Received: 23 August 2022 | Revised: 29 November 2022 | Accepted: 5 February 2023

DOI: 10.1002/nop2.1649

NursingOpen Open Access WILEY

EMPIRICAL RESEARCH MIXED METHODS

Life satisfaction and difficulties experienced by the family members of individuals with thalassemia

Sibel Sevinç

Faculty of Health Science, Nursing Department, Hatay Mustafa Kemal University, Hatay, Turkey

Correspondence
Sibel Sevinç, Faculty of Health Science, Nursing Department, Hatay Mustafa Kemal University, Hatay, Turkey.
Email: sibelsevis@gmail.com

Abstract

Aim: This study aimed to examine the life satisfaction and difficulties experienced by the family members of individuals with thalassemia.

Design: This study design is mix-method research. This research adheres to the COREQ guidelines and checklist.

Methods: The research was conducted in the Blood Diseases Polyclinic of a state hospital in a Mediterranean city in Turkey between February 2022 and April 2022.

Results: The mean life satisfaction scale score was 11.18 ± 5.13, and a negative correlation was found between the mother's age and life satisfaction score ($r = -0.438$; $p = 0.042$, $p < 0.05$). Qualitative analysis of the experiences of the family members of individuals with thalassemia yielded 10 themes.

KEYWORDS
difficulties experienced, family members, individual with thalassemia, life satisfaction

1 | INTRODUCTION

Thalassemia is an autosomal recessive genetic blood disorder. When two carriers reproduce, there is a 50% chance that their offspring will be a carrier, a 25% chance that any offspring will have thalassemia, and a 25% chance that the children will be healthy. Individuals with thalassemia major need regular blood transfusions (Centers for Disease Control and Prevention, 2022; Taher et al., 2018; Viprakasit & Ekwattanakit, 2018). According to the Turkish Society of Haematology, although thalassemia is preventable through the detection of carriers, genetic counselling, and prenatal diagnosis, at least 365,000 thalassemia patients are born and treated annually worldwide. In Turkey, there are approximately 1.3 million thalassemia carriers and 4500 thalassemia patients. The disease is difficult and expensive to treat. The annual cost of treatment for a patient with thalassemia is around 10,000 $. It is therefore beneficial to prevent the birth of diseased individuals, with state support for the implementation of the necessary protective measures. In Turkey, the management of the disease is carried out in university hospitals, state hospitals and thalassemia centres. The blood required for the patients is obtained from the Turkish Red Crescent Society. Turkish Red Crescent is the largest humanitarian organization in Turkey and is part of the International Red Cross and Red Crescent Movement (Turkish Society of Hematology, 2022). Given the rigours of thalassemia treatment and care, the families of children with this disease, particularly primary caregivers, are often also affected. This effect may be greater if the family member is also a carrier or in households where there is more than one patient; life satisfaction may be affected. The determinants of life satisfaction are physical, social, emotional, mental health, psychological well-being, the ability to communicate functionally and effectively, initiation and maintenance of social relations and social connections (Prasoon & Chaturvedi, 2016).

Family and friends of persons with chronic diseases are affected in various ways (Lee et al., 2017; Zhang, 2018). In the context of thalassemia, there is a direct association between parents' and children's education and family income and the quality of life of children with

the disease (Thiyagarajan et al., 2019). Thalassemia affects the quality of life because families have to make sacrifices to accommodate it (Nagiria et al., 2021). Familial factors and social support also affect coping with thalassemia (Palanisamy et al., 2017). Families with children with thalassemia experience psychological stress that positive religious coping methods may ameliorate (Chong et al., 2019).

Studies involving the families of children with chronic diseases including thalassemia have been conducted, but none have addressed the life satisfaction and experiences of the family members of individuals with thalassemia. This study hopes to contribute to filling this gap in the literature, while also emphasizing the importance of preventing genetically inherited diseases. Also, findings can guide practices that can enhance the quality of care in thalassemia patients and increase the life satisfaction of patients' relatives, look at this process from a different perspective and consider it within the scope of solution proposals. Therefore, this study aimed to examine the life satisfaction and difficulties experienced by the family members of individuals with thalassemia.

2 | METHODS

2.1 | Study design

The mix-method research was conducted in the Blood Diseases Polyclinic (BDP) of a state hospital in a Mediterranean city with a high thalassemia patient population between February 2022 and April 2022. The study sample consisted of 22 family members of individuals with thalassemia major who met the research criteria and agreed to participate in the study. The family members of all the clinic's patients (Table 2) were included in the study. The study was carried out in a state hospital of a district in the Mediterranean region. Approximately 100 patients under and upper the age of 18, thalassemia major and minor, Syrian and Turkish nationals are registered in this polyclinic. Syrian participants were excluded from the study because they could not speak fluent Turkish.

Inclusion criteria were as follows: be a relative of a patient dependent on blood transfusion who attends the BDP and be 18 years of age or above without mental confusion, hearing, or speaking problems. Persons who did not meet these criteria, family members of thalassemia intermedia patients and relatives of Syrian patients were excluded from the study.

Data were collected in an activity room at the BDP. This research adheres to the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007).

Regarding instruments, this study adopted a questionnaire including socio-demographic and thalassemia-related items and open-ended questions about the difficulties families experience (Nagiria et al., 2021; Taher et al., 2018; Viprakasit & Ekwattanakit, 2018) and a life satisfaction scale. Before starting the research, participants were informed about the research purpose, and their verbal and written consent was obtained. The researcher administered the questionnaires. The semi-structured in-depth individual interviews were audio-recorded. The duration of each interview was 45–60 min. Two pilot interviews were conducted to test the questions before beginning the study, and two questions were added (Table 1).

