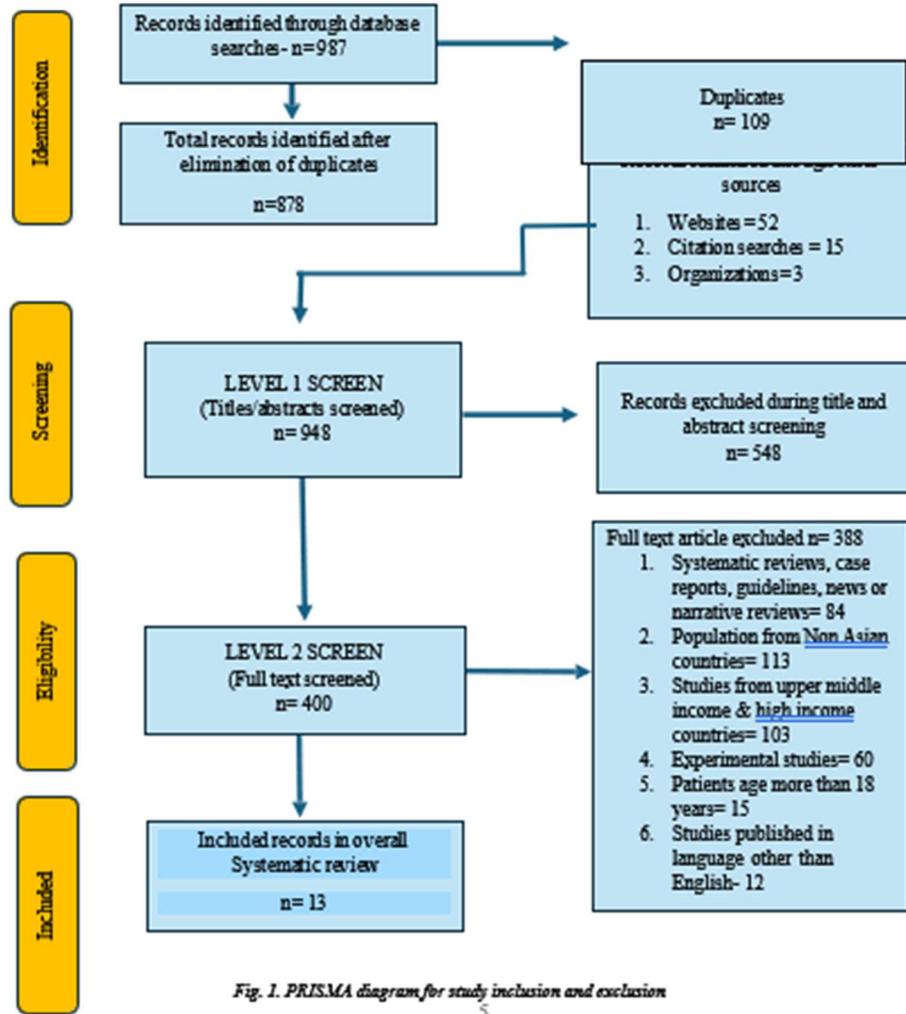


Fig. 1. PRISMA diagram for study inclusion and exclusion

Sr. No	Author	Title	Objectives	Population	Methods	Outcome measures & Results
1	Anna M Hood et al.,2024 ¹	Psychological challenges and quality of life in Pakistani parents of children living with thalassemia	To correlate the dimensions of health with the quality of life of caregivers	Pakistani care givers (Father or mother) of children with alpha &	Observational Cross sectional study Sample size- 100 Sampling technique- Convenience sampling Tools- Ryff's	Pakistani caregivers in our sample generally had significantly lower (30–40 points) quality of life than a referent

