

# “My life has changed suddenly!” Psycho-social problems in mothers of children with cancer

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## Research Article

**Keywords:** Cancer, child, mothers, psychology

**Posted Date:** April 22nd, 2022

**DOI:** <https://doi.org/10.21203/rs.3.rs-1564424/v1>

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# Abstract

**Purpose:** This study aimed to better understand the psycho-social problems in mothers of children with cancer.

**Methods:** This a qualitative phenomenological study. The sample consisted of a total of 15 mothers.

**Results:** The study determined six main themes. The theme of *"first reactions of the mothers when they learned the diagnosis of their child"* comprised of four sub-themes, including *"shock"*, *"sadness"*, *"fear"* and *"denial"*. As the second main theme, *"the effects of the disease on mothers"* had two sub-themes, including *"sadness"* and *"hope"*. The third theme was *"changes in the family"* due to the diagnosis and included two subthemes: *"support of family members for each other"* and *"disruption of family routines"*. The fourth theme was *"involvement in society"*, including sub-themes of *"restricted social relationships"* and *"increased social support by calling"*. As the fifth theme, the *"difficulties related to the disease and treatment"* had one subtheme, named *"disease-related pain"*. The sixth theme was *"increased support factors"*, including two sub-themes: *"need for expert support"* and *"financial support"*.

**Conclusions:** Nursing interventions can help mother of children with cancer cope with disease-related difficulties by providing adequate care and support during the disease process.

## Introduction

Globally there are more than 300,000 children diagnosed with cancer each year (M Van Schoors et al., 2019). Although treatments for childhood cancers have increased the survival rate to 80%, different types of malignancies can cause premature deaths in children with cancer. Cancer is still the second leading cause of death among children aged 5–14 years (Atout et al., 2021). Diagnosis and treatment of pediatric cancer can cause significant disruptions in the life of both children and their families, including painful medical procedures, long-term treatments, unpredictable and debilitating physical symptoms, financial stressors, and social isolation (Bakula et al., 2020).

A diagnosis of pediatric cancer affects not only children but also their families, causing them to face several life challenges (Qadire et al., 2018). Families of children with cancer have deep distress due to the diagnosis (Kelada et al., 2019). The major difficulties they have due to the disease are financial problems, uncertainty, inability to define the disease and its consequences, and psychological problems (Nikfarid et al., 2020). Most of the parents of children with cancer report adverse psychological effects associated with the diagnosis, including symptoms of post-traumatic stress. Compared to other chronic diseases, cancer causes more stress, anxiety and fear in families, leading them to feel helpless and guilty for the child's illness (Modanloo et al., 2019). This can affect not only the parents but also the entire family (Çınar et al., 2021). Insufficient knowledge and coping skills and inability to provide appropriate care cause parents of children with cancer feel inadequate. Therefore, they have serious emotional and physiological stress during the care process, causing physical and mental health issues (Ahmadi et al., 2019).

All family members of children with cancer suffer from this delicate condition, but it is a difficult and unpleasant experience for mothers to observe and endure their child's suffering illness, especially when the child is afflicted by an incurable disease called cancer. It may not be possible for mothers of children with cancer to have psychological and social wellness due to the exceptional care conditions and constant care need necessary for their sick children. It is also exceedingly difficult for them to observe their sick children's suffering and coping with unpleasant complications of chemotherapy (Zareei Mahmoodabadi & Delavari, 2021). As a result of the hospitalization of their sick children, mothers can quit their jobs, cannot provide sufficient care for other family members, and cannot communicate and meet with their friends and relatives. Therefore, mothers of children with cancer need to deal with two sources of stressors: management of the child diagnosed with cancer and management of other family members and their jobs (Omari et al., 2021).

Family health and performance can be improved by recognizing parental problems, reducing stress, and improving parents' ability in functional and mental crisis management (Ahmadi Mahin et al., 2018). Therefore, determining the psychosocial problems in parents of children with cancer, especially mothers who take more care and have more responsibility with sick children, will guide the interventions and measures to be taken in this regard.

There is no Turkish study about the psycho-social difficulties in mothers of children with cancer. Therefore, this study aimed to determine the psycho-social problems in mothers of children with cancer.

## **Aims Of The Study**

This study aimed to determine the experiences, psycho-social problems and needs of mothers of children diagnosed with cancer.

## **Patients And Methods**

This phenomenological descriptive qualitative study was conducted using semi-structured in-depth interviews, one of the qualitative research methods, and prepared according to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist (Tong et al., 2007).

The study was conducted in the pediatric oncology clinic of a Training and Research Hospital in Turkey.

## **Participants**

Purposive sampling was adopted in this study. Participants consisted of mothers of children aged 1–18 years who were formally diagnosed with childhood cancer. Mothers who had communication problems or did not want to participate in the study were not included in the study.

The study was conducted with a total of 15 mothers, performing in-depth interviews with each one separately in a quiet room at the hospital or in the researcher's office. The researcher explained all study procedures before obtaining consent from [blind] participants. This study was performed in accordance with the hospital's ethical standards and the Declaration of Helsinki.