2.2 | Life satisfaction scale

Dağlı and Baysal (2016) conducted a Turkish validity and reliability study of Diener et al.'s (1985) single-factor 5-item Satisfaction With Life Scale and concluded that a 5-point Likert-type Turkish version is suitable for Turkey's cultural context. In this study, responses were scored as follows: (1) I strongly disagree, (2) I agree a little, (3) I agree moderately, (4) I strongly agree, and (5) I agree completely. The higher the score, the higher the respondent's life satisfaction. The scale's Cronbach's alpha in this study was 0.88, in line with Dağlı and Baysal (2016).

2.3 | Data analysis

SPSS (Statistical Package for Social Sciences) for Windows 22.0 software was used in the data analysis. Percentages were used in the descriptive questions. During comparative data analysis, Mann–Whitney *U* test, Spearman correlation analysis and Cronbach's alpha internal consistency tests were used. The statistically significant level of the variables in the study was accepted as $p < 0.05$.

Open-ended questions were analysed via content analysis. In content analysis, which is one of the qualitative research methods, the data unit was determined as the answer given to each question. First, the researcher listened to and transcribed the audio-recordings of the interviews and then repeatedly perused the transcripts, selecting significant statements from the participants'

TABLE 1 Questionnaire items.

How did you find out about your relative's illness?
How did you feel when you learned that your relative has Mediterranean anaemia/thalassemia?
How did you acclimatize to your relative's illness? How would you describe the process of accepting the disease?
How does your relative's illness affect your relationship with your spouse and other children?
Do you receive support from people in your close circle regarding the treatment of your relative's illness? Which forms of support do you receive?
What difficulties do you face in terms of balancing personal care and the treatment of your relative's illness?
What concerns do you have about your relative's treatment?
How do you feel about your relative in light of their illness?
What feelings do you experience personally because of your relative's illness?
How do you socialize with other people or with other patients and their relatives?
Do you have any disease-related advice?

TABLE 2 Participants' profiles.

Participant no.	Age	Relationship to patient	Health status	Child patient M/F age	Child carrier M/F age	Healthy child M/F age	Relatives
1	43	Mother	C	F/18 (EX) F/17 M/7	F/23	—	None
2	47	Father	C	F/18 (EX) F/17 M/7	F/23		None
3	20	Sister	H	F/17	M/6	F/20	Third degree
4	38	Mother	C	M/12	—	M/18 M/15	First degree
5	61	Father	C	M/32	F/40	F/38	First degree
6	34	Father	C	F/11	—	F/5 F/4	Second degree
7	47	Father	C	F/24 M/18	M/26	—	First degree
8	54	Mother	C	F/36	M/26	M/32	None
9	27	Mother	C	F/12	F/10	F/4	None
10	59	Mother	C	F/26 F/24	—	—	First degree
11	43	Mother	C	F/17	M/21 F/11	—	None
12	53	Mother	C	M/24 (EX) F/24	F/21 M/18	—	Third degree
13	59	Mother	C	F/33 F/29	—	M/31	First degree
14	46	Father	C	F/17 F/15	F/11	—	None
15	37	Brother	P	F/39 M/37 F/35 M/33	—	—	None
16	29	Mother	C	M/9	M/11	M/2	None
17	22	Sister	P	F/22 M/21	M/20	—	First degree
18	42	Mother	C	F/22	F/23	—	First degree
19	31	Brother	P	M/31 F/28	F/15	—	First degree
20	64	Father	C	F/33	—	—	First degree
21	21	Brother	P	M/33 M/31	—	F/36	First degree
22	55	Father	C	M/26	—	—	First degree

Abbreviations: C, carrier; F, female; H, healthy; M, male; P, patient.

remarks. Software programs to code qualitative data were not used (Yıldırım & Şimşek, 2021).

2.4 | Trustworthiness

Lincoln and Guba proposed five criteria for qualitative researchers in pursuit of a trustworthy study: credibility (in reference to internal validity), transferability (in reference to external validity), defendability (in reference to reliability), confirmability (in reference to objectivity) and reflexivity (in reference to bias; Korstjens & Moser, 2018). The researcher verified the themes in this study accordingly to ensure the validity of the data analysis.

2.5 | Ethical considerations

Before commencing the study, the written permission of the hospital's management and the approval of the Clinical Research Ethics Committee were obtained. Before conducting the interviews, participants were informed about the aim of the study, their right to withdraw, as well as the procedures involved and that the interviews

would be audio-recorded. All subjects gave verbal and written consent prior to participation in the study.

3 | RESULTS

Participants mean age was 42.82 ± 12.97 (age range: 20–64); 54.5% were women, 54.5% were primary school graduates and 72.7% were unemployed. Of the participants, 45.5% were the mother of a thalassemia patient, 31.8% were fathers, 9.1% were sisters, 13.6% were brothers, and 63.6% were in consanguineous marriage. The mean age of the mothers of individuals with thalassemia was 47.09 ± 10.79 (age range: 27–65) and that of the fathers was 52.64 ± 11.54 (age range: 32–74). Participants mean age at marriage was 27.36 ± 9.45 (age range: 12–42), and for patients, the mean duration of treatment in years was 23.73 ± 8.67 (range: 9–39 years). Families included 1–4 individuals with thalassemia. Others participants' profiles are shown in Table 2.

