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The psychosocial challenges of mothers of children with thalassemia: A qualitative study

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Abstract:

BACKGROUND: Caring for the children suffering from thalassemia is a stressful experience with various aspects making the mothers face various challenges. Thus, the present study aimed to explain the psychosocial challenges of mothers with thalassemia children based on their lived experience.

MATERIALS AND METHODS: In this qualitative study, which was conducted using the phenomenological method, 14 mothers with thalassemia children were selected from two thalassemia treatment centers in Hamadan and Babol (Iran) in 2020 using the purposive sampling method. Data were collected using in-depth and semi-structured interviews and were analyzed by van Manen's phenomenological methodology.

RESULTS: In the first stage of data analysis, 534 initial codes were extracted, which were reduced to 290 by comparison and integration. The primary themes turned into 24 secondary themes after clustering. By comparing the secondary themes, three main themes (i.e., "psychological distress," "bodily burnout," and "mothers' need to empathy and support") with 7 secondary themes (i.e., "emotional exhaustion," "mental strain," "social stigma," "acute psychosomatic reactions," "long-term psychosomatic consequences," "expectation of family support," and support needs outside the family) were extracted.

CONCLUSION: The results indicated that mothers with thalassemia children experience several challenges in various aspects. Therefore, they require care interventions and psychosocial support.

Keywords:

Children with thalassemia, mother, qualitative study, psychosocial challenges

Introduction

Thalassemia is one of the most prevalent chronic genetic disorders among the 60 countries in the world with annually about 100,000 babies being born with this disease. The prevalence of the disease by the Foundation for Special Diseases^[1,2] has been reported to be 26,000 in Iran, with about 800 infants being born annually and being added to this group.^[2]

Many children suffer from thalassemia despite the advanced methods used to

prevent this disease.^[3] This disease has many problems such as being heredity, chronic nature, its appearance in the early years of life, the need for continuous blood and desferrioxamine transfusions, physical abnormalities, frequent hospitalizations, and increased medical costs with a drastic impact on the child growth and development.^[4,5] In one study, the quality of life in 74% of the children with thalassemia was reported low, 44% of them had psychological problems, 64% had pain and discomfort, and 23% had musculoskeletal disorders.^[6]

Thalassemia is a chronic disease starting in childhood. Therefore, mothers have a

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critical role in caring for these children. Many studies emphasize that mothers have a more active role in caring for a child with a chronic illness.^[7,8] These mothers have several roles like caring for the child during continuous blood transfusions and Dysfrol, caring for the child in frequent hospitalizations, caring for the child with different thalassemia abnormalities, and following up different child tests.^[4,5]

Caring for a child with thalassemia exposes the mothers to many challenges. In the study conducted by Piran *et al.*, 49% of the mothers of children with thalassemia major experienced moderate-to-severe levels of care stress.^[9] In addition, it has been revealed that the mothers of children with thalassemia major face many problems such as the history of psychosocial distress, bearing an extra economic burden, and lack of knowledge and its sources.^[10] Worries and fears of the worsening of the disease and concerns over the future of the child are the critical psychological problems and conflicts of these mothers.^[11] Another stressor of parents, especially mothers, is the transfer of the thalassemia gene to the child and responsibility toward the child's illness, making the mother feel guilty and emotionally involved.^[12,13] Chronic physical illnesses such as hypertension, diabetes, and heart disease are more likely to happen among these mothers and may reduce their sense of responsibility for caring for their children.^[5]

Mothers play a central role in caring for a child with thalassemia. Therefore, they are usually faced with several challenges, resulting in a psychosocial burden. Moreover, in Iranian culture and society, mothers are assumed to have the most important role in caring for a sick child. It seems that using qualitative methods, especially phenomenological approach, can provide a deeper understanding of psychosocial challenges usually experienced by mothers with thalassemia children. Although the impact of thalassemia on families has been studied extensively using quantitative approaches, there is limited evidence to evaluate the experience of psychosocial challenges faced by mothers with thalassemia children in Iranian thalassemia literature.^[14-17] The aim of this study was to explain the psychosocial challenges of mothers with children with thalassemia.