## Data Collection

The research team consisted of academics with practical experience and expertise in the field of nursing and medical ethics. After the participants who met the study inclusion criteria were identified, the interviews were conducted at a time convenient for both researchers and participants. Before the interviews, the researcher [DK] explained participants the purpose and design of the study. All researchers had training on qualitative research methods and experience in conducting research. The data were collected through face-to-face in-depth interviews using a semi-structured questionnaire between February 01 and March 15, 2022. In line with the relevant literature, the researchers developed an eleven-question semi-structured questionnaire, using their own knowledge and field experience, to determine the experiences and psycho-social problems in mothers of children with cancer.

Since no new information could be found about the last interview, the data was considered to have saturation, therefore the data collection was terminated (Corbin & Strauss, 1998). The interviews were recorded and lasted around 30 minutes. Observation notes were written immediately after each interview and all interviews were transcribed.

## Data analysis

The interviews were conducted and recorded by one researcher [blind], and the observation notes were recorded and transcribed by other two researchers. The first step of data analysis in this study was descriptive analysis. A descriptive analysis summarizes and interprets research data within the framework of determined themes (Akdemir & Abdurrahman, 2021). After descriptive analysis, a content analysis was applied on the data. A content analysis consists of the following steps: examining the research data, generating code from the data, identifying the themes, creating thematic networks, ensuring the integrity of the themes and interpreting them. Accordingly, the data were organized using descriptive analysis and evaluated using content analysis, whereby the concepts and contexts that would explain the data were reached. In other words, conceptual themes were determined to provide an in-depth examination of the data through descriptive and content analysis. To capture different concepts and categories through in-depth interview data, interviews were conducted until a theoretical saturation, that is, a point where similar contents appeared repeatedly and new categories did not emerge, was reached (Guba & Lincoln, 1989). Both main themes and sub-themes were determined by open coding, and the relations between them were determined by creating discussion and consensus among the researchers. A total of six themes and 14 sub-themes were determined in the study.

# Study Rigour

The rigor of this study was achieved by applying the criteria for readability, transferability, reliability, and relevance suggested by Guba et al. (Guba & Lincoln, 1989). A total of 15 mothers were included in the study. The data were used and transcribed as direct quotes from the non-interpreted and semi-structured interviews. The researchers identified main themes and sub-themes that should be clustered with similar ideas to ensure credibility and reliability.

One researcher (SD) transcribed the data obtained from the interviews. An inductive content analysis was used using interview recordings (Elo & Kyngäs, 2008). This analysis includes three steps: open coding, category creation, and abstraction (Elo & Kyngäs, 2008). All researchers read transcripts of the interview data. This analysis was performed until a consensus was reached among the researchers. The sub-themes were created from the codes with similar meanings.

# Ethical Considerations

This study was conducted in accordance with the principles of the Declaration of Helsinki. An ethical approval was obtained from the Non-Interventional Clinical Research Ethics Committee of a university (...) and an institutional permission from the hospital where the study was conducted. All written materials and audio copies were stored in the encrypted form.

# Results

Table 1 presents the participants' socio-demographic characteristics.

Table 1  
Socio-demographic characteristics of mothers and children

| <b>Characteristics</b>                     | <b>Number</b>      | <b>Percentage</b> |
|--|--------------------|-------------------|
| <b>Gender</b>                              |                    |                   |
| Female                                     | 7                  | 46.7              |
| Male                                       | 8                  | 53.3              |
| <b>Diagnosis</b>                           |                    |                   |
| AML  | 6                  | 40                |
| ALL  | 5                  | 33.3              |
| Other                                      | 4                  | 26.7              |
| <b>Mother's education</b>                  |                    |                   |
| Primary education and below                | 7                  | 46.7              |
| Secondary education and above              | 8                  | 53.3              |
| <b>Socio-economic level</b>                |                    |                   |
| Income equal to expenses                   | 7                  | 46.7              |
| Income less than expenses                  | 8                  | 53.3              |
| <b>Having another child</b>                |                    |                   |
| Yes  | 11                 | 73.3              |
| No   | 4                  | 26.7              |
| <b>Place of residence</b>                  |                    |                   |
| City center                                | 10                 | 66.7              |
| County                                     | 5                  | 33.3              |
| <b>Mean age of the mothers</b>             | 34.73 ± 5.47 years |                   |
| <b>Mean age of the sick children</b>       | 9.40 ± 3.83 years  |                   |
| <b>Mean diagnosis time of the children</b> | 5 ± 6.32 months    |                   |

A total of six main themes and 14 sub-themes were created from the data analysis (Table 2).