Of the participants, 59.1% reported not having been tested for thalassemia before marriage, 81.8% were not informed about the disease, 68.2% were living far away from the BDP and 77.3% were living in the district before marriage. All participants who were parents were carriers, and all siblings, except one healthy sister, were sick.

The mean life satisfaction score was 11.18 ± 5.13 (range: 5–23 points). The Mann–Whitney *U* test showed no significant relationship between socio-demographic variables and disease characteristics and life satisfaction scores. Spearman correlation analysis found a negative correlation between the mother's age and life satisfaction score ($r = -0.438$; $p = 0.042$, $p < 0.05$).

Qualitative analysis of the experiences of the family members of individuals with thalassemia yielded 10 themes, which are shown in Table 3.

TABLE 3 Themes derived from the experiences of the family members of individuals with thalassemia.

Themes
1. Regret over missed opportunities to prevent the disease
2. Efforts to heal individuals with thalassemia
3. Difficulties with disease treatment
4. Accepting the disease
5. Patients' feelings and attitudes
6. Family members' feelings
7. Concerns about individuals with thalassemia
8. Familial emotional experiences
9. Social isolation
10. Awareness of the disease

3.1 | Regret over missed illness prevention opportunities

Older family members stated that they did not get tested for thalassemia when they got married. Some were married outside of the common law because they were under the age of 18 at the time. Some were tested. Some were informed of the opportunity of bearing ill offspring, but they did not understand the seriousness of the disease. Many couples were relatives. A study participant reported having wanted a premarital thalassemia test given that the betrothed couples were cousins, but the test could not identify thalassemia carriers. Participants who became parents regretted the missed opportunity to prevent a preventable disease. One such mother, who married before age 18, commented as follows:

> I got married at the age of 14, and my daughter was born when I was 15. I gave birth to my second child at the age of 17. After we got married (as common law), with "our parents' permission", they said that the test was done before marriage, and they told me that my children would be sick, and I said that I am already married, and I have children. I said I have two daughters, and they said you will take a test. If I had known this before, I wouldn't have entered this marriage. Absolutely not.
>
> (Participant 9)

Another mother expressed regret about her marriage:

> We were also tested, and we were carriers. It was not emphasized much; it was said rather lightly. You can get married. We are not relatives, and we thought that this only applies to people who are related. I was devastated. I have no hope of living. I thought that nothing would make me happy until now. There is bitterness in it; there is regret. Life has not been fair to us… If I knew; I would have convinced my husband somehow. We are the ones responsible; I blame myself a lot. "I feel guilty. I should have broken off the engagement. If I hadn't married… I promised, so I got married." I wish I hadn't married and had such a child.
>
> (Participant 11)

3.2 | Efforts to heal individuals with thalassemia

Most family members applied for admittance to larger hospitals that may heal the sick, changed their city of residence to facilitate the continuation of treatment or commuted to access treatment. Many reported marrow transplantation attempts and efforts to bring a sibling into the world via in vitro fertilization. However, they also reported anxiety due to other transplant patients' experiences. Some were waiting for marrow, and others had given up. A father recounted a conversation he had with a physician as follows:

> They said let's do a bone marrow transplant. We took his brothers; he was an 89% match with his brother. I said, "Doctor, give me a percentage. What is the percentage likelihood that this child will recover?" He said that he will either recover or die. Then I said I would not have it done. I said, "I will take this child to get her treatment once a month." I said, "I can't risk it." I didn't risk it.
>
> (Participant 5)

A mother also opted not to take the risk:

> I'm afraid because friends lost their children, so I was very impressed. I said that it is not under the ground, at least with me, no matter how old it is, I am willing to bring it and take it away, so I can't afford a marrow transplant.
>
> (Participant 16)

3.3 | Difficulties with disease treatment

Although the BDP dispenses blood in an orderly manner, provides iron-chelation drugs and check-ups free of charge, receives social support from the state and reports a high satisfaction rate, all family members reported experiencing difficulties in the course of disease treatment in various dimensions. Transportation problems were reported among patients without a vehicle residing 30–40 km away from the transfusion centre. Financial difficulties were also reported. Additionally, because there is no haematologist at the BDP, patients and their family members must visit hospitals in larger cities for medication reports and annual check-ups, which is both expensive and physically taxing. Difficulties finding blood in the early days of the novel coronavirus (COVID-19) pandemic and during Ramadan were reported, although the latter phenomenon is a yearly challenge. Family members also reported having to ask persons outside the family for blood given that most relatives are thalassemia carriers. To compound the aforementioned issues, working fathers reported taking time off from work on transfusion days as another challenge. The following is a remark from a working father who lives 40 km away from the BDP:

> Financial burden, of course. When we didn't have a vehicle, we were getting off the minibus and getting on the minibus, so we were changing vehicles three times. We were going from this minibus to that minibus––it was very difficult on the roads until evening prayer time, until he went home.
>
> (Participant 2)

Another father discussed his difficulties finding blood as follows:

> We were stressed a week ago about whether we would be able to find blood and from whom we would get it because AB+ is a rare blood type. If you want to borrow money from someone or you want goods or to a borrow a car, you will return those things, but it is very difficult to ask for blood. I have lived with the discomfort of having to ask my friends for blood for years. I'm a carrier, so I can't give it, and my blood type isn't the same. At first, I kept a stash of my brother's blood because his blood type was a match. I also had an uncle, who had a friend at work with the right blood type, but it would have been very difficult for him to ask for it, but I would say, "You have no other choice. You will do this. You will find this blood. You have to find it."
>
> (Participant 5)

