Original Article

The Experiences of Parents of Children with Thalassemia Major in Turkey: A Qualitative Study

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Abstract

Background: Invasive medical procedures and their complications of Thalassemia Major still affect the quality of life of all patients and their caregivers.

Aim: This study evaluates the experiences of parents of children with Thalassemia Major.

Method: The qualitative phenomenological method was used to determine the parents' experiences. The study sample included 14 parents who met the inclusion criteria. Individual interviews, an introductory information form and a semi-structured interview form were used for data collection. The data were analyzed with Colaizzi's seven-step method.

Results: 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, depression, death anxiety, fatigue and burnout. Especially with the COVID-19 epidemic in our country, parents stated that their lives became more difficult and their concerns about their children increased.

Conclusions: Healthcare staffs need to understand parents' psychosocial distress and coping strategies to provide support and guidance from the outset of treatment and care. It is recommended that interventions be planned and implemented in a way that maximizes the quality of life of children and families.

Keywords: Thalassemia major, qualitative study, parents, experience

Introduction

Thalassemia is an autosomal recessive chronic disease that is inherited and is very common in all races. Although it is seen in all races, it is more common in tropical regions such as the Mediterranean, Asia and Africa (Kılınç, 2011). Approximately 300,000-500,000 newborns are accompanied by severe hemoglobin abnormalities, and 50,000-100,000 children die due to Thalassemia Major (TM). About 80% of this rate comes from developing countries (Suryani, 2020). In Turkey, the number of patients diagnosed with Thalassemia Major registered in the Thalassemia Center is 1658 (Aydınok et al., 2018). TM is a chronic condition requiring lifelong care. Therefore, it seriously affects the child and family physically, socially, cognitively and economically (Punaglom, Kongvattananon, & Somprasert, 2019; Hussain, 2021). Children have a long treatment period due to physical problems such as chronic anemia, bone deformities, growth changes, short stature, delay in physical growth. Accordingly, children are prone to anxiety and depression due to separation from family, restriction from social

activities, facial deformities, death anxiety, limitations in school and play activities (Sinlapamongkolkul, & Surapolchai, 2020; Akter, Khatun, & Hossain, 2020; Dhawan, , Sudhesh, & Kakkar, 2021). Children with TM have low levels of coping with stress, adaptation to the disease process, and school success. (Shahraki-Vahed et al., 2017; Akter, Khatun, & Hossain, 2020). In addition, they have anxiety about the future. (Mariani, Mulatsih, & Haryanti, 2020). Thalassemia, which requires careful care and regular blood transfusion, can disrupt the child/family's relationships and psychosocial balance (Heidari et al., 2018; Heidari, & Ahmadi, 2020). The factors affecting the quality of life and self-care of patients with TM are severe anemia symptoms, transfusion frequency, side effects of chelation therapy, multiple diseases, psychosocial conditions such as depression and anxiety (Dhawan, Sudhesh & Kakkar, 2021; Mariani, Mulatsih, & Haryanti, 2020). Although the life expectancy of patients with TM has increased in recent years, invasive medical procedures and their complications still affect the quality of life of all patients and their caregivers (Heidari et al., 2018; Punaglom, Kongvattananon, & Somprasert, 2019; Heidari, & Ahmadi, 2020; Hussai, 2021). In particular, blood transfusion and treatment costs and hospital expenses (such as treatment, care, transportation) are covered by the parents (Heidari &Ahmadi, 2020). Thus, the impact on parents can occur physically, psychologically, socially and financially (Abedi et al., 2020). For this reason, parents who care for their child with thalassemia need supportive care to carry out the treatment and care of their children (Kermansaravi, Najafi, & Rigi, 2018; Heidari, & Ahmadi, 2020). Therefore, failure to determine the treatment and care needs of the parents may cause the child's treatment and care process to be disrupted. (Suryani, 2020, Abedi et al., 2020). In this study, it was aimed to determine the experiences of parents of children with Thalassemia Major regarding the disease process.