Table 2  
Interview questions, themes, subthemes

| Interview questions  | Themes  | Subthemes   | Meaning unit  |
|--|---|---|---|
| Can you tell me about your experience after learning the diagnosis of your sick child?                                     | 1. First reactions of the mothers when they learned the diagnosis of their sick child | Shock<br>Sadness<br>Fear<br>Denial  | Of course, I was shocked (A1).<br>I have been so bad. It is a difficult situation indeed (A2).<br>I am afraid for a moment that I would lose my child. I could not sleep at all. I looked at him and cried (A3).<br>When I first heard it, frankly, I did not believe the doctor. I went to another doctor because I did not trust the health system in my living place (A4). |
| How does the disease affect you mentally? What are your current feelings?  | 2. The effect of the disease on mothers   | Sadness<br>Hope   | I am bad mentally (A6).<br>I hope it will get better (A5).  |
| What has changed in your family members after the diagnosis of your sick child?  | 3. Changes in the family  | Increased support of family members for each other<br>Disruption of family routines | “My husband is more supportive of me than before. He often calls and supports me” (A8).<br>Let's say we broke up (A7)   |
| Did you experience any change in your social life and friendships because of your sick child's diagnosis? Can you explain? | 4. Involvement in society   | Restricted social relationships<br>Increased social support by calling              | “Some people called me, but we do not meet face-to-face with anyone” (A10).<br>“They call me and show more concern than before” (A9).   |
| What are the difficulties you have about the disease process?  | 5. Difficulties related to the disease and treatment                                  | Disease-related pain  | “My son had a seizure for two days. His hands were tense. Those two days were exceedingly difficult” (A11).   |

| Interview questions | Themes                        | Subthemes                                    | Meaning unit   |
|---------------------|-------------------------------|--|--|
| Aid needed          | 6. Increasing support factors | Need for expert support<br>Financial support | “It is important to familiarize people with the diagnosis when they first learn about it. I think it would be better if they talked to us when we first learned about the diagnosis” (A13).<br><br>“We have only one salary. My daughter has needs. We are struggling financially” A(5). |

*Theme 1. First reactions of the mothers when they learned the diagnosis of their sick child*

The mothers were asked “*Can you tell me about your feelings and experience after learning the diagnosis of your sick child?*”. In general, they reported to have shock, sadness, fear and denial. Thus, a total of four sub-themes (shock, sadness, fear and denial) were determined under the theme 1.

The mothers stated that they were shocked when they first learned about the diagnosis and could not believe what they heard (A5, A6, A9). Some of the mothers’ expressions about their feelings are as follows.

*“I was in shock. I was shocked, I did not believe what I heard” (A9).*

*“I was suddenly shocked. My whole world fell apart. I had taken my child to the doctor to see why he was losing weight. He was diagnosed with cancer just in one day. It was a difficult day” (A6).*

The mothers (A1, A2, A7, A8, A10, A12, A15) reported to have sadness when they first learned about the diagnosis.

*“My whole world fell apart” (A12).*

*“I was so sad; I was suddenly devastated. I did not know what would I do and how would I tell it to my child? What would his brothers think, how would he explain his illness to his friends? What would his friends think if he did not go to school? I was adversely affected; I was devastated both physically and mentally” (A15).*

*“I collapsed. I stopped eating and drinking. I couldn't look at my child's face. It was hard for me, so I gave up on everything. Everything was meaningless” (A7).*

The mothers (A3, A13) reported to be afraid of losing their children when they first learned the diagnosis.

*“I was afraid to lose my child. I couldn't sleep at all. I looked at him and cried. May Allah not give disease to anyone.” (A3).*

*“I considered that this boy would die. Because I lost both my father and grandfather due to cancer” (A13).*

The mothers (A4, A11) stated that they denied the diagnosis, wanted to go to another doctor, and did not want to believe what they heard.

*"When I first heard it, I honestly couldn't believe my doctor. I went to another doctor because I did not trust the health system in my place of residence" (A4).*

*"I couldn't believe it. I could never accept this disease" (A11).*

## **Theme 2. The effect of the disease on mothers**

The mothers were asked *"How does the disease affect you mentally? What are your current feelings?"*. According to their responses, two sub-themes were created: sadness and hope.

Eight mothers stated that they were upset.

*"I am pretty bad" (A6).*

*"I cry all the time. I cry even when a vascular access is established for my child" (A14).*

Seven mothers stated that they wanted to be hopeful, using the following expressions:

*"I hope, this will be over. All I want is for my child to recover his health as soon as possible" (A2).*

*"I believe the doctor will cure my child. As I got to know the doctor, I feel relieved. I believe that he will treat my child" (A4).*

*"I hope it will go well. My child develops better than other patients. This is how I console myself" (A5).*

## **Theme 3. Changes in the family**

The mothers were asked *"How was the changes of your family members after the diagnosis of your child?"*. Some of them reported that their family members supported each other, and their family relations were strengthened. However, some mothers stated that their family routines were disrupted, and their families were broken up. Accordingly, two sub-themes were determined as support of family members for each other and disruption of family routines.

The mothers (A2, A3, A9, A11) stated that the support of their family members to each other increased, using the following expressions:

*"My family has become closer to me. My relatives always called and supported me more than before. I mean they were calling twice a month before the illness, now they are calling twice a week. Even if everyone is busy, they call me a lot" (A9).*

*"I get strength from my husband. When I see him next to me, I become stronger" (A11).*

Some mothers stated that their family routines were disrupted due to being away from their home, being hospitalized of their child, and even having to receive treatment of their child in another city. They also stated that they missed their other children very much and wanted to have their family routines back. This situation even gets worse, as the mothers are not allowed to go out of the ward and their husbands are not accepted to the inpatient ward due to the risk of infection. The mothers, who stated that they were away from their home and other children, talked about their feelings with tears during the interview.

