LIVED EXPERIENCES OF PARENTS OF CHILDREN AND ADOLESCENTS WITH CANCER IN TÜRKİYE

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Lived Experiences of Parents of

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ABSTRACT

Lived Experiences of Parents of

Children and Adolescents With Cancer in Türkiye

The purpose of the current study is to investigate the lived experiences of parents of children and adolescents with cancer in Türkiye. In this qualitative study which aimed to understand how having a child undergoing cancer treatment influences the parents, the participants talked about their experiences before the diagnosis, challenging experiences, sources of support, coping strategies and changes in their perspective. Ten parents whose children were between the ages of 7 and 17 and were diagnosed with any type of cancer at least three months ago were interviewed. The data emerged from the interviews were analyzed with the content analysis method. The findings of the study were presented under the headings of being a parent of a child diagnosed with cancer, challenging experiences, sources of support, coping strategies, and changes in perspective. The findings were examined in relation to the literature. Roles and practices of psychological counselors were highlighted. Limitations of the study were identified. Based on the results, recommendations were made for the professionals, policy makers, and researchers.

ÖZET

Türkiye'deki Kanserli Çocuk ve Ergen Ebeveynlerinin Yaşanmış Deneyimleri

Bu çalışmanın amacı Türkiye'deki kanserli çocuk ve ergen ebeveynlerinin yaşantılarını incelemektir. Kanser tedavisi gören bir çocuğa sahip olmanın ebeveynleri nasıl etkilediğini anlamak için yapılan bu nitel çalışmada, katılımcılar teşhisten önceki deneyimlerinden, yaşadıkları zorluklardan, ihtiyaçlarından, destek kaynaklarından, baş etme mekanizmalarından ve bu deneyimin onların yaşama bakış açılarını nasıl değiştirdiğinden bahsetmişlerdir. Bu amaçla, çocuğu 7-17 yaşları arasında olup herhangi bir kanser türü ile tanı almış ve teşhislerinin üzerinden en az üç ay geçmiş on ebeveyn ile görüşülmüştür. Görüşmelerden elde edilen veriler, içerik analizi yöntemiyle analiz edilmiştir. Araştırma bulguları, kanserli bir çocuğun ebeveyni olmak, zorluklar, ihtiyaçlar, destek kaynakları, baş etme stratejileri ve bakış açısında meydana gelen değişimler başlıkları altında sunulmuştur. Bulgular literatürle ilişkilendirilerek incelenmiştir. Psikolojik danışmanların bu konudaki rollerine ve uygulamalarına dikkat çekilmiştir. Araştırmanın sınırlılıklarına değinilmiştir. Sonuçlara dayalı olarak profesyoneller, politika yapıcılar ve araştırmacılar için önerilerde bulunulmuştur.

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For my special story,

To my precious mom…

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION 1

1.1 Purpose of the study 5

1.2 Significance of the study 5

CHAPTER 2: LITERATURE REVIEW 9

2.1 An ecological understanding of childhood cancer 9

2.2 Childhood cancer 11

2.3 Terms and definitions in cancer 14

2.4 Psychosocial considerations in childhood cancer 15

2.5 Childhood cancer in school setting 39

CHAPTER 3: METHOD 45

3.1 Research design 45

3.2 Participants 45

3.3 Instruments 52

3.4 Procedure 53

3.5 Data analysis 55

3.6 Identity of the researcher 56

CHAPTER 4: FINDINGS 59

4.1 Being a parent of child with cancer 59

4.2 Challenging experiences of parents 62

4.3 Unmet needs of parents 84

4.4 Sources of support for parents 87

4.5 Coping strategies of parents 99

4.6 Changes in perspectives of parents 110

CHAPTER 5: DISCUSSION 116

5.1 Discussion of the findings 116

5.2 Limitations of the study 154

5.3 Future recommendations 156

5.4 Conclusion 160

REFERENCES 162

APPENDIX A: DEMOGRAPHIC INFORMATION FORM (ENGLISH) 181

APPENDIX B: DEMOGRAPHIC INFORMATION FORM (TURKISH) 182

APPENDIX C: INTERVIEW PROTOCOL (ENGLISH) 183

APPENDIX D: INTERVIEW PROTOCOL (TURKISH) 185

APPENDIX E: INFORMED CONSENT FORM (ENGLISH) 187

APPENDIX F: INFORMED CONSENT FORM (TURKISH) 189

APPENDIX G: ETHICS COMMITTEE APPROVAL 191

APPENDIX H: QUOTATIONS (TURKISH) 192

LIST OF TABLES

Table 1. Common Terms in Cancer……14

Table 2. Common Types of Childhood Cancer…..…….15

Table 3. Treatment Options in Cancer…...……..…15

Table 4. Demographic Information of the Participants...……47

Table 5. Categories and Sub-categories…….……60

Table 6. Challenging Experiences of the Parents...……62

Table 7. Unmet Needs of the Parents……...…….85

Table 8. Sources of Supports for the Parents…….……88

Table 9. Coping Strategies of the Parents……...……..100

Table 10. Changes in Perspectives of the Parents…….……110

CHAPTER 1
INTRODUCTION

Cancer is one of the most prevalent serious diseases from which children aged 0-19 suffer, and it is the second leading cause of death for children in the world, after injuries (World Health Organization, 2023). It includes many different types that have different patterns and treatment procedures (Erdman et al., 2020; Bhakta et al., 2019). And yet, all types of cancer create significant changes for those who are diagnosed as well as their family members (Darcy, 2018; Gibbins, et al., 2012; Khoury, et al., 2013; Schweitzer et al., 2012).

Cancer is a burden with often long and intensive treatment periods. Hence, it leads to major changes in the lives of children who are diagnosed as a result who are impacted by this process physically, socially and psychologically (Gibbins et al., 2012; Taleghani, et al., 2012). And family members of these children also experience noteworthy shifts in their lives (Björk et al., 2005; Džombić et al., 2020; Young et al., 2021). They too experience physical, social and psychological changes through the course of their child's diagnosis and recovery and their quality of life is affected in many ways as well. Literature on the subject tends to focus on siblings as well as parents.

Studies investigating different challenges the parents may experience during the diagnosis and treatment of children underline that there are a number of issues that make parents overwhelmed and these challenges may reduce their physical and psychosocial functioning (Mogensen et al., 2022; Ovayolu et al., 2014). Additionally, it is also suggested that the quality of life and life satisfaction of parents of children suffering from cancer is lower compared to the parents who have

children with other chronic illnesses (Ovayolu et al., 2014). The common experiences that make parents' lives harder can be listed as adaptation to diagnosis, emotional distress, major lifestyle and daily routine changes, isolation from social contexts, and other family problems including financial issues, sibling problems and couple relationships (Björk et al., 2005; Carlsson et al, 2019; Gibbins et al., 2012; Khoury, et al., 2013, Schweitzer et al., 2012). Studies also show that these challenges are not only limited to the treatment process and the parents tend to have some psychosocial problems such as anxiety, depression, fear of recurrence in the long run even after the child recovers (Wakefield et al., 2021).

The first thing that parents have to deal with is to come to terms with the diagnosis and face the possibility of losing their child to this illness (Schweitzer et al., 2012). This adaptation period includes feelings of shock, anxiety, denial, anger, and deep sadness (Khoury, et al., 2013; Schweitzer et al., 2012). In this period, parents suffer from lack of information about the diagnosis and treatment and experience stress because they do not know how to manage these processes properly, including how to explain the illness to their child (Carlsson et al., 2019; Tremolado et al., 2021).