Materials and Methods

This qualitative study has an interpretive hermeneutic phenomenological method. This is a qualitative methodology used to examine and understand the subjective lived experience of individuals using an idiographic approach.^[18-20] This methodology aims to gain a deeper understanding of the human experience through description and interpretation.

Study sample and the participants

Fourteen mothers with thalassemia children were selected using a purposive sampling method from two thalassemia treatment centers in Hamadan and Babol cities (Iran) in 2020. In the initial analysis stage, each interview was analyzed separately with data related to the phenomenon of mothers' psychosocial challenges extracted and then compared with the data obtained from other interviews and exchanging views with the authors, an agreement was reached. Data saturation was reached with the participation of 14 participants. The inclusion criteria were having a child with thalassemia major, not being the single parent, assuming the mother as the primary caregiver, the absence of chronic physical illness, and a history of psychiatric disorders in the mother.

Data collection

Data collection was done through semi-structured in-depth and face-to-face interviews with the participant. The interviews were conducted in a quiet environment beside the child and selected by the mothers. According to the amount of information, tolerance, and willingness of the participants, each interview lasted 40 to 60 minutes. All interviews were conducted by the first writer (MN).

The main interview questions in the study were "How did you feel the first time you were informed that your child had thalassemia?" and "How has your child's illness affected your life?" Then, the reason was deeply examined. According to participants' responses, other questions like "What part of your life has changed since you found out about your child's illness?" and "Which part of it caused problems to you?" were asked as well. Indeed, in each interview, the mother was asked about the concept and the next questions were asked depending on their responses. The recorded interviews using the tape recorder were written by the authors, with the sentences showing people's understanding of the phenomenon determined.

Data analysis

The data analysis process was performed using van Manen's phenomenological methodology.^[21] The method involves listening to all recordings to familiarize researchers with participants' experiences. Next, they transcribed the digital recordings verbatim. Following the transcription step, thematic statements that contributed to participants' experiences and were of direct relevance to the phenomenon were extracted using van Manen's highlighting approach. Meanings were derived from the statements, which were then organized into themes that were common across all participants.^[22] We also used Van Manen's proposed research activities, as a methodological structure, to guide hermeneutic phenomenology research.^[21,23]

Involvement of the researcher with the research question is always one of the necessities of the study of interpretive phenomenology. The constant question of “What is the experience of psychosocial challenges in mothers of a child with thalassemia?” led the researcher to extract and interpret the themes at all stages of the study. Eventually, organized concepts led to a comprehensive description of the phenomenon. The interviews were transcribed and analyzed using van Manen’s thematic analysis approach. Data gathering and analyses were conducted simultaneously and, as the initial coding was done, it was decided to conduct some subsequent interviews.

Rigor

Strauss and Corbin, citing Lincoln and Guba, have proposed credibility, dependability, confirmability, and transformability to evaluate the robustness of qualitative data.^[24,25] The results of this study were presented to the participants for approval and they expressed their views on the coordination of the results with their experiences to the authors. The results were discussed during meetings with five professors of qualitative studies, and some parts of the text of the interviews were analyzed by them in some cases. The text of the interviews and the process of extracting the topics were provided to other professors in qualitative research for comment. Moreover, the corresponding authors in this study provided the reliability of the research by participatory meditation on the topics through review by members of the research and analysis team of experts in the qualitative study. Moreover, the background was prepared for judging and evaluating others with detailed descriptions.

Ethical considerations

This study was approved by the Ethics Committee of Hamadan University of Medical Sciences (IR.UMSHA. REC.1399.167). An informed consent document provided to each participant explained the purpose of the research,

detailed potential risks, and provided a confidentiality statement of how participant information would be securely handled.