*"It is difficult for me especially to be away from the city I live in. We came here even for the blood test. We're having a tough time due to travelling. The lack of hospitals/doctors providing this treatment in my city is very tiring for us because we come here for every medical examination. Our life pattern is disturbed."* (A10).

*"The most challenging thing for me in this process is being away from my other daughter"* (A14)

*"Having to stay away from my home, be away from my other child, I mean, everything here is challenging for me. My other children live in another city with their aunts. I have missed them too much. Since visitors are prohibited, I only see my husband for a short time in the garden when he comes to visit us. Her friends are calling my daughter to learn when she will return to school. Our life pattern is disturbed. My other children live with their aunt in another city. They always ask me "when will you come, mother?""* (A15).

## **Theme 4. Involvement in society**

The mothers were asked about the differences in their social relationships after their child being diagnosed with cancer. According to their responses, two sub-themes were created: restricted social relationships and increased support by calling. Some comments of the mothers (A2, A4, A5, A6, A8, A13) who stated that their social life was restricted, are given below.

*"Everything has changed. We do not have a social life right now."* (A2).

*"Our social life is over. We do not meet anyone because my child gets an infection. We only talk by phone"* (A6).

Some mothers stated that social support to them increased by phone calls (A1, A3, A5, A7, A9, A10, A11, A12, A14, A15). Some of them also stated that they only talked by phone with their relatives and friends due to the risk of infection, and sometimes they even did not want to pick up the phone.

*"Everyone is calling."* (A1)

*"Friends and neighbors are always calling and supporting."* (A3).

## **Theme 5. Difficulties related to the disease and treatment**

The mothers were asked about the most challenging thing for them in this process. The theme of difficulties related to the disease and treatment was formed according to their responses. This theme had two sub-themes, including pain due to the disease and being away from home/other children.

As the difficulties they had due to the disease and treatment, they reported especially the side effects of chemotherapy and seeing their children suffer.

During the treatment process, seeing their child in fever and pain, and worrying if the disease gets worse were among the most difficult situations for mothers. Some of the mothers' answers to this question are as follows:

*"Seeing my child suffer. I'm under a lot of stress when I see my child suffer. All invasive procedures performed on my child make it difficult for me to cope with the disease because my child is in pain" (A4).*

*"My son had a seizure for two days. His hands tightened; those two days were exceedingly difficult. I had a tough time. It is exceedingly difficult to see my child in pain" (A11).*

*"The most challenging thing for me is the disease of my child" (A13).*

## **Theme 6. Increasing support factors**

The mothers were asked *"What support do you need most?"*. The theme of increasing support factors was formed according to their answers to this question, including two sub-themes of need for professional spiritual support and increased support of friends and spouses.

Some mothers stated that they received support from a specialist psychologist, starting from the time their children were first diagnosed with cancer. Some mothers reported that psychological support should be given during the treatment period as the support they received from the hospital was not sufficient.

*"It's particularly important to familiarize people with the diagnosis when they first learn about it. I think it would be better if they talked to us when we first learned about the diagnosis. I get support from an expert myself, but I need it more intensely." (A13).*

Some mothers have stated that some cancer drugs are not available or expensive in Turkey. Therefore, they reported to have financial difficulties. As the support they most needed, most of the mothers reported to need financial support.

*"I have financial needs. There are treatment costs. I had a job, but I had to quit my job. As a result, my income decreased" (A4).*

*"Being away from home is challenging for me. We are struggling financially" (A6).*

## **Discussion**

This study aimed to determine the psycho-social difficulties in mothers of children diagnosed with cancer. A phenomenological approach was adopted to interpret the mothers' experiences, helping us gain an in-depth understanding of their difficulties. The first reactions of mothers upon learning of the diagnosis of their sick child were shocked, denial, fear and sadness. These sub-themes are the same as the reactions

Küblerr Ross reported for individuals who lost their loved ones. In the Kubler-Ross model, a process of loss, which is defined as being deprived of something, leads to shock/denial, anger, bargaining, depression, adjustment, and acceptance (Günay & Özkan, 2019). The mothers had these reactions and emotions as their children's health deteriorated due to illness. Mahmoodabadi et al. found that mothers experienced disbelief, confusion, and helplessness at the time of hearing about their child's cancer (Zareei Mahmoodabadi & Delavari, 2021). (Cuğ determined that the reactions of parents of children with cancer were rejection, collapse, having a family disaster, being upset, crying, shocked, denial, rebelling, hopelessness and despair (Cuğ, 2021). The parents' emotional reactions to the disease often interact with each other, causing psychopathological problems (Ay & Akyar, 2020). Therefore, psycho-social support to parents, especially to primary caregivers, of children diagnosed with cancer should be started and continued from the first moment of the diagnosis.