Methods

Study Design: The qualitative phenomenological method was used to determine the experiences of parents of children with TM. The phenomenological approach provides an in-depth insight into the experiences of the participants (Speziale et al., 2011). The data obtained using this method were evaluated using Colaizzi's seven-step method for data analysis. This scientific approach ensures the authenticity and rigorous evaluation of the data in accordance with scientific standards (Colaizzi, 1978).

Settings and Participants: This study was carried out from February to March 2021 in the Thalassemia unit of a hospital in the province of Izmir in Turkey. The study population included 84 parents of children in with TM. Purposeful sampling was used, and 14 parents were interviewed before data saturation. In qualitative research, sample size is determined based on reaching data saturation. It has been recommended that the sample size should not too small to limit reaching saturation (Onwuegbuzie & Leech, 2007). It means that the saturation point is reached when there was no more new information in the interviews (Morse, 2015). In the Thalassemia Unit, where the data of the study were collected, there is an interview room and a large room where erythrocytes of children with TM are transfused. The inclusion criteria were: (1) volunteering to participate in the study, (2) being over 18 years old, (3) having no communication problems (visual, auditory or mental), (4) having a child who has been receiving care in Thalassemia Unit, and (5) speaking Turkish.

Data Collection: An introductory information form was used to determine the sociodemographic characteristics of the parents and children, and a semi-structured interview form was used to determine the parents' experiences.

The introductory information form: The form created by the researchers consists of questions about age, education, employment status, and the economic status of the family.

The semi-structured interview form: This form was prepared after a review of the literature (Shahraki-Vahed et al., 2017; Heidari et al., 2018; Heidari & Ahmadi, 2020; Abedi et al., 2020) and expert opinions about its suitability were obtained from ten experts. Corrections were made in line with their suggestions, and then a pilot study was carried out. Three parents were chosen from the study population for the pilot study, and they were excluded from the study sample. The interviews were carried out and the suitability and comprehensibility of the questions were evaluated with experts in the field.

Voice recorder: A Sony ICWDPX240.Ce7 voice recorder was used to record the interviews. It can record up to 32 hours (MP3 8kbps).

Semi-Structured Interview: The individual interviews with the parents who agreed to participate in the study took place in the patient meeting room of the unit to ensure a quiet and comfortable environment. The parents filled out the introductory information form prior to the interviews. Then, the interviews were carried out using the semi-structured interview form. The interviews were recorded with a voice recorder. The interviews were concluded when data saturation was achieved (when the participants' statements started to resemble each other). Each interview lasted 30-45 minutes.

Ethical Considerations: The study was approved by the medical local research ethics committee of Izmir Dr. Behçet Uz Pediatric Diseases and Surgery Training and Research Hospital (24.12.2020, decision number 239) of the hospital where the study was conducted. The names of the participants were kept confidential, and the nurses were identified with codes (P1, P2, P3…).

Data Analysis: The sociodemographic data were analyzed using SPPS 22.0 software. They are shown as numbers and percentages. Colaizzi's seven-step method was used for analyzing the data. In the first step, audio-recordings were saved. Each written transcript was read multiple times by both authors. In the second step, important statements about the experiences of the parents were determined from among transcripts. In the third step, significant expressions were formulated. In the fourth step, the formulated meanings reflecting experiences of the parents were grouped into clusters of three common themes. In the fifth step, the basic structure was defined for the experiences of parents. In the final step, the findings were confirmed by contacting the participants again (Colaizzi, 1978). MAXQDA was used for coding and creating themes.

Truthfulness: In qualitative research, the criteria used for ensuring the reliability of the research results are reliability, verifiability and transferability (Speziale et al., 2011). To ensure reliability, researchers read and classified the transcripts multiple times and independently. To increase the reliability of the data, the authenticity of the data was maintained. In addition, after the transcripts were created, the participants were interviewed again and they were asked whether there were any statements they wanted to add or remove. To ensure reliability, all transcripts were reviewed by an expert experienced in qualitative research and familiar with the subject of the study. The responses of the parents were conveyed in their original forms in order to ensure accuracy.

