

Experience of Parents Caring for Their Children with Thalassemia: Challenges and Issues for Integrative Review

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Abstract

This integrative review aimed to synthesize the experience of parents caring for their children with thalassemia. An integrative review of qualitative studies was conducted regarding the experience of parents caring for their children with thalassemia, and MEDLINE, PsycINFO, SCOPUS, and CINAHL databases were searched from January 1st, 2009 to March 1st, 2018. Five studies involving participants were included. Children with thalassemia affect their parents' lives and perspectives. The six themes identified comprised: concern about children in the future, social death and stigmatization, absent support network, psychological distress, frustration with treatment, and the need for good coping strategies. This integrative review was designed to provide a better understanding of the experience of parents caring for their children with thalassemia. From the core themes, this integrative review led to an evidence-based practice for supporting and managing their condition effectively. Further studies should focus on how to support parents taking care of children with thalassemia.

Keywords : parents' experience, children with thalassemia, integrative review

Parents are important primary caregivers as they are the key individuals who take on the crucial role of caring for children with thalassemia.¹ Thalassemia is a severe chronic inherited disorder of globin synthesis in which the production of globin chains is partially or completely suppressed. This abnormality requires long-term treatment and significant treatments for thalassemia are blood transfusions and iron chelating therapies. Children with thalassemia encounter the impacts from this inherited disease and its treatment and they need to continue to receive care throughout their childhood from their parents.^{2,3} In addition, parents encounter multiple challenges that affect their quality of life when caring for their children with thalassemia.^{4,5} In fact, the child's quality of life depends largely on the corresponding parents' quality of life. Therefore, if parents are overwhelmed by caring for their children, without being provided the support system necessary to solve their problems, this in turn can also adversely affect the quality of life for children with thalassemia.

The empirical studies searched from January 1st, 2009 to March 1st, 2018, showed that many studies illustrated parents' experiences, and comprised: physical distress such as sleep problems, weakness, fatigue, failing to take care of oneself, loss of good health; psychological distress such as anxiety, worry about their child's condition and their future, stress, guilt, uncertainty; social distress such as loss of social activity, social alienation, social death; and spiritual distress such as hopelessness, inexpressible wishes of having an ideal society, stigmatization etc.⁶⁻¹⁰ Similarly, in a quantitative study of the burden of caregivers for children with thalassemia⁹ it was found that 66 % of parents reported they had no happiness in their lives and 82% of them revealed concerns for their child's future.

In addition, culture and context in each area of the study is an influential factor on parents' experiences.^{11,12} For example, there is the study on Southeast Asian and Asian Indian parents of children with thalassemia who lived in the United states.¹³ The research results showed that the parents

not only suffered from caring for their child, it also found that these parents encountered many obstacles to access health care service systems. This was due to limitations around language, lack of health insurance etc. Furthermore, to some context in Iran,⁸ parents reported their stigma and social death from the inaccurate beliefs about the cause of chronic inherited illnesses like thalassemia. False beliefs held by people in society led to parents being seen as disgusting and being excluded from society. For the most part, financial burden was acknowledged to be one of the challenges parents faced due to exorbitant treatment expenses and other expenses incurred from caring for their child (such as traveling to hospital, and parents' daily expenses for taking care of their child during hospitalization etc).⁷⁻¹⁰ This demonstrates that there is a need for health care providers to understand parents' experiences as there might be both similarities and differences in points of concern and vulnerable issues in each area.

This understanding would be useful to improve our comprehensive understanding of parents' experiences and to better promote quality of life for parents and for their children with thalassemia who rely on parental care. The literature review showed similar and different results on the topic of this integrative review. Therefore, this integrative review will help the researcher to synthesize knowledge about parents' experiences who care for their children with thalassemia and will provide a perception of these experiences with the aim of improving healthcare practice.

Aim of this review

The purpose of this integrative review was to synthesize parents' experiences caring for children with thalassemia.