When the mothers were asked to report their current feelings, some of them reported sadness, while others had a sense of hope for their children to get better. Mothers participate more in childcare during their child's illness, therefore employed mothers may have to leave their jobs. As mothers cannot leave their sick children for even a moment while giving care, they do not spare time for social activities, increasing their care burden (Kahriman et al., 2020). In the present study, the mothers stated that they could not even go to the hospital garden because their children were small, that they had financial difficulties, and that they felt sorry for their sick child when they were being treated in pain. One study found the distress rate in parents of children diagnosed with cancer as 13% (Rensen et al., 2019). Qadire et al. determined that parents of children diagnosed with cancer had high levels of anxiety and depression (Qadire et al., 2018). One study about family caregivers of cancer patients found that they were exhausted due to long-treatment process (Nemati & Rassouli, 2018). No mother considers that their child will have this disease one day. The mothers were upset and worn out as their life routines were suddenly destroyed due to the disease. In the interviews, all mothers cried while expressing their feelings and prayed for their children to regain their health and go back to the old days as soon as possible. The mothers only wanted their children to be healthy and they did not want anything else, indicating their helplessness and hope together.

In our study, some of the mothers hoped that their child would respond to treatment and recover. One study determined that mothers of children with cancer were hopeful and optimistic for their children to overcome the disease (Omari et al., 2021). Zadeh et al. found that individuals with better psychosocial and spiritual support had higher perceived hope (Zadeh et al., 2021). Hope plays a key role in how parents cope with their child's illness (Hill et al., 2018). Therefore, it is recommended to carry out support activities to improve hope in mothers of children with cancer.

The support of family members to each other may increase with the diagnosis of cancer, but the diagnosis and treatment process may lead to intrafamilial conflicts (Katz et al., 2019). In the present study, the mothers reported that family support increased after the diagnosis of their child's illness. Family support is one of the factors affecting positive adjustment in parents of children with cancer (Barrera et al., 2004). Family support reduces burnout in families of individuals with chronic disease

(Toledano-Toledano & Domínguez-Guedea, 2019). Verberne et al. conducted a study with caregiver parents of palliative pediatric patients and found that most parents considered their spouses as the main source of support and empowerment (Verberne et al., 2019). One study found that an inner circle support from relatives and friends to mothers of children with cancer alleviated their stress during the treatment process (Molinaro & Fletcher, 2018). Coping with cancer-related stress and problems and protecting family integrity are important to protect the psychosocial health of family members. Positive changes are observed in marriages where communication and emotion sharing between partners are more intense in the childhood cancer process (Çınar et al., 2021). Social support can improve resilience in mothers of children with cancer. Therefore, social support can be provided more frequently to mothers of children with cancer by phone and video calls in quiet rooms.

Most of the mothers stated that their family routines were disrupted due to their child's illness and treatment. One of them stated that her husband slept in the car or commuted from the city where they lived to the hospital where their child received treatment. Several mothers reported that their other children stayed at home or with their relatives, which was difficult for them.

Zareei Mahmoodabadi et al. found that families of children with cancer had several familial difficulties such as parental disagreements, disruption of life routines, lack of care for other children, and vulnerability of other family members due to their child's illness (Zareei Mahmoodabadi & Delavari, 2021). Schoors et al. reported that in addition to being busy with the care for sick child and wanting to spend as much time with this child as possible, parents of children with cancer felt guilty for not providing adequate care and time to their other children (Marieke Van Schoors et al., 2018). In our study, an emotional load was observed in the mothers who reported to miss their other children. Therefore, peer and expert support should be increased in mothers of children with cancer during the hospitalization of their sick child.

The mothers were asked about the differences in their social relationships after the diagnosis of their child's illness. They reported to have no social life and go out because their child was hospitalized for a long time. They also stated that they did not talk to anyone when they went home so that their child would not get an infection. Zareei Mahmoodabadi et al. determined that mothers of children with cancer had changes in their daily lives, communicated less with other children and family members, and their social lives were restricted (Zareei Mahmoodabadi & Delavari, 2021). After their child is diagnosed with cancer, parents feel responsible for their sick children 24 hours a day, therefore their social activities may decrease and family members may have social isolation (Kahriman et al., 2020). Atout et al. conducted a study with caregivers of children with cancer and found that several caregivers were very tired rushing from chores to care responsibilities for their sick child (Atout et al., 2021). In another study, parents of children with cancer stated that they hesitated to have social interaction to protect their sick children. They also reported to have a limited ability to socialize with others due to their child's leukemia treatment, which consumed much of their time. In addition, they were found to envy families of healthy children who did not have to deal with cancer/leukemia problems, causing them to be isolated (Chodidjah et al., 2022). In our study, only one mother stated that everyone was in a good mood, therefore she was angry with

healthy ones. This mother reported to not want to see and talk to anyone. The mother received support from a psychological specialist. Health professionals should also consider the mental health and psychological needs of parents and caregivers of children with cancer.

Some of the mothers reported that their children suffered from pain due to the disease and treatment. One study determined that adolescents with leukemia had serious health problems due to the side effects of chemotherapy, such as bleeding due to recurrent infection and decreased white blood cell and platelet counts, causing their families to have depression (Chodidjah et al., 2022). In another study, mothers of children with cancer stated that they let their children do whatever they wanted because they observed that their children were struggling with illness, suffering, and discomfort (Kim et al., 2020). Vieira et al. discussed the emotional burden in mothers of children with cancer. On their study, one mother stated “*Oh, it’s hard, like, er, she was so little, four or five years old, so it was a very sudden change, right? The treatment was also very hard, very painful. [Replies crying] (...) [Pauses, thinks and replies] Actually, thank God, she responded well, very well*” (Vieira & Cunma, 2020). It is incredibly sad for mothers to see their child suffer. Therefore, it is recommended to plan psychoeducation to strengthen mothers of children with cancer.