Following the first feelings and reactions to diagnosis, parents have to manage high levels of emotional distress throughout the treatment (Gibbins et al., 2012; Picci et al., 2015). The intense and prolonged emotional stress puts parents at risk to develop post-traumatic stress disorder (PTSD), other anxiety disorders, and depression (Ay & Akyar, 2020; Karadeniz Cerit et al., 2017; Ozdemir Koyu & Tas Arslan, 2021; Salloum et al., 2014; Yalug et al., 2011). It is possible to observe that parents show the highest levels of anxiety, depression, and PTSD symptoms especially in the first 3 months of the diagnosis compared to the next months of the

treatment (Katz et al, 2018). It was observed that the parents usually adjust to their new life 3-6 months after diagnosis (Kearney et al., 2015). However, although most of the symptoms parents suffer decrease and stabilize later in the treatment process, it is noticed that some parents may suffer from these symptoms throughout the first year of the treatment (Katz et al, 2018; Lewandowska et al., 2021). It can be said that the first year after diagnosis is a vulnerable period for the parents in terms of emotional distress. And given this vulnerability, it is important to conduct a psychosocial assessment both at the beginning and also later on to determine their needs and apply an intervention plan to make their adjustment process easier and improve their quality of life (Bretones Niedo et al., 2022; Kearney et al., 2015; Racine et al., 2018).

In addition to adjusting to the news of cancer and managing emotions, there are many more challenges that parents have to adjust both physically and psychologically. Cancer treatment requires special medical procedures and hospitalization. It creates a busy schedule that changes the lifestyle and daily routine of the children and their parents (Khoury et al., 2013). Parents experience additional stress as they rearrange their work and life around their child's medical needs and let go of various celebrations or leisure time activities (Santos et al., 2018).

Another concern that parents of children receiving cancer treatment face is isolation. Because cancer treatment requires hospitalization and weakens the immune system of the children, parents and children often have to avoid social contexts (Gibbins et al., 2012; Taleghani, et al., 2012). Moreover, families can be left alone as people in their social network including relatives may not want to interact with them to avoid feeling triggered by the family's experience or to avoid "catching cancer" assuming it is an infectious disease.

The study conducted by Gibbins et al. (2012) reveals additional themes including financial drawbacks of the cancer treatment, problems with siblings, and couple problems. These issues add to the burden that parents carry and make the treatment process even harder for them (Džombić et al., 2020; Khoury et al., 2013; Gibbins et al., 2012; Young et al., 2021).

Research indicates that parents of children with cancer also identify some supporting experiences as resources, which help them develop positive outcomes (Gibbins et al., 2012; Schweitzer et al., 2011). The most highlighted resources supporting parents and making it easier to cope with this process are identified as families and close friends, support from the workplace, and support from the education institutions (Schweitzer et al., 2011). Furthermore, religion and spiritual activities, and support from Non-Governmental Organizations (NGOs) are named as additional supporting experiences for parents through this difficult period (Džombić et al., 2020).

When it comes to Türkiye, it is possible to observe that parents of children with cancer have similar experiences as parents in other countries. Studies conducted in Türkiye show that parents of children receiving cancer treatment also encounter psychological challenges such as anxiety, depression, or post-traumatic stress disorder, as well as physical and social challenges (Günay & Özkan, 2019). Moreover, parents participating in studies also acknowledge the existence of resources that are helpful in their effort to cope with the diagnosis and treatment process (Altay et al., 2014). However, there has been a very limited number of studies focusing on the lived experiences of parents of children with cancer in Türkiye, and their unmet needs and support mechanisms are yet to be differentiated.

1.1 Purpose of the study

The current study aimed to investigate the lived experiences of parents of children receiving cancer treatment in Türkiye. In other words, the current study attempted to explore how parents describe their experiences as a caregiver of a child with cancer to clarify what their challenges are, what types of support they receive, what their unmet needs are and how they cope with and change through this process.

The research questions of the present study are as followed:

- How do parents of children and adolescents with cancer describe their experiences in the process of diagnosis and treatment?
- What are the challenging experiences of parents of children and adolescents with cancer in the diagnosis and treatment?
- What are the supportive needs of parents of children and adolescents with cancer in the diagnosis and treatment?
- What are the sources of support for parents of children and adolescents with cancer in the diagnosis and treatment?
- How do parents of children and adolescents with cancer cope with the diagnosis and treatment?
- How do parents of children and adolescents with cancer change in their ways of seeing self, others and the world as a result of this experience?

1.2 Significance of the study

There are considerable amounts of findings showing that parents are important figures for children receiving cancer treatment and they are also affected from the diagnosis and the treatment process as well as their children in different ways (Björk et al., 2005; Džombić et al., 2020; Young et al., 2021). However, the studies focusing

on the experiences of parents of children with cancer in Türkiye are scarce. Studies show that the experiences of these parents can be varied from culture to culture, especially in terms of their support systems (Khoury et al., 2013; Taleghani et al., 2012). To illustrate, compared to the Western literature, studies conducted in Iran and Lebanon highlight different themes of support such as religious activities, having faith, and extended family support more (Khoury et al., 2013; Taleghani et al., 2012). Hence, it would be important to study parents' experience in Türkiye, establish to what extent it matches the existing literature, and identify what their unique experiences might be.

The significance of the current study lies in the exploration of the personal experiences of parenting children with cancer. Cancer treatment includes many different options based on its types and stages, each eliciting different needs. Although the experiences and supportive needs of parents have common themes, it is possible to observe unique experiences and needs that parents might encounter in the treatment process (Schweitzer et al., 2011). Some of the conducted studies in Türkiye examine the quality of life of parents of children with cancer (Kudubes et al., 2014; Ovayolu et al., 2014). And some research focuses on the psychological outcomes of the diagnosis and treatment process for parents (Çınar et al., 2021; Günay & Özkan, 2019; Yalug et al., 2011). There is one systematic review that examines both the psychological challenges of family and support needs in relation to childhood cancer, and it was seen that most of the studies in Türkiye focuses only on the children's or mothers' experiences (Ay & Akyar, 2020). Literature review showed that there are some different studies focusing on the different dimensions of childhood cancer and the experiences of the parents in Türkiye, but a study that examines challenges, supportive experiences and coping strategies collectively seem to be missing.

1.2.1 Implication for counseling

When the literature regarding childhood cancer is examined, it seems that most of the studies were conducted by the experts in the fields of psychiatry and nursing. These studies also focus on the different dimensions of the experiences of parents of children with cancer such as their challenging experiences, needs, and coping coping strategies (Kalaycı & Çalışkan, 2021; Karadeniz Cerit et al., 2017; Kudubes et al., 2014). However, the studies aim to understand the experiences of children with cancer and their parents from the counseling perspective remain scarce in Türkiye. The current study aims to approach the subject matter from the lens of mental health and wellness, and hence, it can be a guide for mental health professionals, especially for those in the field of psychological counseling. Results of this study can guide mental health counselors and other experts in the field of psychosocial oncology in their individual and family work when they provide services to this unique population. Specifically, counselors at the school settings may benefit from an increased understanding of parents' lived experiences and could be instrumental in facilitating the students' wellness through guiding parents in a supportive way. Results can also be informative in counselors' efforts to develop intervention programs for both parents and children in the treatment process before developing negative outcomes.