Results

The demographic characteristics of the parents: The descriptive characteristics of the parents are shown in Table 1. The mean age of the parents was 36.64±8.18 (min. 28; max. 56).

Content Analysis: In the study four themes were obtained, unprecedented psychosocial distress, social support, financial burden and concern about children in the future.

Theme 1: Unprecedented psychosocial distress: As caregivers to children with thalassemia, worries of various kinds permeated the interviews. There is evidence that the high clinical burden associated with regular treatment for a chronic disease is associated with a high psychosocial burden for the patients and the families. This theme consisted of the sub-themes of shock, sadness, fear, stress, depression, death anxiety, fatigue and burnout (Figure 1). Parents stated that they experienced "shock, sadness, fear, anxiety" when they first learned about their child's illness.

"My child F. was about a year old, he was getting very sick, sleeping all the time, not eating, vomiting. He was always sick. We went to the doctor, he said your son has Mediterranean Anemia. We were shocked there. I am very sad.. It is very difficult to explain… I cried all the time. I still cry whenever I think of it." (P4) In addition, a few of the parents said that they had "death anxiety" for their children when they learned about the disease. *"When I first learned about the disease, I was afraid, nervous, afraid that my child would die. I wish this disease didn't exist, who would want?..."* (P7).

Table 1. Sociodemographic characteristics of the parents

Descriptive characteristics	Number (n=14)	Percentage (%)
Where have you resided for most of your life (2/3)?		
Village	6	42.8
District	4	28.6
Province	4	28.6
Number of children		
1	6	42.9
2	5	35.7
3	2	14.3
4	1	7.1
Number of children with TM		
1	11	78.6
2	3	21.4
Maternal education level		
Literate	1	7.1
Primary School	12	85.7
High School	1	7.1
Paternal education level		
Literate	1	7.1
Primary School	9	64.3
High School	4	28.6
Income Status		
Income is less than expenses	9	64.3
Income is equal to expenses	3	21.4
Income is greater than expenses	2	14.3
Consanguineous marriage status		
Yes	4	28.6
No	10	71.4
Erythrocyte frequency in children		
1 in 3 weeks	5	35.7
1 in 4 weeks	9	64.3
Bone marrow transplantation for children		
Yes	9	64.3
No	5	35.7
Total	14	100.0