It is challenging and burdensome for everyone to care for a child with cancer. Family members may not be ready to take on all responsibilities of their new roles in their child’s care and treatment process, and therefore they may need a great deal of emotional support (Shyarma et al., 2018). In our study, although the mothers reported to receive support from their spouses, family members and friends, they could not receive adequate professional psychiatry specialist support. In Turkey, parents who have children or cancer patients receiving treatment in the hematology/oncology unit can demand a psychologist and, if necessary, a psychiatry consultation. However, the mothers wanted to have regular psychological support. Time constraints, patient density and small number of specialists may prevent to have individual sessions and regular psychological therapy. However, psychiatric and pediatric nurses can provide peer and/or group support to mothers of children with cancer. In one study, some of the parents of children with cancer stated that they received adequate support from health professionals, but some parents reported to receive no professional support and had inadequate perceived support. The parents had difficulty communicating with healthcare professionals who showed little understanding and attention to their well-being (Carlsson et al., 2019). Nurses working in the pediatric oncology hematology service should be given supportive training at regular intervals and strengthen their professional skills in cooperation with psychiatric nurses. Nurses who cannot support patients and their relatives due to their own burnout and perceived failure can be rotated at regular intervals, allowing them to work in different health services.

Studies have reported that families of children with cancer may have financial difficulties (Lavi et al., 2018). One systematic review of 35 studies found that families of children with cancer were affected socio-economically due the disease, whereby especially mothers quit their jobs (Roser et al., 2019). In the present study, most of the mothers reported to have financial difficulties. Due to expensive cancer drugs, increased treatment expenditures, having treatment in different cities, and mothers quitting job due to

care of their sick child, and family income decreases and financial burden on parents of children with cancer increases. In Turkey, the Foundation for Children with Leukemia contacts with families of children with cancer and provides them with financial support. However, this support may be insufficient. Therefore, access and affordability of cancer drugs should be as high as possible through governmental policies and laws, and low-income families of children with cancer should be identified and provided with additional financial support.

## **Study Limitation**

Qualitative studies have limitations in generalizing the results to other areas. The results of this study were produced from the mothers' direct experiences. The interviews were made in the pandemic. Since both the participants and the researchers wore masks during the interview, some of the signs from their facial expressions may have been overlooked.

## **Implications For Clinical Practice**

This study has several implications for nursing practice. First, the mothers' statements inform nurses about the emotional experiences of families whose children are diagnosed with cancer, particularly the impact of the disease on the family due to the diagnosis. This may lead nurses to develop and provide more individualized care, training, and support to families of children with cancer. In addition, the mothers were observed to gain strength from their sense of hope, social support factors, and spiritual support such as praying. Health professionals can identify promising ways of care for children with cancer and empower their mothers to eliminate emotional and spiritual exhaustion, which are important for the well-being of both mothers and their sick children. Especially the mothers' demand for psychological support in our study suggests that health professionals should organize psychoeducation, peer support, motivational interviews and support activities for mothers of children with cancer. Therefore, it is recommended that pediatric nurses should be trained and supported in this regard and work in cooperation with psychiatric nurses.

## **Conclusion**

This study determined that mothers of children with cancer had material, social, emotional and spiritual difficulties. The mothers were emotionally upset, needed psychological specialist support, and had financial difficulty due to treatment and hospital expenses. Those who had to receive cancer treatment for their children at the hospital in another city stated that their family order had deteriorated and that they missed their other children at home because they stayed in the hospital for a long time. The mothers also reported to receive family and friend support through phone calls. Because of the risk of their child getting infection, the mothers had no social relations, did not go out of the hospital, and did not meet with anyone face to face when they returned home. The mothers stated that it was challenging to see their children in pain while receiving treatment, and their only wish was for their children to recover as soon as

possible. Nurses in pediatric cancer units should be able to comprehensively assess the needs of sick children and their caregivers. It is important to support mothers of children with cancer emotionally and spiritually.

## Statements And Declarations

**Funding** “The authors declare that no funds, grants, or other support were received during the preparation of this manuscript.”

**Competing Interest** “The authors have no relevant financial or non-financial interests to disclose.”

**Author contribution** “All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [SD, ÖT and DK]. The first draft of the manuscript was written by [SD] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.”

**Ethics approval** “This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University X (13.05.2019/No2019/213).”

**Consent to participate** “Informed consent was obtained from all individual participants included in the study.”

**Consent to publish** Authors consented to publish.

## CONFLICT OF INTERESTS

The authors declare that there is no conflict of interests.

## ACKNOWLEDGMENT

No external or intramural funding was received.