In addition, research shows that it is important to determine the psychological and social needs of parents and children in cancer care to prevent the health disparity (Deatrick et al., 2022). Health disparity is defined as differences in health outcomes among individuals due to their different social, psychological, and economic needs and it might result from poverty, limited social support or inadequate access to

healthcare services (Venkatapuram, 2019). Such inequalities and lack of social and financial resources for people who are holding minority identities poses a threat to social justice (Bravemen, 2014, Krau, 2015). Promoting social justice is a core counseling value (Herlihy & Corey, 2015). Counselors are expected to facilitate individuals' access to health services and especially advocate for those who are experiencing drawbacks due to their backgrounds (Krau, 2015; Lee, 2013). Making the experiences of these people visible and also conducting need assessments for them are important roles of counselors for social justice and advocacy (Chwalisz 2008). Through deepening our understanding of the experiences and needs of parents of children with cancer, this study has the potential to further equip counselors to first understand the healthcare access concerns among this unique population and then reduce health disparity and promote social justice.

CHAPTER 2

LITERATURE REVIEW

In this section, the theoretical framework of the lived experiences of parents of children and adolescents with cancer will be explained based on Urie Bronfenbrenner's ecological systems approach. Additionally, childhood cancer, its treatment, psychosocial consideration of childhood cancer for the diagnosed children and their parents, and childhood cancer in school settings will be investigated in light of the existing studies in the literature.

2.1 An ecological understanding of childhood cancer

Ecological systems model that was developed by Urie Bronfenbrenner in 1979 provides a solid foundation to explore and understand childhood cancer. Bronfenbrenner (1979) highlighted that human development is shaped by bidirectional interaction between the individual and his/her multiple physical and social environment. Below we would explain the model first and then identify the ways in which this model could be applied to understand experiences of families suffering from a chronic illness.

According to the ecological systems model, there are five subsystems of ecological context that have influence on human development: microsystem, mesosystem, exosystem, macrosystem, and chronosystem. These systems create a nested structure, and they are interrelated with each other (Bronfenbrenner, 1977; Bailey & Im-Bolter, 2018). The microsystems are the immediate environment the individuals inhabit, such as home, school and peers (Bronfenbrenner, 1979). When

these microsystems interact with each other, a mesosystem is established, and the individuals are influenced by these interactions (Bronfenbrenner, 1979). The relationship between the school and home could be an example to the mesosystem. Encompassing the mesosystem, there is a larger social structure on which the individuals do not have to have direct influence, but they are indirectly affected, that is the exosystem. For instance, the parent's workplace and working hours may influence the development of the children indirectly. Another ecological system that includes all of the interactions among these systems is the macrosystem (Bronfenbrenner, 1979). Macrosystem is composed of the more complex societal values and policies like religion, education or health policies and mass media, and it does not only affect the individuals but also the whole society (Bronfenbrenner, 1979; Hosek et al., 2008). The last and the most recent ecological system proposed by Bronfenbrenner is the chronosystem. (Hosek et al., 2008). The chronosystem is composed of the transitions and environmental changes of the individual's life, and it includes both life events like marriage, divorce, starting to the school, and also social and historical changes across lifespan (Hosek et al., 2008).

Kazak, Segal-Andrews, and Johnson (1995) applied the Bronfenbrenner's ecological model to understand the experiences of family members of the children diagnosed with chronic illnesses, and they highlighted that a chronic illness is one of the microsystems itself. In addition, the medical setting, health care teams, and parents are other microsystems, and there are reciprocal interactions among them which create a mesosystem (Kazak et al. 2009; Steele & Aylward, 2009). When it comes to the exosystem, social support systems of parents like family support, work environments, community services influence all of the microsystems, and experiences of parents are shaped based on these structures (Steele & Aylward,

2009). In the macrosystem, the healthcare laws and regulations, the economic condition of the government and culture, religion or beliefs might influence the experience of the parents as supportive or challenging (Steele & Aylward, 2009). The experiences of parents of children with cancer can also be examined in the chronosystem because diagnosing with cancer is a big transition for all family members, and the treatment process takes a long time. The adjustment and experiences of parents might change over time (Hosek et al., 2008; Steele & Aylward, 2009).

Bronfenbrenner's ecological systems theory seems to offer a strong and fitting theoretical framework for the present study. As we investigate the experiences of parents of children with cancer, it would be important to recognize the multifaceted and bidirectional interaction between the individuals and their physical and social environment.

2.2 Childhood cancer

Cancer is defined as a disease that is characterized by uncontrolled division and growth of the body's cells. It has been one of the most common diseases for a few decades in the world. According to the World Health Organization (WHO), about 400,000 children and adolescents suffer from cancer in the world each year, and it is expected that this rate will increase in the next few years. This rate is also increasing among children in Türkiye, and every year 2500-3000 children are diagnosed with cancer in the country (Yiğit, 2018; Kebudi & Alkaya, 2021). On the other hand, while 80% of childhood cancers can be cured in high-income countries, this rate is less than 30% in low-income countries (World Health Organization, 2023). Based on this expectation, WHO launched the Global Initiative of Childhood Cancer, aiming to

construct and sustain high-quality childhood cancer intervention programs for governments to be able to reach 60% of survival of children suffering from cancer by 2030.

Childhood cancers occur between 0-19 years of age. The most common types of childhood cancers in the world are leukemia, lymphomas, brain and spinal cord tumors, and neuroblastoma (World Health Organization 2023; American Cancer Society, 2023). When it comes to prevalence in Türkiye, it is possible to observe similar numbers. Leukemia (33,8%) is the most prevalent cancer in children in Türkiye, and it is followed by nervous system tumors (19,8%) and lymphomas (11,8%) (Uzşen 2021; Yiğit, 2018).

Through the advancement in and expansion of available medical treatments and procedures, the survival rate of childhood cancer has been increasing compared to the past years. Today, about 85% of children with cancer survive 5 years or more, while this rate was about 58% in the 1970's in Türkiye as well as other countries (American Cancer Society, 2023; Yiğit 2018). In addition, the advances in cancer treatment means larger numbers of children, and hence their families, undergo the treatment process and face the related challenges.

The effects of cancer treatment do not end with the treatment process. As pointed out in the previous studies, the parents of children with cancer tend to experience more mental health problems compared to parents of typically developing children even if their children have survived and many years have passed since the treatment process (Howard Sharp et al., 2020). Literature highlights that while parents of these children can adjust to and cope well with the diagnosis and treatment process, there are a significant number of parents who have poor quality of life and experience serious anxiety, depression, PTSD, and other psychological symptoms

following the treatment (Howard Sharp et al., 2020; Quast et al., 2021). Especially, the first two years after the treatment completion is another important period like the first months of the diagnosis because the child continues to recover and has still a risk of recurrence of the disease (Quast et al., 2021). This period requires special attention, care and medical visits which create an uncertainty for all family members who are prone to experience prolonged anxiety, depression, and fear of recurrence in the long run (Quast et al., 2021; Tutelman et al., 2022). Additionally, studies also outline that long-term survivor of childhood cancer, who completed the treatment period five or more years ago, still have a risk to face late effects of the treatment in forms of physical health concerns and psychosocial problems (Erdmann et al., 2021; Koumarianou et al., 2021). And these late effects may weaken the quality of life of both the children and their family members, and the parents' lives are impacted by the above-mentioned challenging experiences (Koumarianou et al., 2021; Williams et al., 2013; Quast et al., 2021; Young et al., 2021).