Figure 1. Unprecedented psychosocial distress code-subcode sections model

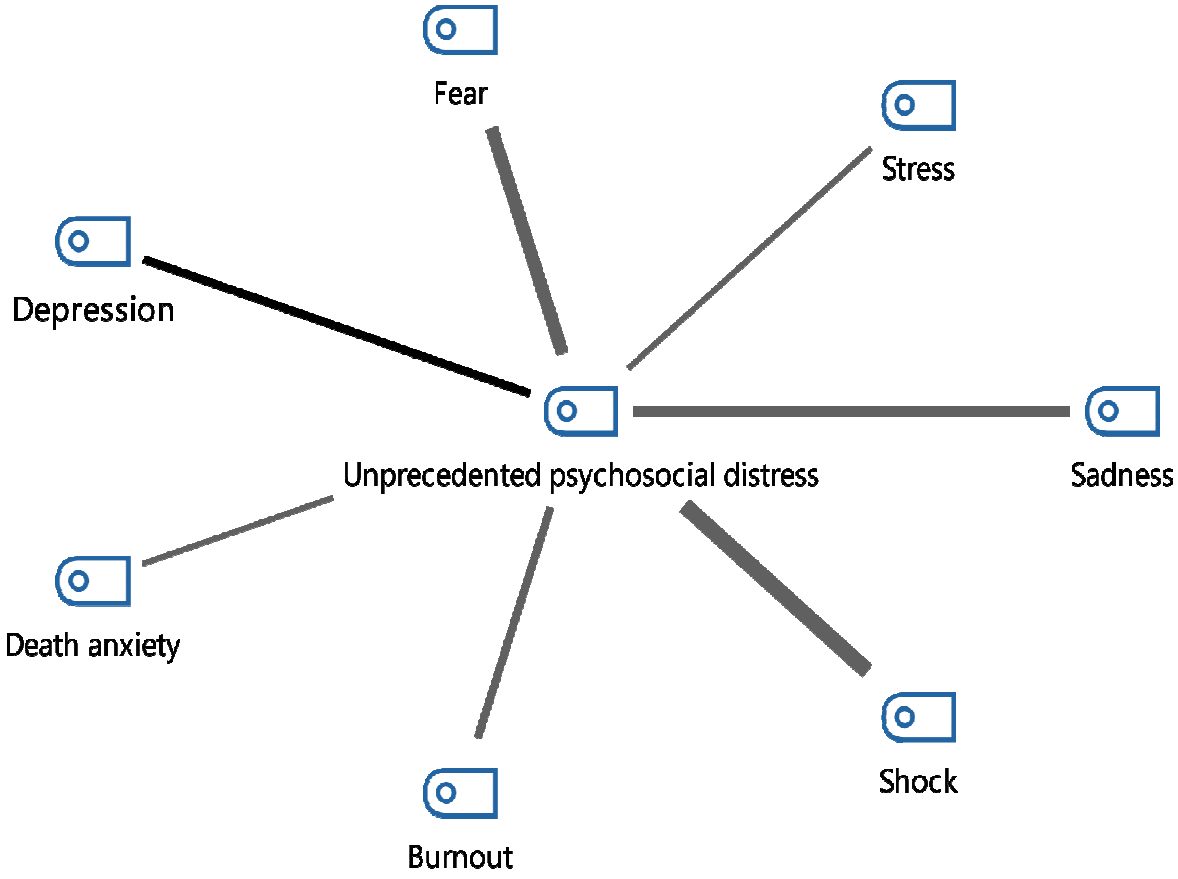


Figure 2. Social support code-subcode sections model

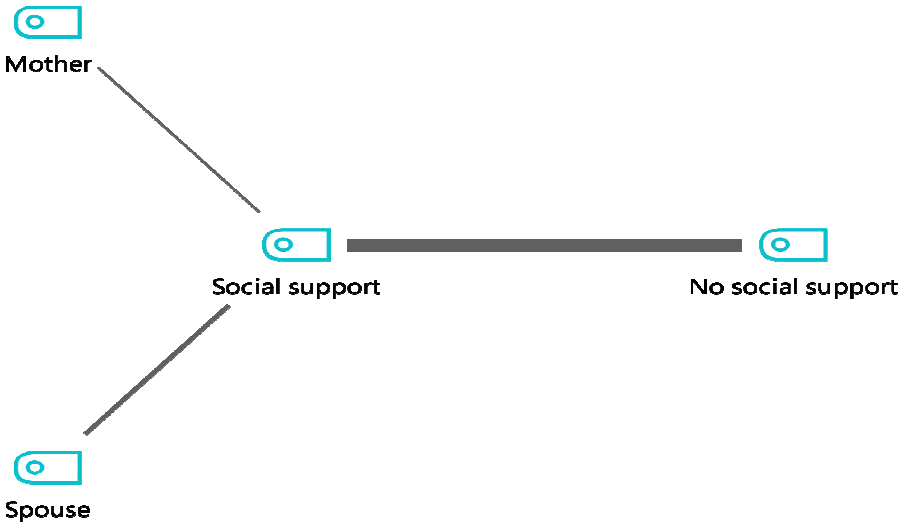


Figure 3. Financial burden code-subcode sections model