## References

1. Ahmadi, M., Rassouli, M., Gheibizadeh, M., & Karami, M. (2019). Predictors of Caregiver Burden among Parents of Children with Cancer. *Iran J Ped Hematol Oncol.*, *9*(4), 253–263. <https://doi.org/10.18502/ijpho.v9i4.1574>
2. Ahmadi Mahin, P., Ahmadi, M., Shoraka, H., & Chegeni, M. (2018). Parents ' Experience of Caring Children with Cancer: A Qualitative Study with Phenomenological Approach. *Journal of Comprehensive Pediatrics, in press*, e655545. <https://doi.org/10.5812/compreped.65545.Research>
3. Akdemir, A. B., & Abdurrahman, K. (2021). Nitel Makalelerin Yöntem Analizi. *Muğla Sıtkı Koçman Üniversitesi Eğitim Fakültesi Dergisi*, *8*(2), 486–502. <https://doi.org/10.21666/muefd.834707>

4. Atout, M., Alrimawi, I., Daibes, M. A., & Abusalameh, E. (2021). The lived experience of family members who care for children with cancer: An interpretative phenomenological approach. *European Journal of Oncology Nursing*, *52*(October 2020), 101978. <https://doi.org/10.1016/j.ejon.2021.101978>
5. Ay, M. A., & Akyar, I. (2020). Psychosocial Status of Turkish Families of Pediatric Cancer Patients. *Journal of Transcultural Nursing*, *37*(3), 227–241. <https://doi.org/10.1177/1043659619849481>
6. Bakula, D. M., Sharkey, C. M., Perez, M. N., Espeleta, H. C., Gamwell, K. L., Baudino, M., Delozier, A. M., Chaney, J. M., Alderson, R. M., & Mullins, L. L. (2020). The relationship between parent distress and child quality of life in pediatric cancer: A meta-analysis. *Journal of Pediatric Nursing*, *50*, 14–19. <https://doi.org/10.1016/j.pedn.2019.09.024>
7. Barrera, M., Gibson, J., Gilbert, T., Weksberg, R., & Malkin, D. (2004). Predictors and mediators of psychological adjustment in mothers of children newly diagnosed. *Psycho-Oncology*, *6*(December 2003), 630–641.
8. Carlsson, T., Kukkola, L., Ljungman, L., Hovén, E., & vonEssen, L. (2019). Psychological distress in parents of children treated for cancer: An explorative study. *PLoS ONE*, *14*(6), 1–18. <https://doi.org/10.1371/journal.pone.0218860>
9. Chodidjah, S., Kongvattananon, P., & Liaw, J. J. (2022). “Changed our lives”: Psychosocial issues experienced by families of early adolescents with leukemia. *European Journal of Oncology Nursing*, *56*(October 2020), 102077. <https://doi.org/10.1016/j.ejon.2021.102077>
10. Çınar, S., Boztepe, H., Ay, A., Yılmaz, P., Güllü, H., Karadavut, B., Burhanoğulları, D., Solmaz, M., & Akyüz, C. (2021). Predictors of parenting stress in parents of children with cancer. *European Journal of Oncology Nursing*, *54*(July 2020). <https://doi.org/10.1016/j.ejon.2021.102022>
11. Corbin, J., & Strauss, A. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*.
12. Cuğ, F. (2021). Çocukları Kanser Olan Ebeveynlerin Tedavi Sürecindeki Psikolojik İhtiyaçları. *Current Approaches in Psychiatry*, *13*(1), 324–336.
13. Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
14. Guba, E. G., & Lincoln, Y. S. (1989). Fourth generation evaluation. In *Fourth generation evaluation* (p. Sage, London.). [https://doi.org/10.1016/8755-7223\(92\)90119-j](https://doi.org/10.1016/8755-7223(92)90119-j)
15. Günay, U., & Özkan, M. (2019). Emotions and coping methods of Turkish parents of children with cancer. *Journal of Psychosocial Oncology*, *37*(3), 398–412. <https://doi.org/10.1080/07347332.2018.1555197>
16. Hill, D. L., Nathanson, P. G., Carroll, K. W., & Theodore, E. (2018). Changes in Parental Hopes for Seriously Ill Children. *Pediatrics*, *141*(4), e20173549.
17. Kahriman, I., Canan Demirbag, B., & Kobya Bulut, H. (2020). An evaluation of the changes experienced by the parents of children with cancer. *International Journal of Caring Sciences*, *13*(1), 448–456.