The following is a statement from a mother who experienced both blood supply and financial difficulties in the early stages of the disease:

> If you find the blood, you can't find the money. If you find the money, you can't find the blood. We went to the big city because someone offered my husband a loan to pay for the treatment. We got out of the car and asked for the money. We were hospitalized for 15 days, and I wondered where I would find the money. I had some earrings, so I sold them and paid that money.
>
> (Participant 12)

3.4 | Accepting the disease

After the initial shock of diagnosis, most family members accepted the disease when they saw patients in worse condition, especially in big hospitals undergoing ongoing treatment. They viewed this experience as a test; from the perspective of the Islam religion, God was testing his beloved servants. A brother who is ill himself compared thalassemia with sickle cell anaemia:

> Thank God, we are fine. We draw blood and move on with our lives. Sicklers (people with sickle cell anemia) have more difficult pains in life. For example, they do not look like people with thalassemia do; they look normal, at least, close to 90% of them. But they have more troublesome and painful crises. I have friends with thalassemia who cannot complete their development because of a damaged jaw or difficulty walking. Thankfully, we are fine. One of us has a little problem with our complexion, but..., we do not have any other problems.
>
> (Participant 15)

Another FM who is a mother reported initially having difficulty accepting the disease until she saw a patient in worse condition than her child:

> It was very difficult for me to accept it. I always saw her dead in my dreams. My frame of mind is not good right now. For example, she dresses up and goes to the market, but there are those who can't do that. I'm grateful when I see them. I say, "What if it was worse?" I see different patients in the metropolitan area.
>
> (Participant 18)

3.5 | Patients' feelings and attitudes

Family members were asked how the patients felt about them. A few said that their children blamed them for their illness, while the majority reported that their children revealed nothing about the issue. A mother whose two daughters are sick stated that each daughter has different feelings and a different attitude toward her:

> The older girl is moderate, but the younger girl is reactive. She says, "Don't go there." She says, "We bear the burden of your husband." She says "Don't come near us from now on. Don't interfere with us. Don't burden me your fears." My little girl is very logical, but my older daughter is emotional. My older daughter says, "Okay, Mom. It's not your fault. Let's look at the future, not the past." My little girl puts up a fight; she says that a day does not pass by without crying and pitying. She says, "Leave me alone."
>
> (Participant 10)

Another mother stated that her daughter does not blame her; on the contrary, she tries to console her:

> She never blamed us. She says, "It's destiny," Mother; it will happen. She says, "Don't we live to die one day anyway?" She doesn't want me to cry in any way. She doesn't take anything into account, so her life is empty. Whether it happens or not, it happens. She doesn't care about anything; she says we're going to die anyway. She seems to have no purpose in life. Maybe she is embittered. I don't know. She is hiding something inside.
>
> (Participant 11)

A mother who has a sick adult daughter (over age 18) reported that her daughter is capable of independently deciding whether to get a marrow transplant and that her feelings toward her are unknown:

> She says, "I am suffering." She says, "Either I will be fine, or I will die." Her eyes have darkened. Yes, she is fed up. We are waiting for news and hoping for good luck about the marrow. She doesn't express herself; she keeps everything inside. I realize there is a problem. She doesn't say, but I know. I know she lives inside herself, and this makes me very sad. I tell my daughter to share her problems, but she doesn't. I wake up at night and hear her crying a lot; she doesn't say…
>
> (Participant 18)

3.6 | Family members' feelings

Family members were asked to describe their feelings. Parents had different feelings than siblings. Most reported being exhausted, having immense love and pity for their sick relative, feeling embarrassed about their role in the illness and having a very strong desire for their relative to recover. They also reported recurrent sadness but noted that they always feel obligated to appear happy and strong in front of the sick individual. Parents who lost a child expressed much deeper feelings and also reported experiencing situations in which they were hurt due to the influence of their social environment. A healthy sister remarked as follows:

> I mean, since we grew up together, we had everything in common, good and bad, everything… I think there is a very different bond between us, me and her… 25% probability… I'm not a carrier or anything, so I feel weird. I don't know if I could get over it as easily if I were in her place. I don't know if I could stand up straight. I guess I would make it harder for myself, go to the hospital or something… She is handling it really well, so I really admire her for that.
>
> (Participant 3)

A mother who lost her 24-year-old son to thalassemia described her feelings as follows:

> They call it the little apocalypse or something like that. You were telling me not to go anywhere. I yelled about where you went to leave me. I didn't talk to any one for three days; I just prayed. Then, my uncle said, "He will die anyway. Why are you spending money and sending him to university?" (The deceased was attending university.) Well, he wanted to go, so he went. I'm so sorry for how he told me that. I was so burned out. Good thing he's gone.
>
> (Participant 12)

A sick sibling made the following comment about their feelings during childhood:

> You can choose the lemon in the orange crate, right? I was such a remarkable person and that made me very sad at that time… I see that little boy walking next to his mother and father with a mask, and people are looking at him carefully; you know, what happened, we can't go out without a mask now. I think it's like that. İt is necessary to think about that child's psyche. We are living the sin of those children. Look, everyone is wearing masks now.
>
> (Participant 15)

A father described always trying to be strong for his child:

> Volcanoes are erupting inside us, but what are you going to do? There is a feeling of guilt toward the child, and there is no future. We are concerned about how peaceful we can make this child's life. Sometimes, I don't want anyone to see my devastation. I have a wife who I am responsible for; if you have a child, you are responsible for him.
>
> (Participant 22)