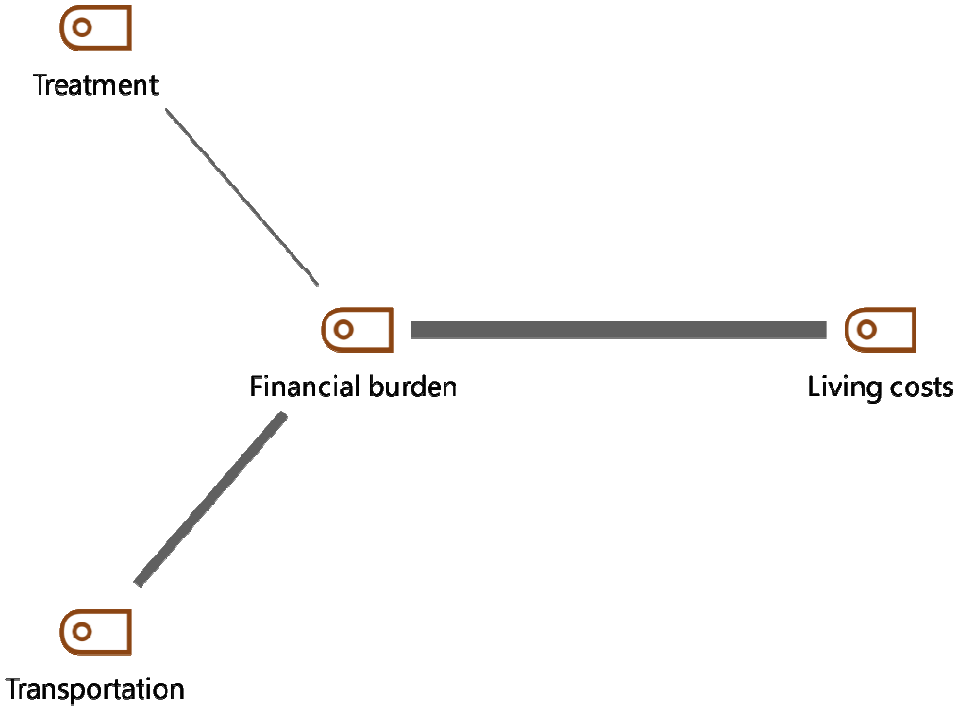
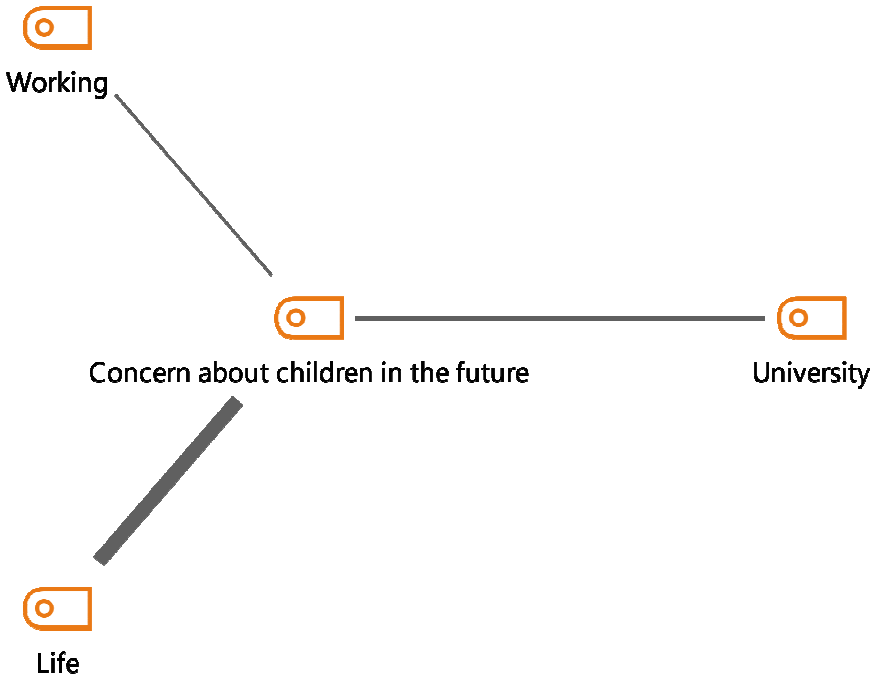


Figure 4. Concern about children in the future code-subcode sections model



One parent (who has two children with TM) stated that her child had psychological difficulties during the care process.