				<p>beta thalassemia</p>	<p>Psychological Well- Being Scale and the Singapore Caregiver Quality of Life Scale Technique of data collection- self reported</p>	<p>sample of caregivers of older adults (ps < 0.001). Self-acceptance and personal growth were consistently significant predictors across quality of life domains. Further, significant interactions were observed. Female caregivers with less self-acceptance had worse mental health and wellbeing and impact on daily life (p < .05). Male caregivers with less personal growth had worse physical health</p>
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						wellbeing (p < .05). caregivers reporting more personal growth and self-acceptance had better mental health and wellbeing. Overall poor quality of life was seen in the caregivers. The quality of life of care givers of children with thalassemia is poorer than the referent sample.
2	Bijit Biswas et al.,2020 ²	Care-Related Quality of Life of Caregivers of Beta-Thalassemia Major Children: An Epidemiologic al Study in Eastern India	To explore the CarerQoL of the caregivers of b-Thalassemia Major (b-TM) children and its various correlates.	Care givers from west Bengal	Design- Observational Cross sectional study Sample size: 324 Sampling : Technique of data collection-structured interview	In the present study, out of 324, 99 (30.6%) caregivers had no fulfillment on carrying out their care tasks. Majority of them (87.3%) had

						<p>problems with their mental health. .</p> <p>Most of them, 206 (63.6%), had some problems with their physical health for their care tasks.(50.3%) reported a lot of financial problem because of their care tasks. Two-third of them (66.4%) reported no support in carrying out their care tasks.</p> <p>caregivers with higher educational level had significantly higher odds of having favourable CarerQoL</p>
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3	Majedeh Nabavian et al., 2022 ³	The psychosocial challenges of mothers of children with thalassemia: A qualitative study	To explain the psychosocial challenges of mothers with thalassemia children based on their lived experience	Iranian mothers of children with thalassemia	Design- Qualitative Phenomenological study Sample size- 14 Technique of data collection- Semi structured face to face in depth interview	The various themes emerged from live experiences among mothers of children with thalassemia are Psychological distress (manifested as guilty, agony, depression and suicidal thoughts), Mental strain due to social stigma, Acute and chronic psychosomatic reactions (manifested as tension head ache, back ache, stomach pain, diabetes, heart problems and cancer), lack of empathy and support (inside and outside the family) and
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						financial instability.
4	Nimra Shafi et al.,2021 ⁴	The Psychosocial and Financial Ramifications of Thalassemia on Parents of Thalassemic	To assess the social, financial and psychological impact of thalassemia on parents of children	Pakistani parents of children with transfusion dependent thalassemia	Study Design: Cross-sectional study Sample size- 237 Tool- Structured questionnaire	80% of the participants acknowledged feeling depressed or sad, with 78% agreeing for recurrence every day or once a week. Upon being asked if they took any medicine for coping with depression 75% responded negatively. 67% of participants identified exhibiting intolerance some of the times with 92% recognizing they were unable to attain any form of enjoyment in their lives

						some or most of the times. 96% (n = 229) of the interviewees
		Children Presented at Tertiary Care Hospitals	suffering from thalassaemia			acknowledged that they were scared about thinking of the grief of their affected child. 92% (n = 218) of the participants conceded to have felt desolated or hopeless about the future some or most of the time
5	Mohammad Sorowar Hossain et al.,2021 ⁵	The parental perspective of thalassaemia in Bangladesh: lack of knowledge, regret, and barriers	To investigate the parental knowledge gaps and perceptions regarding thalassaemia, the barriers confronted by the parents for caring for their thalassaemic	Bangladeshi parents of children with thalassaemia	Design- Cross sectional Sample size- 361 Technique of data collection- Semi structured face to face in depth interview	91.2% parents are regretted for not undergoing premarital screening. . Most families (80%) reported they faced difficulty in collecting blood due to

			children and their attitude to prenatal screening and prenatal diagnosis			lack of support from organized donor's clubs or NGOs. In our study, nearly 40% parents experienced social stigmatisation, which could be associated with the nature of the disease.
6	Nisha Kanaiyalal Prajapati et al.,2021 ⁶	Caregiver Burden and Psychiatric Morbidity among Caregivers of Children with Thalassemia Major: A Cross-Sectional Study	To assess the caregiver burden and psychiatric morbidity among caregivers of children with thalassemia major	Gujarati parents of children with thalassemia	Design- Cross sectional Sample size- 245 Sampling technique- Purposive sampling	33.06% of caregivers were having severe burden, 30.61% were having moderate-to-severe burden, 27.34% were having mild-to-moderate burden, and 8.97% were having