3.7 | Concerns about individuals with thalassemia

Family members experience anxiety about securing a reliable blood supply in the future, as well as about individuals with thalassemia finding employment and making a living and being able to get married. They reported having concerns about death and stated that this anxiety intensified during the COVID-19 pandemic. Parents also worry about what their children's lives will be like after they die. A mother reported getting up at night to check on her daughter:

> I'm worried about something happening to her while she's sleeping. I wonder if something will happen (crying).
>
> (Participant 8)

Another family member expressed her concerns about her sick relative's future:

> I am so worried about finding a blood donor. Will there be a miracle? Will there be a cure for this disease? She graduated; will she find a job?
>
> (Participant 10)

Another mother expressed concern about her child's illness taking a negative turn:

> Is something going to happen on the way to the hospital while taking medicine? They say that even when he is taking blood, if it goes too far, his heart may stop. Since corona is out, we are more afraid.
>
> (Participant 16)

A father expressed concern about his daughter's illness and whether she would find a husband who would accept her condition:

> For example, will she want to get married? Will the man she marries accept her with her illness? Will there be good developments in the future? Will she get a bone marrow transplant and get rid of this disease?
>
> (Participant 6)

3.8 | Familial emotional experiences

Family members reported that the entire family is affected by one member's illness. However, the illness is not generally discussed within the family unit. Rather, the sick individual is treated normally, but all family members pay more attention to them. Family members also reported that parents who lost a child were greatly affected and that siblings had a particular emotional burden because of their status as bone marrow transplant candidates. One father stated:

> The little boy knows that he will give marrow. He says, "I will save a life." They are in love with each other. The doctor advised us to terminate the last pregnancy. I cannot deny what God gave; the carrier was born. Now, he will give his brother marrow.
>
> (Participant 14)

A mother who lost her 18 year-old-daughter to thalassemia described how her other daughter, who also has thalassemia, was affected by the death:

> Now, the girl in the house fears that that the same thing that happened to my other daughter will happen to her sister. She's also very introverted. Is it because she thinks she will be like her sister? If you could only have seen her at that funeral (crying). About her future, her father says she should go to university, but she says, "I can't study. Give me my university money, so I can travel around."
>
> (Participant 1)

Another mother who has an irresponsible husband and a daughter with thalassemia and who also lost her 24-year-old son to the disease commented as follows:

> My husband came to his senses after burying his child; it means nothing me. My other son wonder what we

> will do if my daughter (his sick sister) dies like her brother. Children's psyche is upside down. Everyone is trying to support one another. My youngest son visited the cemetery for six months. He started to see the water he spilled (from his eyes) as his brother's tears; I don't send him anymore. Everyone is trying to appear strong for each other. My deceased son was very fond of his brother, who is now studying at university. He used to call his brother his savior because he was going to give him a bone marrow transplant. When he died, he gave his last water (crying).
>
> (Participant 12)

3.9 | Social isolation

Family members were asked whether they had a social group where they could share their experiences and feelings with other patients and their relatives. Most reported experiencing the disease within their family unit and stated that they very rarely share it with anyone outside the family, including other patients. One mother said that she only interacts with other patients and their relatives when they meet at the hospital:

> There are a few people we meet, but we don't always see each other. We talk when we come across each other, like at a marrow transplant or spleen surgery. She didn't make any friends. There was a group here to donate blood, and she passed away. She had sickle cell; she used to support us. She was trying to hold the group together. Now, no one is talking to anyone.
>
> (Participant 11)

A sick sibling described a similar situation:

> There are no social groups. They say, "Why forms a group when the patients' mental health is not good?" We don't want to remember much, like that we are sick. There are people who speak unconsciously. Everyone seems to be about to explode. Everyone's psyche is broken. We talk when we meet here, but nothing more.
>
> (Participant 15)

A mother reported feeling misunderstood and not wanting to talk about her emotions and her child's illness, even within the family:

> No matter how close she is, she listens and gets bored somewhere and simplifies what she is going through. For example, I got away from the environment, and when my closest sister-in-law called me for tea, if my daughter said come home, I wouldn't drink that tea so as not to stress her out. We isolated ourselves from everything so that we could care for them, so that they wouldn't get infected, so that they could relax at home.
>
> (Participant 10)

3.10 | Awareness of the disease

One family member undertook a personal mission to inform everyone about the disease and how it changes lives, but many persons who are trying to raise awareness of thalassemia have reported that they are still not taken very seriously and that it is necessary to draw more attention to the disease with support from the state.

> Everyone should learn (about thalassemia) so that sick children are not born. Is there still a sick child? It's hard for me. I am extremely sad. This disease was unknown in the past, but now we know that more people should be given booklets about it; everyone should be informed. Screening should be done in schools. This disease should not spread anymore. It is thought that if the parents are not related, a healthy child will be born, but we (my spouse and I) are not related. Even though I suffer, my child suffers more than I do.
>
> (Participant 11)

Another family member explained that thalassemia burdens both the family and the state and should be prevented:

> We say that nobody understands if it hasn't happened to them. The law passes, and they have to get a test before they get married, so the state does not break the marriage. The disease is a burden on everyone: mother, father, the state––and the state pays for the medicine for the sick person's lifetime. Men will say that they have to leave women who they will have sick children with, even if they love them like crazy.
>
> (Participant 20)

4 | DISCUSSION

About half of the study participants were mothers, and more than half were in a consanguineous marriage and had been receiving treatment for an average of 23 years. Most had not been tested and informed about the disease before marriage and were residing far away from the BDP. Aydınok et al. (2018) examined the profiles of individuals with thalassemia in Turkey and found that the patient profile in Turkey is similar to the usual profile.