"We learned about my first child's illness in October 2017. He had been sleeping for the last month, they said, his blood was low. They were then discharged home…. Then we found out that he was a carrier. We had a test for my other child when the mother was pregnant, I learned with the gene test. We were very upset for a month. I stopped eating. We were very afraid of why it happened like this, we thought it was too bad, we were shocked." (P5). Another parent said, *"I take care of everything. I pay attention to his medicines, his food, everything. I tell you foods that contain iron, I warn you not to eat. For example, I never give grape molasses…"* (P8).

Six of the parents in the study stated that they experienced fear and anxiety due to the complications of the treatment process.

"If my child does not use his medication regularly, his iron becomes too high. I'm afraid that there will be other troubles. They (doctors) told us everything. I also researched on the internet…Unfortunately, some children are very similar to each other. I am very careful with everything so that it does not happen. I hope not…" (P11).

Another parent said, *"…we go to the hospital all the time, we thank God when we think of other diseases. But we are sorry for our child's illness, we try not to reflect it on him, we try to find a solution. Also we had a child again because of the bone marrow, but unfortunately he didn't either."* (P8).

Another parent who has a child with a diagnosis of older age TM stated that the burden of care for their two children decreases as the age of the child gets older.

"When my child was young, we had a hard time. My child was very scared and always crying when he stuck the needle while drawing blood. I was so sad at that moment... I was so worn out... It is very difficult to draw blood. I panic every time I go. I get stressed as if I can't draw blood. Fortunately, we were relieved when we grew up." (P10).

Parents stated that their concerns about their children increased due to COVID-19 and that they had difficulties in the care process.

"We were worried that we would get a disease from school, we do not send them to school either... We do not accept guests in the house so that the virus does not get infected. My children cried to go out. I have a very hard time convincing them about these issues. I didn't know what to do, I was helpless desperate, I was exhausted" (P9). However, one of the parents stated that she gave better care to her child because they stayed at home during the pandemic and that she was afraid because of the transmission of the COVID-19. *"It got better when I stayed at home because of the virus. I took better care of my child. We were just scared when we were coming and going to the hospital. Her immunity is already low, the environment is crowded... So I'm afraid."* (P14).

In addition with the emergence of COVID-19, there has been a decrease in the reserves of existing blood units in our country, as in many countries. Therefore, parents had difficulties in the process of erythrocyte transfusion of their children due to the decrease in blood reserves

"In the first days of the pandemic, our nurse called us before my child came to collect blood. He said that there may be a problem with the presence of blood in the hospital. For this reason, they asked us to bring someone who can give blood to our child. At that time, we had some trouble and stress in finding someone. How do we find someone? Nobody wants to come to the hospital, there is a virus. Where we live is very far from the hospital. Fortunately, we were able to find someone. But there was no need in the hospital, but we got nervous..." (P3).

Theme 2: Social support

Social support is an important component, especially psychosocial support. Respect for the individual and kind words are the basis for this support. It is important to feel this kind of support in the community (Figure 2). Some parents defined the people they receive social support from as "spouse and mother".

*"Sometimes I feel helpless, I feel tired. I do not even send my child to the street alone. I always walk behind him. My family… No one was with me, only my wife was with me…" (*P1). Another parent said, *"When my child was first born, I was working in the fields. We are farmers. After all, I couldn't take care of my child, I'm so sorry, I cry whenever I think about it. My biggest regret. My husband's mother did not take care of my child.*

That's why I had to take my child to the fields, my child grew up in bad conditions. I always blame myself... I wish I could have raised it better." (P2).

Especially with the COVID-19 epidemic in our country, parents stated that their lives became more difficult. *"I take care of everything for both of my children (mother). No one is supportive, they just ask if you went or came. In the pandemic, everything became more difficult."* (P9).

All of the mothers in the study stated that they control their children to take their medications regularly. In addition, fathers also stated that their wives are more interested in their children's medications.