						<p>little or no burden. 8.5% of caregivers had major depressive disorder, 4% had generalized anxiety disorder, and 0.8% had alcohol use disorder.</p>
7	Maryam Alizadeh et al.,2019 ⁷	Caregiver burden and related factors in parents of children with Thalassemia	To evaluate caregiver burden of parents of children with thalassemia major and factors related to it.	Iranian parents of children with thalassemia	Design- Cross sectional Sample size- 120 Sampling technique- Proportional randomized Sampling Tools and techniques of data collection- Zarit caregiver burden scale	<p>The results of this study showed that the majority of families of children with thalassemia had a high level of personal stress, and in general, 45.8% of the families tolerated high level of caregiver</p>

						burden.
8	Atiye Karakul et al., 2022 ⁸	The Experiences of Parents of Children with Thalassemia	To evaluate the experiences of parents of children	Turkish parents of children with thalassemia	Design- Qualitative phenomenological study Sample size- 14	Four themes of the interviews were established: unprecedented psychosocial distress, social support, financial burden and concern about children in the future. Parents stated that they experienced shock, sadness, fear, stress,

		Major in Turkey: A Qualitative Study	with Thalassemia Major.		Sampling technique- Purposive sampling Tools and techniques of data collection- Semi structured interview	depression, death anxiety, fatigue and burnout. Especially with the COVID- 19 epidemic in our country, parents stated
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						that their lives became more difficult and their concerns about their children increased.
9	Aziz et al.2021 ⁹	Psychosocial problems of Pakistani parents of Thalassaemic children: a cross sectional study done in Bahawalpur, Pakistan	To determine the psychosocial problems of parents of thalassaemic children.	Pakistani Parents of children with Thalassaemia	Design- Cross sectional study Sample size- 100 Sampling technique- Convenient Tools and techniques of data collection- Patient Health Questionnaire-9	29 percent of the parents had moderate to severe depression. . The high depression in these people is due to uncertainty about the future of their child, criticism by relatives, and some level of conflict with their spouse. Economic status is affected in 56% of parents. Majority (36%) of the parents are unable to focus on daily work. Most of the parents (56%) are feeling

						downgraded by the relatives.
10	Gita Septyan a et al.,2022 ¹⁰	The Mental Burden of Parents of Children with Thalasse mia	To identify the level of family burden among care givers of children with thalassemia	Indonesia n Parents of children with thalasse mia	Design- Cross sectional study Sample size- 71 Sampling technique- Convenient sampling Tools and techniques of data collection- Family care giver burden scale	Majority of the parents are experiencing mild to moderate care giver burden which make them feel isolated,and disappointed. The next question item with the second highest level of burden is concerning insoluble problems during treatment. In the sub-variable of environment, 63.4% of the respondents perceived moderate level of burden. In the sub-variable of environment,

						the burden is caused by “anxiety of not being able to properly take care their children.”
11	Aziz Shahra ki-vahed et al.,2017 ¹¹	Lived experiences of Iranian parents of beta-thalassemia children	To explore the lived experiences of parents of children with thalassemia	Iranian Parents of children with thalassemia	Design- Qualitative phenomenological study Sample size- 15 Sampling technique- Purposive sampling Tools and techniques of data collection- Semi structured and in depth interview	After analysing the interviews, four main themes were extracted, including “Gray marriage consanguinity”, “Burdened with increased number of thalassemia children”, “Socio-familial worries” and “Inexpressible wishes for having an ideal society”. The various psychosocial issues of parents listed down from the