In this study, life satisfaction scores were low, and life satisfaction was not affected by socio-demographic variables and disease characteristics. George-Levi and Laslo-Roth (2021) found that mothers of children with developmental disabilities had low life satisfaction.

Mothers of ill children were also found to have higher levels of anxiety about the future than fathers of ill children and the parents of disease-free children (Bujnowska et al., 2019). Wang et al. (2020) found that the life satisfaction of mothers of children with cerebral palsy could be improved through the support of family and friends. In the present study, life satisfaction was low regardless of all variables. The difference can be explained by the fact that thalassemia treatment is difficult and laborious.

As thalassemia patients' mothers' age increased, life satisfaction scores decreased. Distress, anxiety, depression, grief and loss were negatively associated with caregivers' hope, while there was a positive association with caregivers' mental and physical health, hope for the patient's recovery and self-efficacy. Hope was also associated with caregivers' coping strategies (Duggleby et al., 2021). Similarly, this study showed that fatigue increased with age, which, in turn, affected life satisfaction, as mothers became more exhausted by the treatment process with time.

Ten themes were derived from the participants' comments. The first was regret over missed opportunities to prevent the disease. In addition to premarital unawareness of the disease, most couples were consanguineous and therefore more likely to encounter a carrier partner. According to Angastiniotis et al. (2021), religious and cultural factors and population unawareness impact genetic prevention. Autosomal recessive disease is associated with consanguineous marriage. Boardman and Hale (2019) indicated that a key barrier affecting the uptake genetic risk is the lack of family history of genetic disease. This study showed that although premarital testing is mandatory, especially in the region where the research was conducted, the measure does not prevent the birth of sick children for various reasons, which triggers parents' regret.

Participants made efforts to heal their sick relatives. Kazancı et al. (2017) found that pre-implantation treatment and genetic diagnosis were cost-effective alternatives compared to the expenses thalassemia patients incur. When patients and their family members' labour loss and the disease's psycho-social dimension are added to these expenditures, the burden on the country's economy increases. Erman and Aksoy (2020) investigated lymphoid reconstitution in paediatric thalassemia patients after stem cell transplantation and found that all patients were alive and blood transfusion independent 1 year after the transplant. Despite these results, patients should be followed-up carefully due to the severe infection risk (Taher et al., 2018). In this study, although the only cure for the disease is transplantation from a suitable donor, participants did not want to take the risk. We recommend evaluating patients' transplantation eligibility at a younger age, increasing marrow donation and allocating more resources to transplantation.

All study participants experienced a range of difficulties similar to those of thalassemia patients and their relatives in other countries (Nagiria et al., 2021; Palanisamy et al., 2017; Souliotis et al., 2020). Given that the present study was conducted in a Muslim country, participants experienced additional difficulties with the blood supply in the holy month of Ramadan when blood donation is prohibited. This discrepancy can be explained by differing religious beliefs.

All participants accepted the disease when they saw patients in worse condition. Chong et al. (2019) highlighted the importance of religious practices and stress-coping strategies for the parents of children with thalassemia. Spirituality eases acceptance of the disease and allows people to become accustomed to it over time. Furthermore, patients' quality of life is affected by socio-demographic variables (Adam, 2019; Foong et al., 2022). Patients' reactions differed according to their personality traits, the effects of the disease, and socio-demographic variables.

Participating family members experienced anxiety and a spectrum of emotions. Thiyagarajan et al. (2019) found that children's and parent's education and family income impacted the quality of life of children with thalassemia. In Papua New Guinea parents were concerned about the prognosis of the disease, the unavailability of iron-chelating drugs, a reliable blood supply, the financial burden of the disease, and their child's appearance (Nagiria et al., 2021). In the present study, participants had similar concerns and feelings. Moreover, it was reported that the disease affects each family member differently. Studies conducted in other countries found that patients and their relatives experienced disease-related social stigma (Hossain et al., 2021; Nagiria et al., 2021). This study's results are similar. This can be explained by people's preference for internalizing the disease to avoid contemplating patients who lost their lives; many do not enjoy conversation on the subject in their social environment due to the depth of their sorrow and because they are afraid of the stigma.

This study's participants wanted to increase thalassemia awareness. Successful prevention of thalassemia, especially by reducing the birth of new patients, is cost-effective (Hashim et al., 2018; Hossain et al., 2017, 2021; Shahzad et al., 2017). A Malaysian study recommended enhanced preventive strategies and suggested that health providers plan cost-efficient services (Ibrahim et al., 2020) similarly; this study associated the sensitivity of persons whose whole lives have been affected by thalassemia to the difficulties they experience during the course of treatment.

5 | LIMITATIONS

The research results are subjective to the relatives of the one Blood Diseases Polyclinic (BDP) of a state hospital. They cannot be generalized to all thalassemia and their relatives.

6 | CONCLUSIONS

Based on the research findings, it is important to increase the prevalence of premarital testing and screening during pregnancy, provide genetic counselling post-test and for couples in consanguineous marriages, and emphasize the severity of the disease. More public resources should be allocated to solve transportation problems, recruit and retain specialized physicians, etc.