Method

Design and search strategy

PRISMA's systematic reviews for examining and unifying literature was utilized.¹⁴ MEDLINE, PsycINFO, SCOPUS, and CINAHL were searched from January 1st, 2009 to March 1st, 2018. The keywords used were 'parent', 'parents', 'mother', 'father', 'perception', 'perspective', 'view', 'experience', 'caring', 'thalassemia', 'children', 'child', 'baby'. Relevant research articles were retrieved from the database suggestions. Journal articles were included in this review if they:

1. Were articles published between 2009 to 2018.
2. Were available in English.
3. Were primary qualitative research studies.
4. Involved optional and mandatory parents' experiences caring for children with thalassemia.
5. Were limited to those involving parents, mother or father with one child or more with thalassemia for at least 6 months to 1 year.
6. Were concerning children who had received treatment for thalassemia including blood transfusions and iron chelation therapy.

Data extraction and synthesis

A thematic synthesis was used for this integrative review to collate the findings.¹⁵ Data extraction and synthesis information were based on objective, sample and setting, methodology, gathering of data, data analysis, conclusions, strengths and limitations and future implications.

Strategies to enhance rigor in integrative reviews

The PRISMA statement consisted of a 27-item checklist and 4 phase flow diagram to meet the standard reporting of a systemic review with rigor. The PRISMA's framework was designed for a systematic review and meta-analysis. However, in terms of an integrative review, this method was a challenge in combining multiple data sources. Therefore, an integrative review was chosen with an integration concept with samples provided of all the processes applied and illustrated by PRISMA.

Data Abstraction/ data evaluation

The empirical report included types of methodology in qualitative research and consisted of five qualitative approaches. According to the data evaluation of PRISMA, they described the evaluation in overall terms of quality. The author chose from 628 articles and determined the exclusion criteria as follows: no full text, no qualitative approach, not in English, published more than 10 years ago, considered a duplicate, representative of primary data sources and/ or irrelevant. Finally, the author identified 5 articles that met the criteria set out to answer the research questions of this study. A total of 623 articles were removed and 5 articles were selected from at least 98 articles on parents' experiences caring for children with thalassemia. Data were collected from focus groups, semi-structured and face-to-face interviews conducted in Jordan, Iran, Malaysia, and The United States. (Table 1)

Results

Six themes were identified: concern about children in the future; social death and stigmatization; absence of support network; psychological distress; frustration with treatment and; the need for good coping strategies. Details as follows:

Concern about children in the future: parents showed great concern about their children's future due to the parents' awareness of the impacts of thalassemia and its treatment. This includes a gradual worsening of the condition in children with thalassemia. This then leads to the parents' heightened concern about their children's future including factors such as progression of the disease, concern about treatment and complications, children's education, job, employment and life prospects, developmental growth, delayed menses, self and body image, marriage and starting a family. As an example, in the words of parents:

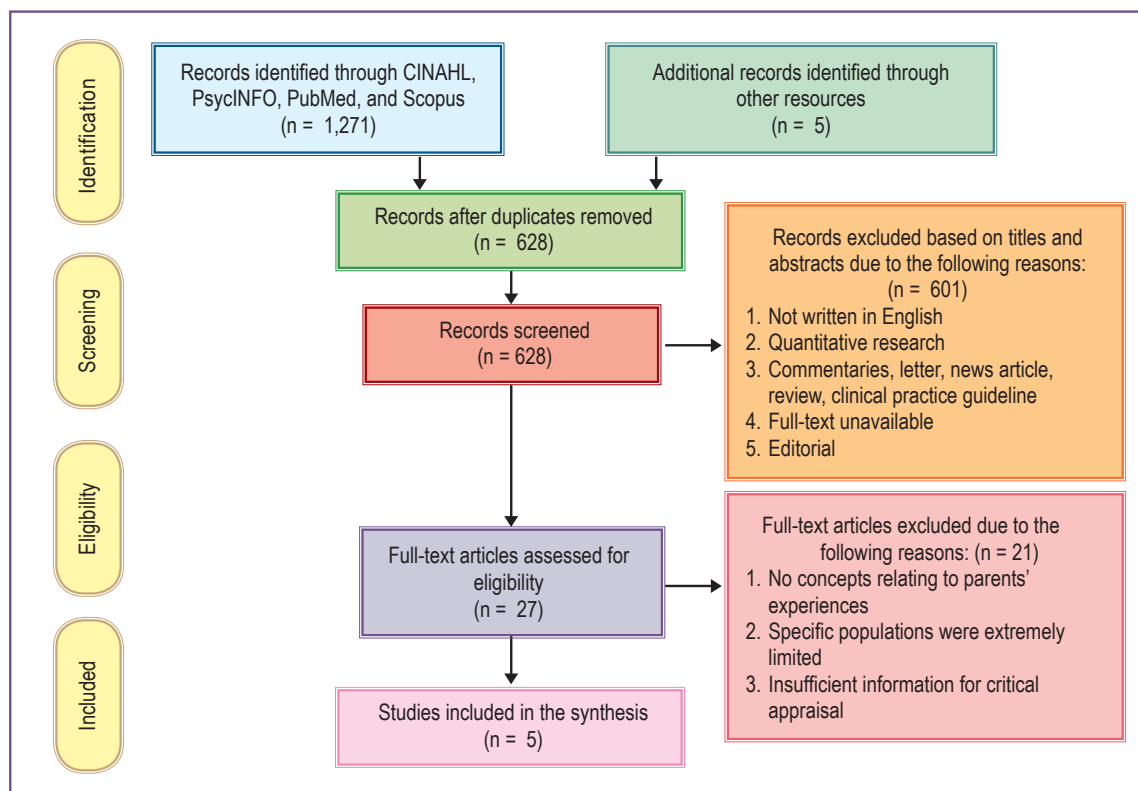


Figure 1: PRISMA flow diagram on the outcomes of search strategies.

Table 1: The relevant selected articles followed PEO format for qualitative research.¹⁶

Author, Year	Population	Exposure	Outcome or themes
Liem et al., 2011 ¹³	14 Southeast Asian and Asian Indian parents of children with thalassemia.	To describe the challenges, including sociocultural and socioeconomic barriers, faced by an urban immigrant population in the United States affected by thalassemia.	1) Impact of thalassemia on parent, affected child and family 2) Sociocultural and socioeconomic barriers to health care access 3) Family and social support network and coping mechanism
Wahab et al., 2011 ¹⁷	24 parents of children with thalassemia.	To explore the concerns, beliefs and feelings about thalassemia.	1) Concerns 2) Treatment 3) Coping mechanisms
Shahraki-vahed et al., 2017 ¹⁸	15 parents of children with thalassemia.	To explore the experience of parents of children with thalassemia.	1) Gray marriage consanguinity 2) Burdened with increased number of thalassemia children 3) Socio-familial worries 4) Inexpressible wishes for having an ideal society
Pouraboli et al., 2017 ⁸	22 parents of children with thalassemia.	To explore the experiences of parents who have children with thalassemia.	1) Immersion in suffering 2) Stigma and social death 3) Uncertainty about future 4) Absence of a support network
Shosha et al., 2018 ¹⁰	23 mothers of children with thalassemia.	To explore challenges facing Jordanian mothers when having a child with thalassemia.	1) Unprecedented psychosocial distress 2) Additional financial burden 3) Deficiency of knowledge and its source

*"Life was full of problems, when you had [sic] the children with thalassemia, the problems were complex. As children got older, when they grew up, they need the job, life and marriage. When I thought about these topics, my body starts trembling. My son was a slow student, he suffered from many educational problems. The teacher complained him when he didn't do his homework, he was [sic] encountered with many problems."*¹⁸

*"Her friends had all obtained menstruation, why had they had their menses but my child had not? When she asked me. Why she had not gotten her period. Why not? I did not know how should [sic] will I talk to her (Group 3 – parent)"*¹⁷

*"Last week, I heard this girl got engaged and the man didn't know she had thalassemia. When the man knew, he did not want to marry her: (R.U., father, Pakistani)"*¹³

Social death and Stigmatization: the parents spent more time providing continual care for their children and this affected the parents as they no longer visited their relatives as often, nor did they have the chance to participate in social activities. Furthermore, in some areas it was shown that parents suffered from a lack of real understanding or from misconceptions about the cause of thalassemia in others. The inaccurate belief of their community about thalassemia led some people in the community to cast blame and some treated the children and their parents like criminals or implied they were punished by God. This impacted parents, with some concealing their child's illness, and others refusing to participate or discuss their children with thalassemia with others. Unfortunately, some parents experienced exclusion or stopped having a relationship with their relative altogether. As an example, in the words of parents:

*"I'm away from my friend because I did not have time, I'm really busy...I need to stay beside my son ...he was very important for me more than my friends."*¹⁰

*"People treated [us] unwisely and stigmatize us. They talked about my child's illness unfairly... Unfortunately, that was how they viewed thalassemia and blamed this disease."*¹⁰

*"I usually did not tell anyone about it besides our family, because of somebody who didn't know us but they heard from rumors that my kids had thalassemia and they thought that I had disease. 'Oh, she had AIDS, HIV'."*¹³

Absence of a support network: the parents reflected on their experiences caring for children with thalassemia and spoke of an absence of support networks. In addition, they lacked information about thalassemia, felt social isolation, and an absence of professional and health care system support, and financial support.

Absence of information about thalassemia: parents reflected on the absence of information on thalassemia such as: the causes of the disease; treatments, and its side effects

and; lack of information to enhance the parents' role in caring for their child/children. As a result, parents could not interpret many of the clinical signs and symptoms of thalassemia and parents found it difficult when confronted with unpleasant symptoms experienced by their child/children. As an example, in the words of parents:

*"I didn't understand exactly what thalassemia was. At the first time, the doctor told me that my child had anemia and asked me if I had thalassemia and I answered no... the doctor told me that thalassemia was an inherited disorder... but I did not know really what the doctor meant. (Participant 14)"*¹⁰

*"Sometimes I asked nurses and doctors about my son's problems, but... they were busy. (Participant 8)"*¹⁰

*"I could not just travel due to many restrictions, including where to go to attach the blood bags and if he felt bad, what I should do, these all were limitations."*¹⁸

Absence of social, professional and health care system support: parents of children with thalassemia were confronted with social alienation due to inaccurate belief and superstition about the causes of the disease. This adversely affected parents who felt loneliness and helplessness. In addition, some parents experienced an absence of professional support and deficiencies in health care systems. For instance, inadequate expertise of the healthcare team, insufficiently equipped healthcare team and also not enough experienced nurses in intravenous lines administration. This led to parents feeling dissatisfied. As an example, in the words of parents:

*"We need advice or counseling sessions by an expert. We would be angry because he would not listen to us."*¹⁷

*"Lack of supportive behaviors in health care personnel and lack of holistic care for supporting the families might reflect many obstacles that required effective ways to cope with many challenges [sic] issue."*⁸

Absence of financial support: parents worried about lack of financial support because of the characteristics of thalassemia that require continuous long-term treatment throughout their children's lives. This means, parents need to spend a lot of money to cover the cost of transportation when visiting hospital for follow-ups or for blood transfusions, the cost of special food requirements and relaxation activities to decrease tension and anxiety of children. Meanwhile, parents often had to leave their jobs to take children to hospital and this was a financial burden. As an example, in the words of parents:

*"I need to pay for the cost of transportation or need to pay for the taxi every time when I took [sic] my child to hospital and I also need to buy special diet for my child."*¹⁰

"Sometimes, I did not have a single cent of money in my pocket to pay for the taxi. But since my child had an

appointment I had to take her to hospital. When she was on blood transfusion she told me, she was hungry. I cried and was feeling very sad as I had no money in my pocket.”¹⁷

Psychological distress: parents’ psychological distress occurred for the first time when parents became aware of the diagnosis of their child’s thalassemia. They felt shock, disbelief, and sadness. After that, signs and symptoms caused by pathophysiology of thalassemia showing in their child included the effects of its treatments that their child encountered. These included fatigue, exhaustion, failure to thrive, easy to fall prey to infection due to low immunity, growth and delayed secondary characteristics, body changes, body image, suffering from such treatments as drilling blood, blood transfusion, iron chelation, loss of activities with peer group, school absenteeism etc. This created tension on the part of the parents. Furthermore, parents reflected on problems that occurred within the family related to having children with thalassemia as parents tended to spend more time taking care of children with thalassemia when compared with other children. The sick child’s condition increased the feeling of love towards children with thalassemia and this in turn created a feeling of discrimination and jealousy among the other children. Moreover, in some parts of this study where there was a high prevalence rate of thalassemia caused by consanguinity through marriage, parents felt guilty because they perceived themselves as the cause of illness in their child. Finally, parents were also concerned that healthy female children within the family may lose their opportunity of having a happy marriage as prospective husbands may choose not to marry them because they are part of a family with thalassemia. These factors adversely affected parents and caused tremendous psychological distress. As an example, in the words of parents:

“After Dr. A informed us about our child diagnosis with thalassemia. I did not believe [sic] him, I felt shock. We went to another hospital to confirm the result...My child asked me why Mr. B’s son was taller than me. Why had he grown more than me? Why did I have to receive frequent blood transfusion and my sister not? These questions indeed hurt me.”⁸

“I am very sad; it is a true disaster when I saw my son in pain and unlike other boys. (Participant 3)”¹⁰

“It scared me so much. I also had a healthy child that I [was] concerned she might lose her opportunity in her marriage life because [she] did not have the man [who] wants to marry her after [he] saw the sick child in the family.”¹⁸

“There were many problems involved with kept [sic] healthy child besides the sick child. Some of the problems were involved to parents and some to the child; Diet problems and preparing separate meals for the sick child, paying attention to the special needs of these children, different [sic] of skin color appearance and change in their facial shape, when compared with that of the healthy one, these were all problems.”¹⁸

Frustration with treatment: parents reflected on their frustration with treatment which had occurred in the past and was still ongoing in the present, in particular concerning ineffective health care systems that could not prevent the birth of children with thalassemia. There was also the inadequacy of the thalassemia diagnostic test in the past that led to having the children with thalassemia. Therefore, parents now had to suffer, having to purchase blood for required blood transfusions for their children with thalassemia. Moreover, some parents shared their experience of not having access to a desferal pump and medications that affected the children who then received ineffective treatment since they were forced to share one desferal pump with other patients. In addition, some parents reported issues with access to health care systems such as living in remote areas. This meant parents faced difficulties in travelling to the hospital, and some parents had to move to another city in order to be close to the thalassemia center. Barriers encountered also included language limitations of certain groups in society. As an example, in the words of parents:

“I was usually seeking for someone who could donate blood for my child. I donated my own blood several times. Some soldiers were ready to sell their blood. I had to find them to pay for and purchase their blood.”⁸

“Our English skills were adequate for communication in every day. However, we felt difficulty to understand medical terminology when the conversation [was] with the healthcare team”¹³

The need for good coping strategies: parents tried to cope with their suffering arising from caring for their children. The coping strategies focused on improving their children’s lives and well-being. Parents tried to search for information about thalassemia through communication with physicians and nurses, they tried to cope with self-education, tried to instill a sense of normality in their children, and tried to trust in their faith and religion to maintain their hope for treatment. As an example, in the words of parents:

“It never affected her. I treated her as a normal child. I always told my family that, ‘you did not need to be pity her’. Since my daughter was a child, as she was growing up, I kept telling her about her disease, what was wrong with her, and she had taken it very good.”¹³

“But most of all, I put the most of my trust in God because he could do miracles that no doctors out here could do. And so, I believed we went through life...most of our suffering, most of the things we went through made us stronger spiritually and as a person.” (B.R., mother, Hmong)”¹³

“I was able to cope with my problems through strong faith in my religion. I was Muslim. I believed in the Qada’ and Qadar to deal with my suffering. I was hopeful that one day my child would be cured of their disease.”¹⁷

Discussion

The synthesis results identified six themes: concern about children in the future; social death and stigmatization; absence of support network; psychological distress; frustration with treatment, and; the need for good coping strategies. However, we re-conceptualized all of the themes to consider the latent significant challenges and issues within the themes that were shown. We identified two important points: psychosocial and financial problems. Both need to be considered to enhance the potential ability of parents who care for their children with thalassemia.