"If I do not tell, my child does not use his medication regularly. Sometimes she goes to her friend, she goes to his aunt, but it may be that he forgot to buy it back then. Also, I get up before him every morning, I don't send him to school without taking his medicine…" (P5).

Theme 3: Financial burden

Financial difficulty due to loss of income and increased expenses related to treatment, transportation, and living costs during their children's admission to the hospital was the main cause of financial burden for these parents. This theme consisted of the sub-themes of treatment, transportation, and living costs (Figure 3). Parents who came from different cities for the treatment process of their children stated that they had economic difficulties especially related to transportation, treatment and care process and current expenditures at the hospital.

"We do not live in İzmir. We're here for my child's treatment. Both of my children have TM. We come to the hospital once every three weeks for one and once a month for the other. There is no one where I live or where I can leave my child. We all come and go together… We have to be here early in the morning. That's why we leave the house early (around 5 in the morning). Breakfast, lunch, dinner, we eat everything from outside. Sometimes I bring our groceries from home, but I can't always bring meals with two children. Travel money, food, expenses of the disease... We sold our car because of this disease. It made our lives more difficult to go to the hospital for four people all the time by bus." (P14).

Similarly, another parent said,

"When we get here, we get up at five in the morning. We come here by two buses. It is both costly and more tiring for us." (P3).

One of the parents said that when the children were young, they could not return home due to the long transfusion process. For this reason, he stated that from time to time, they have more economic difficulties due to the fact that they also have hotel expenses.

"We used to come to the hospital from afar. When my child's blood did not end, it was late, we could not catch the train. We had to stay in Izmir. Sometimes we stayed at the hotel and sometimes with our relatives. It was a very difficult day for us economically." (P12).

In addition some of the parents stated that they also have expenses such as food and beverage, as they spend a full day in the hospital. *"When we come here (to the hospital), we bring a lot of food. Because our economic situation is not good. Since we stay here all day… We come early in the morning and go late in the evening. So we have to bring something from home."* (P1).

Theme 4: Concern about children in the future

The treatment of thalassemia is very strenuous and causes suffering for both parents and children throughout the child's life. The major concern was the need for their children to be strong and healthy. This theme consisted of the sub-themes of life, university, and working (Figure 4). Most of the parents stated that they are worried about the health status of their child in the future.

"My child was two years old when we learned about the disease. We had not even heard of the name of the disease. We expected the disease to be worse, I wonder what will happen? I was worried if he would die or be disabled after a certain age." (P4).

Another parent said,

"We plan our whole life around our child. I am so afraid that something will happen to him. I am always stressed. When we get here, tests are done. That something bad will happen to them... That someone will say something bad to me... I'm afraid... I don't know how this feeling will go..." (P13).

Parents whose children are older stated that they have concerns about how to treat their children when they need to go to university in a different city.

"He goes to school, I think about him all the time. In case something happens to him. I'm afraid that something will happen. How will it be if he goes to university sometime in the future, how will he get blood, what will he eat. What do we do if he goes to a good University in a different city? Is there a place to take blood? So school is very important to us.…" (P10).

Similarly, one of the parents whose child was older had concerns about their child's future working life. *"So now how will my child work in the future, he cannot do heavy work. When he is working at a job, he will have to take a vacation every month to go to the hospital for his illness. I don't know how they will accept it, I feel anxiety when I think about them. He has to go to the hospital every month. For example, it is not an hour thing, my child has to be in the hospital all day…"* (P7).

Discussion

In this study, which was carried out to determine the experiences of the parents of the children with TM, about the disease process, four themes were obtained: unprecedented psychosocial distress, social support, financial burden and concern about children in the future. Parents face many psychological problems due to the care of their child 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. In our study, it was revealed that parents experienced feelings such as shock, sadness, fear, anxiety and depression, especially in the first period when the child was diagnosed with TM. It has been revealed that these feelings still continue in parents whose children are young. Hussain et al. (2021), in a study conducted in Pakistan, stated that parents with children younger than five years of age had higher depression and stress levels.