While these challenges were observed by the researchers, families tend to not undergo routine psychosocial assessment that could give way to prevention or intervention. Family members need special and systematic psychosocial assessment in both early and later periods of the treatment process (Kazak et al., 2015).

In summary, despite having far better treatment options and survival rates, cancer remains to be known as a life-threatening disease. Moreover, the treatment process remains highly challenging due to various factors including its lengthy nature and side-effects. Hence, cancer continues to create fear, anxiety, and additional struggles for both children and their parents (Somkome, 2020; Gibbins et al., 2012; Patterson, et al., 2004). Intentional and systemic psychosocial assessment is needed to support the families.

2.3 Terms and definitions in cancer

There are some basic terms and definitions that are mostly utilized in the literature regarding childhood cancer and treatment. To facilitate readers' understanding of families' experiences with cancer, brief definitions of these terms, common types of childhood cancer and its treatment, obtained from the official websites of American Cancer Society (2023) and National Cancer Institute (2023), will be provided here. Table 1 shows the common terms in cancer.

Table 1. Common Terms in Cancer

Terms	Definitions
Oncology	Branch of medicine that studies diagnosis and treatment of cancer
Hematology	Branch of medicine that studies blood and blood tissues, including blood cancers like leukemia or lymphoma
Benign tumors	Not spreading and non-cancerous tissue that is mild compared to cancer
Malignant tumors	Cancerous and spreading tissue and they are mostly life-threatening
Metastases	Spreading of the tumors to other parts of the body
Staging	To determine where the cancerous tissues spread and what the level of the disease is
Prognosis	Outcome of the disease and the possibility of the recovery and treatment
Recurrence	Cancer comes back some time after the treatment in the primary tissue or a different tissue
Remission	Partial or complete disappearance of cancerous tissue
Follow-up	Screening the people's health condition after the end of active treatment
Long-term effects	Side effects that are observed long after the end of the treatment

Sources: American Cancer Society, 2023 & National Cancer Institute, 2023

Some types of cancer are more common in childhood period. Table 2 briefly defines the most common types of childhood cancer, including the diagnosis of the children of the participating parents in the current study.

Cancer treatment can require different treatment plans depending on the types and stages of it. Studies highlight that these treatment options can be applied separately or also used together (Schirrmacher, 2019). Table 3 summarizes the most common treatment options in cancer.

Table 2. Common Types of Childhood Cancer

Type of Cancer	Definitions
Leukemia	A bone marrow and blood cancer that is the most common and accounts for 28% of all pediatric cancer. The most common types of leukemia in children are acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML). ALL is most common in children aged between 2-5. AML tends to spread more widely during childhood ages
Brain and spinal Cord tumors	The second most common type of pediatric cancer, and it accounts for about 26% pediatric cancers. Depending on the location of tumors, there are different types of brain and spinal cord tumors, and these different types have different treatment progress
Neuroblastoma	A type of cancer which is related to the early and immature nerve cells called neuroblast. It affects infants and young children, especially under 5-year-old and it accounts for about 6% of pediatric cancer. It is not a common disease for children older than 10-year-old
Lymphoma	A cancer related to the lymphocytes, which are a type of immune system cell, and may also influence the bone marrow. Two major types: Hodgkin lymphoma (HL) and Non-Hodgkin lymphoma. HL accounts for about 3% of all pediatric cancer and is rare in the early childhood period and it is the most common type of cancer among adolescents. NHL accounts for 5% of all pediatric cancer and commonly affects children aged between 5-19
Osteosarcoma	One of the most common types of bone cancer in children. It accounts for about 2% of pediatric cancer and it is common in adolescents.
Ewing sarcoma	Another most common type of bone cancer in children. It accounts for about 1% of all pediatric cancer and is common in teens, but it may also influence younger children
Soft tissue sarcoma	A type of cancer which can start in muscles, fat, blood vessels and different parts of the body. It accounts for 6% of pediatric cancer and it is common in children aged between 15-1

Sources: American Cancer Society, 2023 & National Cancer Institute, 2023

Table 3. Treatment Options in Cancer

Treatment	Definitions
Chemotherapy	A treatment plan including the drugs killing the tumors or slowing the uncontrollable growth of cancer cells. It is the most common treatment option for cancer treatment
Radiotherapy	A treatment plan including high-dose radiation and aiming to kill cancer cells, and slow down the prognoses of the disease
Surgery	A treatment plan including the medical procedure of removing the cancer tissue
Immunotherapy	One of the newer treatment options compared to other treatment plans; It includes a biological therapy that uses materials made from living organisms
Transplantation	A treatment plan including the procedure of replacing blood-forming tissue with the healthy tissue. This replacement can be done with the person's own tissue or from a donor. It is generally used in treatment of blood cancers, like leukemia and lymphoma

Sources: American Cancer Society, 2023 & National Cancer Institute, 2023

2.4 Psychosocial considerations in childhood cancer

Although there are many different improvements in medical treatment and that survival rates of cancer have increased in recent years, childhood cancer is still seen as a life-threatening disease. There is no doubt that having a diagnosis and going

through an exhausting treatment process hinder the psychosocial functioning and the quality of life of the family members as well as the diagnosed child both during and after the treatment (Dongen-Melman & Sanders-Woudstra, 1986; Evan & Zeltzer, 2006; Castellano-Tejador et al., 2016). In this section, the psychosocial experiences of diagnosed children and the parenting children with were reviewed separately in light of the previous studies.

2.4.1 Experiences of children and adolescents with cancer

While the current study's focus is the experiences of parents, it was intended to provide a summary of experiences of children and adolescents with cancer since as the ecological approach recognizes, childhood cancer is a microsystem that is in direct interplay with the parents' experiences (Kazak et al., 1995). Having an understanding of the unique experiences of children and adolescents would facilitate a deeper understanding of the parents' experiences.

Cancer is a disease that necessitates complex treatment procedures which then require life changes (Ebob-Anya, 2022). Children cancer patients are affected by this treatment process differently compared to the adult patients because of their developmental needs and differences (Mcloone, 2021). In addition to physical challenges of the cancer treatment, children are vulnerable to experience severe psychological challenges in their sensitive periods of developmental milestones, and cancer treatment can affect them in the short and the long term (Maurice-Stam, 2022; Darcy, 2019).

A longitudinal and inductive study by Darcy, Enskär, and Björk (2019), focusing on experiences of young children living with cancer, outlines children's struggles in a comprehensive manner. In this study, twelve children, who were

diagnosed at the ages between 1-6 years, were interviewed three years after the diagnosis, and three main categories were identified from the children's answers.