						<p>above themes are worries (due to parental ignorance regarding premarital screening, effects of consanguineous marriage and uncertainty about future of thalassemia children), unacceptable social responses like sympathy and blame towards the child and family, Guilt of parents because of giving birth to child with thalassemia.</p>
12	Samiksha Sahu et al.,2023 ¹ ²	Psychiatric disorders and caregiver burden in children with transfusion	To screen the psychosocial problems and assessme	Indian Parents of children with thalassemia	Design- Observational Cross sectional study Sample size- 46 Sampling technique-	On assessment by Caregiver Burden Scale, moderate caregiver burden was perceived in domains of

		dependent β-	nt of psychiatric morbidity among		Purposive sampling	general strain, isolation, disappointment , emotional involvement, and environment. 28.2% of caregivers suffer from depression, 4.3% from bipolar disorder, substance use disorder (10.9%), somatisation disorder (13.04 %), and 6.6% suffered from anxiety disorder. 62.7% of parents were diagnosed with psychiatric problems .
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		thalassaemi a and their caregivers	thalassaemi c children and their caretakers, along with an assessment of caregiver		Tools and techniques of data collection- Care giver burden scale	
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			burden in them.			
13	Gavneet Kaur Pruthi.,2020 ¹³	A study of quality of life among parents having children with Thalassemia	To determine the quality of life among parents of children with thalassemia	Indian Parents of children with thalassemia	Design- Cross sectional study Sample size- 20 Sampling technique- Convenient sampling Tools and techniques of data collection- WHOQOL -BREF	It was found that mothers of children with thalassemia, reported greater no of physical problems and feelings of meaninglessness of life and dissatisfaction with their own self. Parents having children with Thalassemia had severe financial stress (74%). Among parents, the quality of life was poorest in the domain of psychological domain (Mean=36.3), followed by physical domain (mean=40.85), environmental domain (mean=44.45), and social domain (mean= 50.75)

Literature Review

In general, caregivers of children with thalassemia across different regions struggle with severe psychological, physical, and financial burdens, often receiving little support. Mental health issues such as depression and anxiety were common, with social stigma and financial stress exacerbating the situation.

Study Results and Outcomes:

Majority of the population were from India. 10 studies were Cross sectional studies and 3 studies were phenomenological studies. The description of the selected studies are given in Table 2. The synthesis of these study findings are divided into the following headings: a. Psychological issues b. Social issues c. economic issues d. Caregiver burden

Psychological issues

Many parents reported different levels of psychological distress like guilty, agony, depression and suicidal thoughts. Parents even mentioned about various psychosomatic manifestations like tension head ache, back pain and stomach ulcer^{3,5}. Most of the parents reported that the recurrence of these symptoms occur once in a week.⁴ Majority of the parents did not feel satisfied and are constantly feeling lack of happiness throughout their life^{5,9}. Desolation and hopelessness were seen in various care givers of children with thalassemia⁴. Many parents displayed fear, shock, death anxiety of their children, fatigue and burnout⁸. Many studies highlighted that the parents have moderate to severe depression.^{3,10} Most of the studies concluded that the parents have constant worries and feeling of guilty^{12,13}. The factors predisposing to guilt are parent's ignorance about the disease and consanguineous marriage that led to the birth of child with thalassemia.

Social issues

Major social concern for the parents of children with thalassemia is lack of support within and outside the family. Social stigma related to the disease is the crucial area of concern^{3,5}. The parents reported that the various responses they are receiving from society are sympathy, blame, judgement and various advices from the society without support³. Some parents emphasized about their conflict with the spouse. So many parents were socially downgraded by the relatives in the family for giving birth to a child with thalassemia.⁹

Financial issues

All the studies included in the systematic review unanimously pointed out about the financial burden of the parents due to life long blood transfusions and hospitalizations. Entire family stability is hampered by the economical constraint developed out the treatment of the child with thalassemia¹⁻¹³. Financial burden is the most important problem of parents in lower and middle income countries like India.