Therefore, if parents get tired of looking after their children (if they are psychologically burn out), if the necessary support system cannot be provided to solve their problems, it can negatively affect the quality of life of both themselves and the children with thalassemia. Shahraki-vahed et al. (2017), Shosha (2014), Ishfaq et al. (2015), Pourobili et al. (2018), emphasized that mothers with children with BTM need psychological and emotional support. Suggestions arising from this integrative review have been outlined to help develop a holistic nursing intervention to support parents and to promote the potential ability of parents to cope with their suffering successfully. 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

In this study, most of the parents mentioned that there is no one around who can provide social support. Some parents stated that they received support from their mothers or spouses. A parent, both of whose children were diagnosed with thalassemia, stated that they need social support because the treatment days are different and they must come to the hospital from a distant region. Heidari and Ahmadi (2020) found that that parents with children with thalassemia feel lonely. Raman et al. (2019), revealed that parents need social support.

Families of children living with thalassemia have their own wishes, such as promotion of the people's viewpoints, not attaching stigma to the family with a sick child, good social support of sick children and psychological comfort to the family so that the difficulty of having a sick child is facilitated and they are given the chance to have a pretty good life.

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 (Punaglom, Kongvattananon, & Somprasert, 2019). The socio-economic level of the parents in this study is low, and most of them come to the

hospital from different cities. Although the treatment of thalassemia is free and daily in our country, families must allocate a serious budget for transportation. In addition, children spend a day in the health unit for transfusion. Therefore, an additional budget should be allocated for nutrition. Considering that the economic situation of the parents in the study is not good, transportation costs and expenses during the day force the economic conditions of the families. In the study of Shosha (2014), Ishfaq et al. (2015), Inamdar et al. (2015) found that parents with children with thalassemia experience economic difficulties due to the treatment process and transportation to the hospital.

Shahraki-Vahed et al. (2017), Shosha and Al Kalaldeh (2017) stated that families with low income experience more problems related to transportation to the hospital, nutrition and regular follow-up. Children should come to the thalassemia unit in the morning to have the necessary tests done before the transfusion. Since they come from out of town, children eat their morning, noon and evening meals outside. In addition, the children stated that their parents had economic difficulties due to both transportation to the hospital and nutritional expenditures during the time spent in the hospital.

The results of the study are similar to the literature. The economic level of the parents also included in our study is low and they use public transportation to reach the hospital. This process makes it more difficult for children to reach the hospital. In this study, parents living in the same place as the hospital stated that they did not have any problems with transportation. So, the fact that the health institutions where thalassemia treatment is carried out are in all settlements will prevent families from experiencing economic difficulties due to situations such as transportation and nutrition. In our study, almost all the parents stated that they were worried about the future of their children. They stated that the situations that his children will encounter, such as the course of the disease, the treatment process, and the treatment options, cause them anxiety. Shosha (2014), Inamdar et al. (2015) stated that mothers experience anxiety and fear of death due to uncertainty about their future. It is very important to support parents psychosocially in order to eliminate their worries about the future and fear of death. Parents should be given accurate information about their children's health status and diseases by health professionals.

Study limitation: This study's findings will contribute to the Thalassemia literature, but it has some limitations. The study was conducted in a single center; therefore, it cannot be generalized. Generalizability to the overall population of parents of children with TM undergoing blood transfusion therapy in Turkey is limited by the participants' demographics and the study setting.

Conclusions: Thalassemia Major is a major public health problem which is a chronic illness causing burden on families. The results of the study revealed that the parents who have a child thalassemia experience several psychological problems, and large financial cost to health services. So they needs to benefit from consultative and supportive services of the health system. Therefore, it is necessary that the health system and healthcare staff be aware of consequences ahead of the parents with thalassemia and take vital actions to support them. They need to understand parents' psychosocial distress and coping strategies to provide support and guidance from the outset of treatment and care.

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