First theme was recognizing the differences between themselves and their peers and wishing that they could be like their peers. Their physical differences such as hair loss or having tubes on their body, having a more dependent relationship with their caregivers and having lower levels of energy that inhibit play were identified as examples to this theme. Second theme was the need for security and control. Suddenness of the diagnosis and the start of the treatment, having unplanned hospital visits, having health care professionals touch their body and implement the necessary procedures without any explanation or permission were identified as some of the experiences that contribute to the child's sense of losing control. The third and last theme from this study was feeling lonely and left out. Cancer treatment requires significant sacrifices for long periods of time. Missing school and the social interactions that come with it as well as remaining in isolation due to a jeopardized immune system appeared to lead to a lack of connectedness and feelings of loneliness for the children which seemed to continue when they came back to school as well due to experiences such as not having enough energy to engage in play or being left out by the peers. Another notable finding from Darcy et al.'s (2019) was that parents expressed that their children overlooked social codes throughout the treatment, and they have started to behave in ways that were socially inappropriate. To illustrate, children could have a very hard time finishing a play session, holding onto a game even if others have had enough.

One of the important studies by Gürcan and Atay Turan (2020) examining the experience of adolescents receiving cancer treatment in Türkiye revealed themes very similar to the themes by Darcy, Enskär, and Björk (2019). The study was

conducted with twelve adolescents aged 12-18 years by using descriptive qualitative research design and revealed two larger themes. The first main theme was coined as being an adolescent with cancer, and it included the sub-themes of changes in health, restriction of freedom, and feeling lonely. First, participating adolescents expressed that the treatment changed their body in numerous ways, and side effects of the chemotherapy made them feel sick. Second, adolescents expressed losing their freedom, and they reported experiencing this life as undesirable because the required treatment imposed certain restraints such as, restriction of certain food items and the necessity of being in isolation to prevent infection. And the third and last sub-theme was adolescents' sense of deep loneliness. They reported that they could not share their feelings and thoughts with their close friends, and they missed their school and social life. Because their physical looks and body images had changed, they felt ugly and avoided others which has disconnected them further, and hence, increased their feeling of loneliness.

The second main theme that Gürcan and Atay Turan (2020) derived from their data was coined as coping with cancer, and it consisted of two sub-themes of psychological growth and hope for healing. The majority of participants expressed that their perspectives on life had changed; they did not feel too much sadness about daily problems and they were more mindful after the disease. In addition, they stated that this disease was not permanent, and they had hope for healing and getting better. This hope appeared to both contribute to their psychological wellbeing and growth, and support their recovery.

Conducted studies confirm that the experiences of children and adolescents receiving cancer treatment have rather similar experiences. Changes of body image, missing their daily routine, schools and friends and also feeling lonely are major

challenging issues for children and adolescents with cancer (McLoone, 2021; Vena & Copel, 2021; Darcy et al., 2019; Gürcan et al., 2020).

These findings can also be reviewed from the lens of International Classification of Functioning (ICF) which was informed by the biopsychosocial approach and developed by the World Health Organization (WHO, 2001). ICF provides an international standard for examining and potentially increasing the functioning of a person with a disability or illness by taking into account both the medical and social factors which they have experienced through exploring four domains of (1) body functions, (2) body structures, (3) activities and participation, and (4) environmental factors (WHO, 2001).

Indeed, the studies identified above showcases how childhood cancer impacts a child's and adolescents' functioning especially at the first three levels (WHO, 2007). Children and adolescents treated for cancer do experience changes in the domain of body function whether it is their energy level, sleep quality, or psychomotor systems. Those who had surgical procedures experience changes in the body structure domain. Activities in which they can engage and their participation in different social contexts change throughout the treatment process. Children and adolescents are likely to experience difficulties in carrying out their daily life, education program or household tasks.

When it comes to the fourth domain, which is the domain of environmental factors, it would be equally important to understand the ways in which certain healthcare policies and systems might be a barrier and facilitator of children's and adolescents' functioning. In addition, ICF points out that attitudes of certain individuals such as health care professionals, friends and immediate family members might be a facilitator of the children's and adolescents' functioning (WHO, 2007).

Hence, it is pivotal to study parental experiences and find ways to support those who do have the potential to contribute to the patients' functioning. Next, we shift our attention to the literature focusing on experiences of parents of children with cancer.

2.4.2 Parenting children with cancer

Parenting of a child with cancer has many facets. Studies show that cancer leads to major changes in family dynamics, and parents of children with cancer experience common challenges (Gibbins et al., 2012; Khoury et al., 2013 Taleghani et al., 2012). Although most of the findings focused on the challenging experiences of these parents, studies also investigated supporting experiences of parents of children with cancer (Gibbins et al., 2012, Schweitzer et al., 2011). In this section, the experiences of being a parent of a child diagnosed with cancer will be examined to reflect on the challenges they face and support they receive.

2.4.2.1 Challenging experiences of parents

In the light of the literature, the main challenging experiences of parenting children with cancer are identified as adaptation process, emotional distress, major lifestyle and daily routine changes, parents' isolation from social contexts, and other different problems in family dynamics (Gibbins et al., 2012; Khoury et al., 2013; Taleghani et al., 2012). In this section, these experiences will be introduced in detail.

2.4.2.1.1 Adaptation to diagnosis and treatment

A study by Schweitzer, Griffiths, and Yates (2012) examined the parental experiences of childhood cancer through interpretative phenomenological analysis in Australia, and it derived that parental experiences of facing diagnosis were intense and unique,

but the common and the most important phenomenon was the vulnerability of their child and facing the potential of losing him/her. The study emphasized that parents' first reactions to diagnosis was shock, sorrow, and denial of the potential mortality of their offspring. Another study in Sweden, regarding the parent's experiences of the diagnosis and treatment process of childhood cancer, found that the parents defined the diagnosis time as chaotic and uncontrollable, and they expressed a deep sense of unfairness and anger in the beginning (Carlsson et al., 2019).

Existing studies also stated that it was a challenging experience for parents to see their children suffer from treatment side effects (Tan et al., 2022; Warman, 2021). A qualitative study conducted with four Latina mothers of children with cancer has shown that it was difficult for mothers to observe their children experiencing the side effects of the cancer treatment and it was unbearable for them to witness their child in pain (Warman, 2021).

In addition to the difficulty of the first feelings and witnessing the side effects of the treatment, another challenge in the adaptation process for parents was talking about cancer with their child (Tan et al. 2022). A study by Tan et al. (2022) stated that mothers did not want to tell their child that this disease was serious, and they tried not to use the word "cancer". Also, it was emphasized that they could not know how to inform their child and they needed support from professionals in this period (Tan et al., 2022).

When the studies conducted in Türkiye are examined, it is possible to observe similar results. A quantitative study conducted with 130 parents and examining the burnout and coping skills of parents of children treated in oncology and hematology services in Türkiye indicated that the parents reacted with hopelessness, shock, denial, and deep sadness when they were faced with the diagnosis of childhood

cancer (Uzun, 2016). Another qualitative study with 12 parents also supported the mentioned findings and it contended that the parents experienced astonishment, shock, and denial at the very first time of the diagnosis (Günay & Özkan, 2019). Moreover, the participants stated that in the beginning of the process they thought that cancer was a life-threatening disease and it reminded them of the possibility of death of their children (Günay & Özkan, 2019). Similar to international studies, studies conducted in Türkiye also highlighted that facing side effects of the cancer treatment was a very stressful experience for the parents especially since there was nothing they could do to protect their children from these side effects (Ay & Akyar, 2020).