Results

Fourteen mothers of children with thalassemia participated in the study. Demographic characteristics of participants are presented in Table 1.

At the first stage, 534 primary themes were extracted. After merging the primary themes, they were reduced to 290 based on similarities and differences. After clustering the primary themes based on the similarities, 24 secondary themes were extracted. The next step of thematic analysis was to extract the subthemes and reach the main themes, where 3 main themes and 7 subthemes were finally reached [Table 2]. This was done by the research team according to the experts’ opinions.

The main and subthemes with an example of the participants’ expressions are as follows:

Psychological distress

Repetitive hospitalizations of the child along long-term and exhausting care reduce the tolerance threshold and lead to mental confusion of mothers. They feel great agony when they see their child suffering. Furthermore, since many mothers feel guilty about having such a child, they suffer from depression and some have suicidal thoughts. Furthermore, the vague future of their child’s education, work, and marriage makes them fear and feel anxiety. Their negative psychological experiences and the stigma of others to have a sick child have caused them to lose their motivation. This main theme has the following three subthemes:

- a. Emotional exhaustion: The mothers state that because of the high psychological pressure, they do not have the strength and patience to take care of their other

Table 1: Demographic characteristics of the participants

Participants	Age	Employed	Education	Blood relationship with the spouse	The number of children with thalassemia
Participant 1	38	No	High school	Yes	One child
Participant 2	33	Yes	High school diploma	No	One child
Participant 3	43	No	High school	No	One child
Participant 4	45	No	High school	No	One child
Participant 5	31	Yes	High school	Yes	More than a child
Participant 6	34	No	High school diploma	Yes	One child
Participant 7	38	No	High school diploma	No	More than a child
Participant 8	28	Yes	University	Yes	One child
Participant 9	22	No	High school	No	One child
Participant 10	25	No	High school	No	One child
Participant 11	37	Yes	University	Yes	More than a child
Participant 12	35	No	High school	No	One child
Participant 13	40	No	High school	Yes	More than a child
Participant 14	50	Yes	University	No	One child

Table 2: The main and secondary themes that have emerged in the lived experiences of the mothers

Secondary themes	The main theme
Emotional exhaustion	Psychological distress
Mental strain	
Social stigma	
Acute psychosomatic reactions	Bodily burnout
Long-term psychosomatic consequences	Mothers' need to empathy and support
Expectation of family support	
Support needs outside the family	

children and spouse. Some of them are not even in the mood to take care of them and they are so worried and anxious under the pressure of their child's illness that they have nightmares. A mother of two thalassemia children says, "Blood transfusions and Dysfral are so excruciating that I am nervous and bored. I cannot stand it at all. I am so upset to see the suffering of my children that I do not sleep well at night and most of the time I wake up screaming and I am always impatient during the day" (Participant No. 7)

- b. Mental strain: The mothers have many overwhelming issues and cannot do their daily tasks properly. One of the most important problems that occupy the minds of these mothers confusing them is the feeling of guilt for their marriage and blaming themselves for the suffering of their children. A mother says, "After my son's spleen surgery, I feel scared and I am constantly worried that he will get a new disease. When I see my child's gradual death, I suffer from a guilty conscience, as I caused it with my marriage. I want to suicide as I damaged my baby with a sick gene" (Participant No. 5)
- c. Social stigma: Another point making the mothers upset is the unconscious judgment of others about their child. This renders the mothers heartbroken so that it makes them cry during the interview. Mothers state that as others only know that their child receives blood, they think that the situation is definitely bad restricting the mother's interactions with those around her which leads to isolation. Regarding this, a mother says, "People in my family have told me that our children may get sick while playing with your child. When the old people in the family want to talk about me, they tell each other that this poor thing has a baby with cancer. Because of this, I cannot go to party. They strangely look at me" (Participant No. 1).