7 | RELEVANCE TO CLINICAL PRACTICE

Increasing awareness of marrow and blood donation as well as increasing the number of patients and their relatives who want to be included in social groups related to the disease, especially with the involvement of health professionals such as nurse psychologists and social workers are also recommended measures. Individuals with thalassemia and their relatives can be included in activities to increase awareness about the disease. Internal medicine and haematology clinic nurses should consider these results in the practice of disease management; the research findings can inform training, planning, and the approach to patients and their relatives, and these approaches can enhance the life satisfaction of patients' relatives.

ACKNOWLEDGEMENTS

The author would like to thank all participants for sharing their experiences. Gratitude is also due to Nurses Serpil Tıraşcı Kondakcı and Ayşe Durna for their support during data collection. We would like to thank Editage (www.editage.com) for English language editing. In memory of my father and my grieving process.

FUNDING INFORMATION

This research was conducted and written without support or funding from any commercial organization.

CONFLICT OF INTEREST STATEMENT

The author declares no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICAL APPROVAL

Prior to the study, we obtained written permission from the faculty administration and approval (13.01.2022/1-25) from the Hatay Mustafa Kemal University Medical Faculty clinical research ethics committee.

ORCID

Sibel Sevinç https://orcid.org/0000-0001-9757-3259

REFERENCES

Adam, S. (2019). Quality of life outcomes in thalassaemia patients in Saudi Arabia: A cross-sectional study. *Eastern Mediterranean Health Journal*, *25*(12), 887–895. https://doi.org/10.26719/2019.25.12.887

Angastiniotis, M., Petrou, M., Loukopoulos, D., Modell, B., Farmakis, D., Englezos, P., & Eleftheriou, A. (2021). The prevention of thalassemia revisited: A historical and ethical perspective by the thalassemia international federation. *Hemoglobin*, *45*(1), 5–12. https://doi.org/10.1080/03630269.2021.1872612

Aydınok, Y., Oymak, Y., Atabay, B., Aydoğan, G., Yeşilipek, A., & Ünal, S. (2018). Türkiye ulusal talasemi kaydı: hastaların demografik ve hastalık özellikleri, kontrol programının başarısı ve sorunları [A national registry of thalassemia in Turkey: Demographic and disease characteristics of patients, achievements, and challenges in prevention]. *Turkish Journal of Hematology*, *35*, 12–18. https://doi.org/10.4274/tjh.2017.0039

Boardman, F. K., & Hale, R. (2019). "I didn't take it too seriously because I'd just never heard of it": Experiential knowledge and genetic screening for thalassaemia in the UK. *Journal of Genetic Counseling*, *28*, 141–154. https://doi.org/10.1002/jgc4.1042

Bujnowska, A. M., Rodríguez, C., García, T., Areces, D., & Marsh, N. V. (2019). Parenting and future anxiety: The impact of having a child with developmental disabilities. *International Journal of Environmental Research and Public Health*, *16*, 668. https://doi.org/10.3390/ijerph16040668

Centers for Disease Control and Prevention. (2022). *Thalassemia*. https://www.cdc.gov/ncbddd/thalassemia/facts.html

Chong, L. T., Chong, M. C., Tang, L. Y., Ramoo, V., Chui, P. L., & Hmwe, N. T. T. (2019). The relationship between psychological distress and religious practices and coping in Malaysian parents of children with thalassemia. *Journal of Pediatric Nursing*, *48*, e15–e20. https://doi.org/10.1016/j.pedn.2019.05.016

Dağlı, A., & Baysal, N. (2016). Yaşam doyumu ölçeğinin türkçe'ye uyarlanması: geçerlik ve güvenirlik çalışması [Adaptation of the satisfaction with life scale into Turkish: A study of validity and reliability]. *Elektronik Sosyal Bilimler Dergisi [Electronic Journal of Social Sciences]*, *15*(59), 1250–1262. https://doi.org/10.17755/esosder.75955

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assesment*, *49*(1), 71–75. https://doi.org/10.3390/ijerph16040668

Duggleby, W., Lee, H., Nekolaichuk, C., & Fitzpatrick-Lewis, D. (2021). Systematic review of factors associated with hope in family carers of persons living with chronic illness. *Journal of Advanced Nursing*, *77*, 3343–3360. https://doi.org/10.1111/jan.14858

Erman, B., & Aksoy, B. A. (2020). Talasemi majör hastalarında kök hücre transplantasyonu sonrası ımmün yeniden yapılanmanın değerlendirilmesi [Immune reconstitution in patients with thalassemia major after hematopoietic stem cell transplantation]. *Turkish Journal of Immunology*, *8*(3), 113–119. https://doi.org/10.25002/tji.2020.1238

Foong, W. C., Chean, K. Y., Rahim, F. F., Goh, A. S., Yeoh, S. L., & Yeoh, A. A. C. (2022). Quality of life and challenges experienced by the surviving adults with transfusion dependent thalassaemia in Malaysia: A cross sectional study. *Health and Quality of Life Outcomes*, *20*, 2. https://doi.org/10.1186/s12955-021-01897-4

George-Levi, S., & Laslo-Roth, R. (2021). Entitlement, hope, and life satisfaction among mothers of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, *51*, 3818–3828. https://doi.org/10.1007/s10803-020-04832-6

Hashim, S., Sarwar, M., Arsalan, A., Awan, I., & Naseem, S. (2018). Frequency of carrier screening and preventive orientation among first degree relatives of thalassaemia patients. *Journal of the Pakistan Medical Association*, *68*(1), 50–54.