2.4.2.1.2 Emotional distress

Given its demanding nature, cancer has an emotional toll on everyone involved in the process, most certainly including the parents of the children going through the cancer treatment. The treatment process, including hospitalization, surgery, regular clinical appointments, and changes in family dynamics, roles and routines, leads to high levels of parental emotional distress (Džombić & Ogresta, 2020).

Studies have shown that parents of children with cancer experience various challenging feelings, such as anxiety, fear, sadness, and uncertainty (Gibbins et al., 2012; Schweitzer et al., 2012; Somkome, 2020). These challenging feelings might cause some physical and psychological problems for parents. It is found that parents exposed to stressful feelings suffer from physical symptoms including insomnia, headaches, and weight changes. In addition to these symptoms, they are prone to develop depression, post-traumatic stress disorder (PTSD), and other anxiety disorders. (Maryam et al., 2022; Picci et al., 2015; Seth, 2022).

A hermeneutic qualitative study examining the lived experiences of parents of children with cancer in Lebanon reported that the shock reaction in the diagnosis process triggered very high levels of stress on parents, and most of the parents highlighted that it was the most overwhelming feeling they had experienced in the whole treatment process. The study also noted that living with uncertainty was a major issue and it increased parents' stress and anxiety levels (Khoury et al., 2013). Likewise, Taleghani et al. (2013) also conducted a hermeneutic qualitative study with 15 parents of children diagnosed with cancer in Iran and focused on their lived experiences. Participating parents revealed that parenting a child with cancer can lead to emotional instability, anxiety, and depression, and they expressed feeling trapped by the thought of death of their children in this process (Taleghani et al., 2013).

These results are consistent with the study by Ovayolu et al. (2014), focusing on the quality of life of the caregivers of children with cancer in Türkiye. Researchers outlined that caregivers of children with cancer feel anger, guilt, despair and also, they experience exhaustion, depression, and anxiety as well as physical health problems.

Additional studies conducted in Türkiye support the relation between developing PTSD and parenting children with cancer. A study conducted with 117 parents of children with cancer indicated that 17 % of mothers of children with cancer suffered from PTSD symptoms (Moğolkoç, 2014). Another study by Karadeniz Cerit et al. (2017), examining mothers of children who underwent oncological surgery and their reactions and PTSD symptoms, had consistent findings and showed that cancer treatment, hospitalization and surgical procedures can trigger

PTSD symptoms on mothers, and lack of information and support can worsen these reactions.

2.4.2.1.3 Lifestyle and daily routine changes

Cancer diagnosis and treatment bring about noteworthy changes in lifestyle and daily routines of both parents and family. After diagnosis, cancer becomes the very first and maybe the only major item on the family's agenda. Studies have shown that parents usually structure their daily lives around their children's school before the diagnosis. However, after the diagnosis, the medical need of the child becomes the determining factor (Schweitzer et al., 2012; Džombić & Ogresta, 2020).

Additionally, other fundamental routines at home like mealtime and leisurely activities undergo a shift to accommodate the treatment requirements (Khoury et al., 2013). Santos, Crespo, Canavorra, and Kazak (2018) reported in a study of family rituals of children with cancer and their parents in Portugal, that there are two categories of changes in family: (1) loss of the family rituals, and (2) transformation of the family rituals. The loss of the family rituals includes the loss of mealtime, regular celebrations, or weekend activities. And the transformation of the family rituals means that the basic rituals have to be re-established in a different way. To illustrate, birthday celebrations cannot be at a restaurant because of the necessity of isolation. Another example is that the whole family cannot eat together at the same table at the same time because of isolation or hospitalization. These changes can cause a lack of socialization and communication within the family.

Another important point that changes the parents' and family routine and affects the socialization is the working hours of parents. Research reveals a tendency where one of the parents spends more time at work while the other parent takes care

of the child in the treatment process. Mothers generally quit their job and spend time caring for their children, and the fathers mostly have to work more to balance the economical drawbacks (Somkome, 2020; Nicholas & Gearing, 2009; Bennett Murphy et al., 2008).

When it comes to the studies in Türkiye, it is possible to find similar results. A qualitative study by Yildirim Sari et al. (2013), and conducted with twelve parents, focusing on the experiences of parents of children with cancer and need physical care, highlighted that parents had difficulties to lead their daily routines in the treatment process. Moreover, there are also studies that confirm that the fathers spend limited time with their children, and mostly the mothers care for the children and undertake the treatment process, which further changes the family routines (Günay et al., 2019; Ovayolu et al., 2014).

2.4.2.1.4 Parental isolation from social contexts

Research illustrates that one of the challenging experiences of parents of children with cancer is being isolated from social context (Gibbins et al., 2012; Khoury et al.,2013; Taleghani et al., 2012). This increased isolation is explained by various factors that can be grouped as (1) family-initiated reasons, and (2) reasons facilitated by decisions of other individuals. For instance, since the children undergoing cancer treatment have a lower immunity and higher risk of infection, parents limit their social contact in an effort to protect their child's health (Khoury et al, 2013). Additionally, certain treatments, such as a bone marrow transplant increases the need for isolation in terms of the infection and the children and their parents have to stay in an isolated room for 4-6 weeks after the transplant (Luo et al., 2019; Mangurian et

al., 2018). Understandably, such a condition creates additional emotional burden for both caregivers and the children (Luo et al., 2019; Mangurian et al., 2018).

With respect to the second category, literature suggests that others' emotional processes and beliefs might limit family's socialization. People who are not familiar with cancer and its treatment may not want to communicate with the child diagnosed with cancer and their family since this situation makes them anxious and scared. And they may avoid witnessing the realities of this serious disease including the possibility of its causing death (Taleghani et al., 2012; Džombić & Ogresta, 2020). Taleghani et al. (2012) also reported that some people believe that cancer is a contagious disease, and they might be infected if they get in contact with a person with cancer. Hence, they do not contact the families in the treatment process, adding onto the reason why children diagnosed with cancer and their parents have limited sources for socialization.

Çınar et al. (2021) reported in a study of parenting stress in parents of children with cancer in Türkiye that the parents suffer from the same distancing and lack of social support. These results of the study were consistent with an earlier study from Türkiye which has identified social isolation as one of the experiences decreasing the quality of life of the parents of children with cancer (Ovayolu et al., 2014).

2.4.2.1.5 Other problems in family

According to systematic review study of existing literature across the world by Gibbins, Steinhardt, and Beinart (2012), challenges on financial issues, couple's relationship, and problems with siblings of children with cancer are other significant experiences that parents can encounter during the cancer treatment. The review study

includes 28 qualitative studies regarding the experiences of parents of children with cancer, and across different cultures and genders, the following three themes are repeated in the studies.

First, as it is mentioned in the lifestyle and daily routine changes section, one of the parents usually quit their job because of caring for their child. This situation naturally creates a financial drawback. In addition to this, cancer treatment has many requirements, like special medical products, limited dietary options, hospitalization, and restricted transportation. All of these lead to additional financial burden for the parents (Džombić et al., 2020; Gibbins et al., 2012; Khoury et al., 2013).

Second, problems in marital relationships are another noteworthy challenge for parents. The above-mentioned division of tasks between parents where mothers are more involved in caring during the treatment and the fathers are responsible for the financial aspects causes them to spend limited time together and experience communication problems between them (Young et al., 2021; Taleghani et al., 2012; Clarke, 2006).