Bodily burnout

The results of the study revealed that mothers usually experience many acute and long-term psychosomatic reactions within the body which can have a dramatic negative effect on their physical health and lead to bodily burnout. A wide range of acute and chronic diseases such as tension headaches, heartburn, heart problems, diabetes, open-heart surgery, hysterectomy, and cancer have been created in these mothers due to the exhausting

life that exacerbates their state further. This main theme includes the following two subthemes:

- a. Acute psychosomatic reactions: Caring for a thalassemia child has caused many psychosomatic problems in mothers because of its many hardships. Furthermore, given excessive child care and grief and discomfort, they constantly suffer from severe attack headaches and bone pain, and stomach ache. A mother says, "I do not have the time and ability to take care of myself at all. I became weak from inside. I used to be active, but now I suffer from hand and foot pain, migraine headaches, and so on. My stomach aches when I see that my child is behind his peers and those of his age" (Participant No. 2)
- b. Long-term psychosomatic consequences: Caring for a thalassemia child has caused negative long-term and irreversible psychosomatic consequences in mothers. Every participant suffered from a chronic physical illness that not only makes it more difficult for them to care for the child but also exacerbates their physical problems. Most of the mothers have so many chronic physical problems that make them concerned and anxious about losing their health and how their sick children would live without them. One of the participants says, "When I found out my child was sick, I was so stressed that I started bleeding profusely and had a hysterectomy. I have all kinds of chronic diseases such as high blood pressure and diabetes, due to these stresses. I also have a heart problem recently. I am always worried about who will take care of my sick child if something happens to me." (Participant No. 8).

Mothers' need to empathy and support

The mothers state that the burden of thalassemia children is so great that they can never deal with it alone. Their complaint is about disability in all physical, psychological, and economic dimensions. The participants in their live experience described the supportive needs to maintain their health, which appear in different ways in their experience. Those who bear the burden of care alone, are no longer able to bear all these problems, and need the help of others are even satisfied that a family member or other relative just listens to them to calm down and reduce their stress. Economic challenges are among the most damaging problems for mothers as well. They say they should be covered by the Relief Foundation. This main theme has the following two subthemes:

- a. Expectation of family support: The mothers need the cooperation of all family members to care for a sick child. They state that their spouses are engaged in earning money and they bear the burden of care alone and suffer a lot of physical and mental harm. Mothers say family members should support them physically and emotionally. A mother says, "Now that my own problems like hypertension and back pain and a

thousand other misfortunes have increased, there is no one to help me and I am living alone with this situation. "If my husband and children had helped, I would not be so sick now. At least, if they had listened to my heartache, I would calm down". (Participant No. 9)

- b. Support needs outside the family: In addition to supporting family members, the participants also need financial, spiritual, and social assistance from the health-care system. Most mothers must be aware of thalassemia to care for their children. In addition, if the treatment team educates and supports them, it will be of great help to them and the children will have fewer problems. Mothers also point to the dire financial need to provide medication and deferoxamine, needing the assistance of a specific illness organization.

A mother said, *"The cost of treatment has increased so much that I use only one deferoxamine for my two sick children, and sometimes I do not even have the money to provide it. I do not know much about my children's problems. I take them to the local clinic and to someone when they get sick but no one guides me. I wish there was a doctor to help us. I myself need help now"* (Participant No. 10).