Caregiver Burden

Majority of the parents displayed moderate to severe care giver burden. The feeling of disappointment, anxiety and isolation are the negative outcomes of care giver burden^{6,7,12}. Even a few number of parents have reported that they are suffering from various psychiatric illness like depression and bipolar disorder due to the mental strain.¹²

DISCUSSION

The study findings from Anna MH on Psychological challenges and quality of life in Pakistani parents of children living with thalassemia showed that there is a poor quality of life observed in the parents of children with thalassemia. Self acceptance and personal growth of parents were badly affected. The study concluded that there is a significant relationship between the mental health being of parents with self-acceptance and personal growth. This study findings are supported by a study conducted by Thiyagarajan et al on the Assessing the role of family well-being on the quality of life of Indian children with thalassemia. The mean score for Psychological wellbeing of parents is 83.11 which is very low. There is a significant relationship found between the poor psychosocial wellbeing of parents and their educational level¹⁴.

Majority of the mothers experienced various levels of psychological distress in the form of agony, guilty, depression and suicidal thoughts. Mothers expressed their concerns regarding their mental strain due to social stigma. The study conducted by Hanayah Anwar et.al on Prevalence of Psychological Distress among Mothers of β -Thalassemia Children in a Developing Country also interpreted that the psychological distress in mothers of children with thalassemia is 65.1% which ranges from mild to severe psychological distress.¹⁵

The study findings from studies conducted by Atiye Karakul et al, Aziz et al, Gavneet Kaur et al and Majedah N et al conclude that most of the parents are experiencing higher levels of stress arising from financial instability. All these studies are conducted in Lower middle income countries like Iran , India and Pakistan. A study conducted by Sohail Safdar et al showed that Total cost (both direct and indirect) for the management of thalassemia was quite high and this cost puts significant economic burden on the affected thalassemic families in developing countries. In private sector 56.8% had to pay nothing while others had to pay from Rs. 500 to Rs. 2000 per visit. In the government sector cost per visit in 35.5% was up to Rs. 500 while others had to pay between Rs. 501 to more than Rs. 2000.Total expenditure (private and government sector) per month was Rs. 9626 for each patient¹⁶.

The studies conducted by Samiksha Sahu et al, Nisha Kanaiyalal et al and Maryam Alizadeh et al. highlighted that majority of the parents have moderate to severe care giver burden while taking care of children with thalassemia. The major reason for care giver burden are due to lack of satisfaction in care, fear of uncertainty about the future of the child, lack of enough knowledge about the disease and due to inability to focus on various tasks at home. A qualitative phenomenological study conducted by Batool Pouraboli et al on care giver bureden of parents of

children with thalassemia that the major reasons for care giver burden are immersion in suffering, stigma and social death, uncertainty about future, and absence of a support network¹⁷.

CONCLUSION

Over all, this systematic review of literature provides a detailed overview of the substantial psychological, social and financial burden of parents of children with thalassemia. As family members are one of the key components of the care system of patients with chronic diseases, such as thalassemia, and as the main goal in nursing of children is improving the care provided for children and their families. The findings of the review indicates that unmet needs of parents and caregivers of children with thalassemia should be taken into consideration. Poor quality of life in caregivers of children with thalassemia, indicates the importance of a lifelong psychosocial support for prevention of mental health issues, including promotion of a clear understanding of the disease.

There is a need to design various parent empowerment programs in order to provide an optimal family well being and to enhance the psychosocial wellbeing of the parents and children with thalassemia. A holistic approach should be selected for planning various interventions for the parents of children with thalassemia. Awareness among close family members, relatives, friends, and the community would also be extremely helpful for social support. Financial support is required to lessen their stress. A multidisciplinary approach to managing the disease and psychosocial support is required for the management of thalassemia and to minimize the burdens on both patients and families. Prenatal screening programs and prenatal counselling should be included as routine activities in maternity hospitals. Special units involving psychiatric experts for addressing psychiatric morbidity of caregivers of thalassemia should be facilitated and caregivers should be screened at regular intervals for early detection and management of psychiatric morbidity in order to provide better caregiving to the thalassemia children. Social and professional networks for psychosocial support and self-help groups should be planned for support and counseling for reducing the caregiver burden of caregivers of children with thalassemia major.

Conflict of interest

The authors certify that they have no involvement in any organization or entity with any financial or non-financial interest in the subject matter or materials discussed in this paper.

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