Last, siblings of children with cancer are also affected by these lifestyle changes. A systematic review study by Young, Bowers, and Bradford (2021), dealing with the experiences of the families of children and adolescents who have brain tumors, highlighted that siblings can be missed out during the treatment. In this study, it is observed that siblings can feel deep-seated anger and rivalry because they spend limited time with their parents and miss them. Participating siblings expressed that they need more support in their school tasks or other daily activities, but they cannot reach their parents. Therefore, it can be concluded that siblings too experience adaptation problems and unique challenges as their parents do (Young et al., 2021; Gibbins et al., 2012; Taleghani et al., 2012; Khoury et al., 2012).

Another systematic review study focusing on the psychosocial status of families of pediatric cancer patients in Türkiye features that siblings strive to adapt to their new lives, and they are at risk to develop psychosocial problems. And as parents try to meet their needs, they can experience a burden of care which increases their likelihood of developing psychological problems (Ay & Akyar, 2020).

2.4.2.2 Needs of parents

When the literature was covered, it can be observed that the need assessment of the parents of children diagnosed with cancer was generally made based on inferences from their challenging experiences by the professionals. In a qualitative study, focusing on the needs of the parents of children and adolescents treated for cancer, conducted in Spain by Bretones Nieto et al. (2022), twenty parents were interviewed and based on the answers, five main themes were determined as the priority areas of needs of the parents. These themes included health problems of parents, stressors of parents, fears or worries, coping and informal social support, including emotional or instrumental support from their families and friends (Bretones Nieto et al., 2022). Additionally, it was also highlighted that parents stated their needs about their child's education, formal support, including information from health care professionals and social support from NGOs (Bretones Nieto et al., 2022).

Another qualitative study conducted in Singapore by Tan et al., (2020), focusing on the experiences of the parents of children and adolescents with cancer, emphasized the similar needs. In this study, ten parents of children and adolescents receiving cancer treatment were interviewed, and the parents reported their informational needs about the disease, financial burden of the treatment process, moral and emotional needs (Tan et al., 2020).

Studies conducted in Türkiye also emphasized the similar needs of parents of children and adolescents receiving cancer treatment as the above studies highlighted (Altay et al., 2014; Ay & Akyar, 2020; Günay & Özkan, 2019). The study by Altay et al. (2014) stated that the primary needs of caregivers of children with cancer were emotional or psychological and informational support. Social needs, including the moral, financial and practical support were other mentioned needs of the parents of children treated for cancer in Türkiye (Altay et al., 2014; Ay & Akyar, 2020; Günay & Özkan, 2019; Ozdemir Koyu & Tas Arslan, 2021).

2.4.2.3 Sources of support for parents

As mentioned above, cancer diagnosis and treatment process include different challenging experiences for the whole family (Gibbins et al., 2012, Young et al., 2021). And these experiences can result in physical and emotional exhaustion for parents of children receiving cancer treatment. However, literature also shows that these experiences might create positive outcomes when parents receive valuable support (Gibbins et al., 2012, Schweitzer et al., 2011).

The above-mentioned qualitative study conducted in Australia by Schweitzer et al. (2011) clarified four basic resources that parents of children diagnosed with cancer can benefit from as a support while their child undergoes the treatment process. Conducted with ten parents of children receiving cancer treatment, this study identified four important resources, namely family support and friends, supportive workplace, the education system, and being accepted (Schweitzer et al., 2011).

First, participating parents expressed that the extended family and friends network were a huge support. Parents indicated that it was a positive experience to find people that might have never experienced the same challenges, but support them unconditionally (Schweitzer et al., 2011).

Second, a supportive workplace seemed to ease a parent's burden. As it is mentioned in the challenging experiences section, children's doctor appointments and hospitalization force parents to arrange their working hours and daily routine, and sometimes they need to quit their job and experience the financial drawback (Džombić & Ogresta, 2020; Khoury et al., 2013). In this study, it was observed that the workplace's offering flexible working hours and days, and earning a satisfactory salary were noticeable supporting experiences that parents appreciated in that challenging process (Schweitzer et al., 2011).

Third support was how the parents experienced the education system. Because the treatment process causes attendance problems and children miss their coursework for a long time, they have a risk of repeating a grade which creates anxiety for both parents and children. However, if the school principals guarantee that the child will be supported in their education setting and will not fall behind in the education schedule, parents experience a deep relief (Schweitzer et al., 2011).

The fourth and last supporting experience of parents was being accepted by the wider community. In this study, parents expressed that they felt themselves as an outsider when their children were diagnosed with cancer. And yet they felt confident when they encountered helpful behavior and generous attitudes from the people outside of their circle. And this type of community presence was perceived as a supporting experience by them (Schweitzer et al., 2011).

The study by Nicholas et al. (2009), focusing on the experiences of fathers of children with cancer in Canada adds spiritual practices to this list of support that make it easier for parents to cope with the treatment process. Parents reported that engaging in spiritual activities, such as praying or receiving spiritual counseling, made them feel like they do something meaningful for their children's health, which in turn seemed to reduce their level of anxiety. And the findings of the above-mentioned systematic review study by Gibbins et al. (2012) was consistent with this study and highlighted that religious practices could be a coping mechanism for parents.

Studies conducted later on not only confirmed that social, workplace, educational and community support mattered to parents of children with cancer but also revealed additional resources. A study in Croatia by Džombić and Ogresta (2020) stated that the assistance offered by nongovernmental organizations (NGOs) is an important supportive action for parents, because these organizations create an environment where parents can communicate with each other and be socialized. Also, organizations that raise money for families in need are identified as another support for the parents who have financial difficulties (Džombić & Ogresta, 2020). Additionally, parents also have an opportunity to be informed about the diagnosis and treatment process in these organizations, and this informational support fulfills an important need and relieves their worries about the uncertainty of the process especially when it is provided by healthcare professionals (Džombić & Ogresta, 2020; Gibbins et al., 2012).

Patterson et al. (2004) stated different resources of the parents which were not commonly mentioned in the literature. This qualitative study was conducted with 99 parents of children diagnosed with cancer and examined the experiences of them in

this period. In addition to the above-mentioned resources, it was highlighted that the diagnosed children had become an important resource for the parents by being strong and behaving maturely. Moreover, Patterson et al. (2004) also asserted that the other parents who experienced a similar situation had become another important resource for the parents. They were relieved when they could get information and advice about the process from the other parents of children treated with cancer (Patterson et al., 2004).

Studies show that parents of children receiving cancer treatment report a number of positive outcomes of the treatment process if they receive enough resources and support (Gibbins et al., 2012; Schweitzer et al., 2011). The most highlighted positive life experience can be summarized as increased awareness of the preciousness of the present moment. Participating parents expressed that they wanted to be cognizant of the importance of life and found meaning in every moment that they are together. They reported that they attempted not to postpone the opportunities they could experience together because they recognized how fragile life was (Schweitzer et al., 2011). Second, the sense of family and relationship among family members underwent a change in a positive way (Gibbins et al., 2012; Porter et al., 2019; Schweitzer et al., 2011). A study by Porter et al. (2019) that was focusing on the couples parenting children with cancer in the US argued that couples' relationships were strengthened if they were supported. Although the division of labor causes parents to communicate less, Gibbins et al. (2012) also highlighted that parents worked as a team in this period and this divided labor has the potential to make partners' relationship better especially if they did not have enough support from others. Also, they stated they experienced personal growth and felt the sense of surviving. Furthermore, it is shown that parents give an increased attention to family

units, and other relationship dynamics in the family are also nurtured (Gibbins et al., 2012; Schwitzer et al., 2011).