Discussion

The health and living status of the mothers of thalassemia children has always been of interest to researchers. In some studies, suffering from illness and stressful life of mothers has been stated because it changes their quality of life.^[26,27] When the child is suffering, it is associated with the mother's feelings of sadness and suffering. One of the most important sufferings of the mothers in the study was psychological distress. Other studies have also reported that mothers experience suffering such as fatigue, insomnia, and physical and mental complications.^[7,27] A study by Abu Shosha and Al Kalaldehy showed that mothers of thalassemia children suffer from many psychological problems.^[4] In addition, Shahraki Vahed showed that the parents of children with thalassemia experience many problems in various emotional, psychological, social, and family aspects.^[27] Furthermore, the results of other studies by Pouraboli *et al.*^[28] and Heidari and Ahmadi^[29] revealed that difficulties of caring of thalassemia children consequently resulted in psychological tensions to their parents. Hence, efforts should be made to alleviate the suffering of mothers by providing appropriate psychological care facilities for mothers of children with thalassemia. Despite the key role of psychologists and psychiatrists in helping identify and solve psychological problems, their contribution to solving problems has not been considered. Accordingly, it is necessary to conduct activities such as education and counseling programs for radio and television, as well as introducing available

centers to increase mothers' self-care knowledge. The thalassemia patients' support association can use the cooperation of psychiatric nurses in care centers under its supervision to solve mothers' psychological problems.

In the present study, the mothers suffered from acute psychosomatic illnesses (headache and back pain), chronic (diabetes and heart disease), and incurable due to the sufferings and hardships of child care and many concerns about their children's present status and their future. The mothers reported that their illnesses were due to psychological stress associated with their sick child, reducing their physical strength. Moreover, they have stated that they did not have enough time to maintain their health. These issues can have a dramatic negative effect on mothers' physical health and lead to their bodily burnout. Consistent with the present study, Saldanha showed that about 1.5% of the mothers with thalassemia children in the first 2 years of treatment of their child experience various psychosomatic diseases and need the support of others to continue the process of treating the child.^[30] Teaching cognitive emotion regulation strategies and adaptive strategies has been shown a great effect on reducing mothers' psychosomatic illnesses and with proper education, these mothers should be helped to choose appropriate emotion regulation styles and adaptive strategies and physical health.^[31] The mothers need the support of their relatives and those around them to solve this problem and continue the care process. Moreover, the treatment team should have special measures to support them and help these mothers to continue the child care process by providing the necessary training for self-care.

When describing their experiences, the participants stressed the role of empathy and support within and outside the family and its effect on their health status. The supportive needs of mothers had different aspects, like the need for support from their spouses, other family members, health-care groups, and appropriate insurance services. Dahnili *et al.* showed that the parents of children with thalassemia, especially mothers, were more likely to face physical, emotional, and social problems than the children themselves and needed comprehensive support for child care.^[32] In a qualitative study, Qada Abu Shosha *et al.* showed that support and health education by members of the treatment team is a good solution to reduce the challenges, stress, and problems of mothers with thalassemia children.^[10] The need for financial support was of the most critical needs of mothers. Vahab *et al.* discuss the financial problems in treating chronic genetic diseases among children because of the need for frequent visits and long-term treatment.^[33] Financial problems were considered as important challenges for

mothers caring for children with thalassemia major.^[34] The participants also mentioned financial problems in that study.^[33] Dealing with such issues calls for the government's efforts to remove the sanctions and considering drug allowances for parents and the efforts of community benefactors, it also calls for the benevolent of the community to rush to help these mothers.

Limitation and recommendation

Lack of generalizability of the findings to the mothers of thalassemic children in other different geocultural contexts, due to small number of participants, and contextual nature of the findings are the limitations of this study. Although to enhance our sample representativeness, we tried to carefully select our participants. Similar studies should be performed in other countries to confirm the results of this qualitative study. Another possible limitation of this qualitative study is interpretation bias. Two researchers independently analyzed data for theme development to deal with this and to prevent missing any themes. Recall bias from study participants during data collection and interviews was another limitation. However, the researcher has no control over how each participant chooses to answer the research questions.

Conclusion

The lived experiences of mothers with children with thalassemia show that they have many challenges in various aspects. The most important sufferings of the mothers are psychological stress, negative psychosomatic consequences, and need for personal, social, and economic support. Hence, relatives and health-care providers should adopt special measures to support mothers of children with thalassemia.

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Conflicts of interest

There are no conflicts of interest.

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