Hossain, M. S., Hasan, M., Petrou, M., Telfer, P., & Mosabbir, A. A. (2021). The parental perspective of thalassaemia in Bangladesh: Lack of knowledge, regret, and barriers. *Orphanet Journal of Rare Diseases*, *16*, 315. https://doi.org/10.1186/s13023-021-01947-6

Hossain, M. S., Raheem, E., Sultana, T. A., Ferdous, S., Nahar, N., Islam, S., Arifuzzaman, M., Razzaque, M. A., Alam, R., Aziz, S., Khatun, H., Rahim, A., & Morshed, M. (2017). Thalassemias in South Asia: Clinical lessons learnt from Bangladesh. *Orphanet Journal of Rare Diseases*, *12*, 93. https://doi.org/10.1186/s13023-017-0643-z

Ibrahim, H. M., Muda, Z., Othman, I. S., Unni, M. N. M., The, K. H., Thevarajah, A., Gunasagaran, K., Ong, G. B., Yeoh, S. L., Rivai, A. M., Razali, C. H. C. M., Din, N. D., Latiff, Z. A., Jamal, R., Mohamad, N., Ariffin, H. M., & Alias, H. (2020). Observational study on the current status of thalassaemia in Malaysia: A report from the

Malaysian Thalassaemia registry. *BMJ Open*, *10*, e037974. https://doi.org/10.1136/bmjopen-2020-037974

Kazancı, E. G., Bektemür, G., Bener, S., & Beylik, U. (2017). Talasemi hastalığında preimplantasyon genetik tanı ve tedavisinin geri ödeme kapsamına alınmasının değerlendirilmesi [Evaluation of preimplantation genetic diagnosis and treatment (PGDT) reimbursement scheme for thalassemia]. *Health Care Academician Journal*, *4*(3), 135–146. https://doi.org/10.5455/sad.13-1508401717

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *The European Journal of General Practice*, *24*(1), 120–124. https://doi.org/10.1080/13814788.2017.1375092

Lee, A. A., Piette, J. D., Heisler, M., Janevic, M. R., Langa, K. M., & Rosland, A.-M. (2017). Family members' experiences supporting adults with chronic illness: A national survey. *Families, Systems & Health*, *35*(4), 463–473. https://doi.org/10.1037/fsh0000293

Nagiria, V. R., Vince, J. D., & Duke, T. (2021). Living with thalassaemia in Papua New Guinea: The experience of children, adolescents and their families. *Journal of Paediatrics and Child Health*, *57*, 1589–1593. https://doi.org/10.1111/jpc.15538

Palanisamy, B., Kosalram, K., & Gopichandran, V. (2017). Dimensions of social capital of families with thalassemia in an indigenous population in Tamil Nadu, India – A qualitative study. *International Journal for Equity in Health*, *16*, 109. https://doi.org/10.1186/s12939-017-0609-8

Prasoon, R., & Chaturvedi, K. R. (2016). Life satisfaction: A literature review. *International Journal of Management Humanities and Social Sciences*, *1*(2), 25–32.

Shahzad, A., Rafiq, N., Ullah, I., Asad, M. J., Ahmad, M. S., & Waheed, U. (2017). Knowledge, attitude and practices (KAP) of the families of β-thalassaemia children in thalassaemia centers of Rawalpindi and Islamabad. *Journal of the Pakistan Medical Association*, *67*(9), 1434–1437.

Souliotis, K., Golna, C., Nikolaidi, S., Vatheia, G., & Hasurdjiev, S. (2020). Access to health care for patients with thalassaemia in Greece: A cross-sectional study. *Eastern Mediterranean Health Journal*, *26*(12), 1482–1492. https://doi.org/10.26719/emhj.20.118

Taher, A. T., Weatherall, D. J., & Cappellini, M. D. (2018). Thalassaemia. *Lancet*, *391*, 155–167. https://doi.org/10.1016/S0140-6736(17)31822-6

Thiyagarajan, A., Bagavandas, M., & Kosalram, K. (2019). Assessing the role of family well-being on the quality of life of Indian children with thalassemia. *BMC Pediatrics*, *19*, 100. https://doi.org/10.1186/s12887-019-1466-y

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Turkish Society of Hematology. (2022). *'Turkish Society of Hematology' Beta thalassemia carriage and disease*. http://www.thd.org.tr/thd_halk/?sayfa=akdeniz_anemisi#a1

Viprakasit, V., & Ekwattanakit, S. (2018). Clinical classification, screening and diagnosis for thalassemia. *Hematology/Oncology Clinics of North America*, *32*, 193–211. https://doi.org/10.1016/j.hoc.2017.11.006

Wang, Y., Huang, Z., & Kong, F. (2020). Parenting stress and life satisfaction in mothers of children with cerebral palsy: The mediating effect of social support. *Journal of Health Psychology*, *25*(3), 416–425. https://doi.org/10.1177/1359105317739100

Yıldırım, A., & Şimşek, H. (2021). *Sosyal bilimlerde nitel araştırma yöntemleri [Qualitative research methods in social sciences]*. Seçkin Yayıncılık.

Zhang, Y. (2018). Family functioning in the context of an adult family member with illness: A concept analysis. *Journal of Clinical Nursing*, *27*, 3205–3224. https://doi.org/10.1111/jocn.14500

How to cite this article: Sevinç, S. (2023). Life satisfaction and difficulties experienced by the family members of individuals with thalassemia. *Nursing Open*, *10*, 3914–3924. https://doi.org/10.1002/nop2.1649