The author found that psychosocial problems were significant in the synthesis of the articles. In brief, the results from all of the articles in this integrative review showed psychosocial problems parents faced from caring for their children with thalassemia. These problems were caused by many factors such as disease, treatment and its side effect, life-changing impact in the day-to-day social activities of the parents, the sick child and their sibling/s. All of these reflected the source of the problem and the parents' need for support to alleviate their suffering.¹⁹⁻²² Suggestions arising from this integrative review have been outlined to help develop a holistic nursing intervention⁸ to support parents and to promote the potential ability of parents to cope with their suffering successfully. Programs could include the promotion of parents' role in taking care of their children, and the development of a thalassemia database to share necessary information through digital technology. One example, is setting up a Line group connecting parents of children with thalassemia as a useful channel for them to immediately access information they want.²³ In addition, genetic counseling programs were added to this integrative review. The goal of genetic counseling was to promote a better understanding of the consequences of the disease, increasing knowledge of the risk of disease or transmission of disease, reducing anxiety, making the right choices, finding ways to prevent the transmission of abnormalities to children and to make informed decisions about family planning. In brief, genetic counseling was an important nursing intervention to help parents to alleviate suffering and to find different ways to solve their problems. Finally, genetic counseling was seen an important strategy of the health care system to decrease the incidence rate of new patients.^{17,24}

However, the author found that one of the most crucial issues was social death and stigmatization, and this was prevalent in the study in Iran.⁸ People in society believed thalassemia was caused by a supernatural power or was a punishment from God, or because someone had done something wrong against the norms of society. These views were reflected in most of the people in Iran, who still lacked informed knowledge about thalassemia. This led to the child and families being criticized by society resulting in social death. Families had to conceal their child's illness. The study also reflected the disparity in society, and this needs to be resolved urgently by all parties in order to allow children and families to live in society with dignity and well-being. Due to

these challenging issues, parents still faced limitations in terms of their vulnerability related to belief and social values. Therefore, further study is needed to better understand this vulnerability with an ethnographic research as an approach to reach the required research questions. After that, the information gained from a qualitative approach could be used to construct an appropriate nursing intervention to promote a proper understanding of the disease to people in society.

Financial problems seemed to be a universal cause of suffering of parents with children with thalassemia since the disease requires prolonged care and treatment and frequent hospitalization. It was the greatest problem seen, especially among parents in the lower socio-economic group.^{9,13,18} This reflects the need for financial support as a necessary factor to help parents to reduce suffering from caring for their child and to promote the quality of care and the quality of life in both the parents and their child. Therefore, financial support should be considered by policymakers, at least in the form of health insurance, to be determined as a health right for citizens to alleviate the parents' suffering arising from caring for their children with thalassemia.²⁵ Moreover, most of the studies raised unemployment as one of the burdens facing parents as they frequently needed to take leave from their jobs to take their child to hospital.¹⁷ Therefore, policymakers should cooperate with employers to determine guidelines to help parents.

This study looked at how health care providers need to help parents to cope with their lives by applying specific strategies. These include: promoting the caring role of parents; developing a thalassemia database; implementing a genetic counseling program and; policymakers creating appropriate health insurance policies. Further study is needed to understand some topics where the understanding is still limited to help healthcare providers to provide the appropriate nursing intervention to alleviate parents' suffering. Moreover, these nursing interventions should integrate a holistic approach particularly when it comes to the relevant issues of religion, belief, and society's values.²⁶

Conclusion

According to the results of this integrative review, parents of children with thalassemia faced many challenges arising from caring for their child. These comprised concern about children in the future, social death and stigmatization, absence of support networks, psychological distress, frustration with treatment, and the need for good coping strategies. These results show that health care providers should be concerned with the suffering of parents who care for children with thalassemia. This is because parents are crucial and play an important role in providing quality care for their child. Therefore, to attain a better quality of life for both parents and their children, health care providers should provide the appropriate holistic nursing care or interventions to alleviate suffering. They should provide the appropriate support program for challenges and issues in caring for children with

thalassemia. In particular, psychological support should be given to enhance the capacity of parents' skill to cope with their situation. Finally, these improvements will enhance

parents' capacity to sustain their role in taking care of their children, which will lead to a better quality of life for parents and children alike.

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