18. Katz, L., Fladeboe, K., Lavi, I., King, K., Kawamura, J., Friedman, D., Compas, B., Breiger, D., Lengua, L., Gurtovenko, K., & Stettler, N. (2019). Trajectories of Marital, Parent-Child and Sibling Conflict during Pediatric Cancer Treatment. *Healthy Psychology, 37*(8), 736–745.  
<https://doi.org/10.1037/hea0000620>.Trajectories
19. Kelada, L., CE, W., Carlson, L., Hetherington, K., McGill, B., McCarthy, M., Miles, G., Cohn, R., & Sansom-Daly, U. (2019). How Parents of Childhood Cancer Survivors Perceive Support From Their Extended Families. *Journal of Child and Family Studies, 28*, 1537–1547.
20. Kim, M. A., Yi, J., Wilford, A., & Kim, S. H. (2020). Parenting Changes of Mothers of a Child with Cancer. *Journal of Family Issues, 41*(4), 460–482. <https://doi.org/10.1177/0192513X19881191>
21. Lavi, I., Fladeboe, K., King, K., Kawamura, J., Friedman, D., Compas, B., Breiger, D., Gurtovenko, K., Lengua, L., & Katz, L. (2018). Stress and marital adjustment in families of children with cancer. *Psychooncology, 27*(4), 1244–1250.
22. Modanloo, S., Rohani, C., Shirinabadi Farahani, A., Vasli, P., & Pourhosseingholi, A. (2019). General Family Functioning as a Predictor of Quality of Life in Parents of Children With Cancer. In *Journal of Pediatric Nursing* (Vol. 44, pp. e2–e8). <https://doi.org/10.1016/j.pedn.2018.08.013>
23. Molinaro, M. L., & Fletcher, P. C. (2018). The Balancing Act: Mothers' Experiences of Providing Care to Their Children With Cancer. *Journal of Pediatric Oncology Nursing, 35*(6), 439–446.  
<https://doi.org/10.1177/1043454218794667>
24. Nemati, S., & Rassouli, M. (2018). Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. *Scandinavian Journal of Caring Sciences, 32*(1), 309–316. <https://doi.org/10.1111/scs.12463>
25. Nikfarid, L., Rassouli, M., Farahani, A. S., Beykmirza, R., Alsadat, T., & Khoshnazar, K. (2020). Perspectives of Afghan refugee mothers on the experience of caring for a child with cancer: a qualitative analysis. *EMHJ, 26*(6), 680–686.
26. Omari, O. Al, Roach, E. J., Shakman, L., Sunderraj, S. J., Francis, F., & Joseph, M. A. (2021). The Lived Experiences of Mothers Who Are Parenting Children With Leukemia. *Cancer Nursing, 44*(6), E374–E381. <https://doi.org/10.1097/NCC.0000000000000898>
27. Qadire, M. Al, Suliman, M., & Tawalbeh, L. (2018). Predictors of Anxiety and Depression among Parents of Children with Cancer. *Psycho-Oncology, January*, 1–4. <https://doi.org/10.1002/pon.4634>
28. Rensen, N., Steur, L. M. H., Schepers, S. A., Merks, J. H. M., Moll, A. C., Grootenhuis, M. A., Kaspers, G. J. L., & van Litsenburg, R. R. L. (2019). Concurrence of sleep problems and distress: prevalence and determinants in parents of children with cancer. In *European Journal of Psychotraumatology* (Vol. 10, Issue 1). <https://doi.org/10.1080/20008198.2019.1639312>
29. Roser, K., Erdmann, F., Michel, G., Winther, J., & L, M. (2019). The impact of childhood cancer on parents' socio-economic situation—A systematic review. *Psycho-Oncology, 28*, 1207–1226.
30. Schoors, Marieke Van, Mol, J. De, Morren, H., Verhofstadt, L. L., Goubert, L., & Parys, H. Van. (2018). *Parents' Perspectives of Changes Within the Family Functioning After a Pediatric Cancer Diagnosis: A Multi Family Member Interview Analysis*. <https://doi.org/10.1177/1049732317753587>

31. Shyarma, R., Shyam, R., & Grover, S. (2018). Coping Strategies used by Parents of Children Diagnosed with Cancer. *Indian Journal of Social Psychiatry, 34*, 249–254.  
<https://doi.org/10.4103/ijsp.ijsp>
32. Toledano-Toledano, F., & Domínguez-Guedea, T. M. (2019). Psychosocial factors related with caregiver burden among families of children with chronic conditions. *BioPsychoSocial Medicine, 13*(6), 1–9.
33. Van Schoors, M, De Paepe, A., Norga, K., Cosyns, V., Morren, H., Vercruyssen, T., Goubert, L., & Verhofstadt, L. (2019). Family Members Dealing With Childhood Cancer\_ A Study on the Role of Family Functioning and Cancer Appraisal. *Frontiers in Psychiatry, 10*(1405).
34. Verberne, L. M., Kars, M. C., Meeteren, A. Y. N. S., Bergh, E. M. M. Van Den, Bosman, D. K., Colenbrander, D. A., Grootenhuis, M. A., & Delden, J. J. M. Van. (2019). Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study. *European Journal of Pediatrics, 178*, 1075–1085.
35. Vieira, A. C., & Cunha, M. (2020). My role and responsibility: mothers ' perspectives on overload in caring for children with cancer. *Revista Da Escola De Enfermagem Da USP, 54*, e03540.
36. Zadeh, E. F., Parry, Y., & Eshghi, P. (2021). Hope in Iranian mothers of children with cancer: a descriptive correlational study. *Supportive Care in Cancer, 29*, 3697–3705.
37. Zareei Mahmoodabadi, H., & Delavari, Z. (2021). The Lived Experiences of Mothers Having children with Cancer: A Qualitative Study. *Journal of Social Behavior and Community Health, 5*(2), 719–728.  
<https://doi.org/10.18502/jsbch.v5i2.7829>