When it comes to the studies in Türkiye, there are limited resources focusing on the supporting experiences and positive outcomes that parents of children with cancer can encounter in the treatment process. A study by Altay et al. (2014) examined the social support needs of mothers of children with cancer in Türkiye. The study was conducted with 88 mothers, and found that mothers needed different types of social support, and they reached these supports via different resources, but mostly through their families (83%). Physicians (44.6%), nurses (38.4%), friends (30.7%), and neighbors (24.6%) were other noteworthy sources of support for mothers. Also, the study showed that the most important needs of mothers of children with cancer were emotional and informational support. However, it was highlighted that the mothers could obtain less social support than they needed. These findings are important for the parents of children receiving cancer treatment in Türkiye, and they are consistent with the studies conducted in other countries.

Another study by Ozdemir-Koyu and Tas-Arslan (2021), examining the symptoms of caregiver burden for parents of children with cancer and conducted with 172 parents, found that social support is a strong moderator reducing the psychological symptoms of parents' burden such as anxiety and depression. However, the study did not specify the types of social support that were discussed in the above-mentioned study by Altay et al. (2014).

All in all, when the studies conducted in Türkiye regarding the supporting experiences and needs of this population are reviewed, there are no comprehensive studies focusing on the helpful support that can be a resource and meet the existing

supportive needs of parents. More studies focusing on the supporting experiences of parents of children receiving cancer treatment in Türkiye is needed.

2.4.2.4 Coping strategies of parents

After talking about the challenging experiences of parents of children receiving cancer treatment, it is important to highlight how they cope with those situations and what coping strategies they use in the diagnosis and treatment process. Lazarus and Folkman (1984) defined coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding resources of the person" (p. 141). In other words, coping includes all psychological and behavioral strategies that make it easier to handle stressful situations and crises (Desai et al., 2016). Lazarus and Folkman (1984) highlighted different dimensions of coping. First, coping is a process-oriented response, not a stable or trait-oriented attribute, and these responses can change constantly during the process (Lazarus & Folkman, 1984). Second, coping is not an automated adaptive behavior, and it is important to differentiate between coping and automatic responses that do not require effort (Lazarus & Folkman, 1984). Third, coping strategies include all efforts that people think or do to manage that situation, and it cannot be determined as working well or badly (Lazarus & Folkman, 1984). Last, coping does not mean only mastery, managing is a better word to express it because it includes both accepting, avoiding, minimizing, and tolerating the event as well as mastering (Lazarus & Folkman, 1984).

Literature on this subject divided coping into three categories as appraisal-focused coping, emotion-focused coping and problem-focused coping (Lazarus & Folkman, 1984; Patterson et al., 2004; Sodi & Kgopa, 2016). Appraisal-focused

coping involves how the people think about the situation and what types of perspectives they have, such as denying what is going on or focusing on the positive sides of the event, and maintaining hope (Patterson et al, 2004; Sodi & Kgopa, 2016). It generally interferes with the thinking process and thoughts (Sodi & Kgopa, 2016). Emotion-focused coping refers to the way of managing and releasing overwhelming feelings such as humor, crying or being strong (Lazarus & Folkman, 1984; Miedema et al., 2010; Patterson et al., 2004). Problem-focused coping includes the ways of problem solving and its steps such as defining the problem, thinking about pros and cons of the situation, and acting to solve the problem, such as seeking information about the issue, being organized and taking actions (Lazarus & Folkman, 1984; Miedema et al., 2010; Patterson et al., 2004). The most used parental coping strategies for childhood cancer may vary from culture to culture, yet literature shows that there are common strategies used by parents of children treated for cancer (Desai et al., 2016; Ghorbani et al., 2020; Lyu et al., 2019).

The results of the Miedema et al.'s (2010) qualitative study highlighted the majority of parents of children with cancer used emotion-focused coping strategies. The study was conducted with 28 English and French caregivers of children treated for cancer and it showed that some of the parents used emotion-focused coping by trying to hide overwhelming emotions and some of them used positive emotion-focused coping by seeking support, humor or fun and writing their feelings and experiences.

The review study conducted by Desai, Rivera and Backes (2016) examined how Latino caregivers of children with chronic illness cope with the chronic illnesses while caring for their children. The study involved 21 research focusing on the coping strategies of parents of children with chronic pediatric illnesses, including

cancer, conducted between in 1985 and in 2014, and it identified major coping strategies of these parents as religion and spirituality that is a form of appraisal-focused coping strategy, expressing their feelings to family members that is a emotion-focused coping strategy, and being informed about the illness, that is one of the problem-focused coping strategies.

One more study examining the coping strategies of parents of children with chronic illness showed that parents used both three types of coping strategies (Sodi & Kgopa, 2016). The qualitative study was conducted with 10 participating mother caregivers of children diagnosed with a chronic illness in South Africa and it was found that emotion-focused coping was the most common coping strategies among caregivers of children suffering from chronic illness and the mothers sought support from their relatives or a group of people having experiences to feel sense of belonging. Moreover, mothers also tried to reach information and educate themselves about the illness of their children as a problem-focused coping. Sodi and Kgopa (2016) also emphasized that mothers utilized appraisal-focused coping by accepting the situation and facing the realities of illness.

Another qualitative study focusing on the coping strategies of Chinese parents of children receiving cancer treatment by Lyu et al. (2019) asserted that the most prominent coping strategies that parents used are increasing bonding among family members and seeking support that are the types of emotion-focused coping and also optimistic thoughts, and not disclosing the unfavorable information that are appraisal-focused coping strategies.

Literature asserted that the parents of children receiving cancer treatment in Türkiye used similar coping strategies (Usluoğlu, 2018). The study conducted with 24 caregiver of children with cancer in Türkiye showed that parents utilized both

three type of coping strategies however the least used strategy is the problem-focused coping, and seeking the information about the disease and its treatment is the most common form of this coping strategy (Usluoğlu, 2018). Almost all of the participating parents applied emotion-focused coping by trying to be strong for the role of being a parent and seeking the support from their surroundings (Usluoğlu, 2018). Additionally, they tend to maintain their hopes and be positive and also trust God to cope with that situation as a form of appraisal-focused coping (Usluoğlu, 2018).

When the general picture about the experiences of parents of children and adolescents treated for cancer was considered, their challenging experiences, needs, sources of support and coping strategies can be evaluated in light of the ecological system approach because their experiences as a whole shows layers as indicated by the ecological system, which were microsystem, mesosystem, exosystem, macrosystem and chronosystem (Kazak et al. 2009; Steele & Aylward, 2009). Ecological framework would continue to guide our understanding as we reflect on the assessment and management of psychosocial problems experienced in relation to childhood cancer, which will be explored in the next section.

2.4.3 Assessment and management psychosocial problems in childhood cancer

As it was stated above, childhood cancer has significant psychosocial effects on all family members. Although these psychosocial effects and needs of children with cancer and their families were highlighted by multiple studies, it can be observed that systematic psychosocial care appears to be missing even in the pediatric cancer intervention programs (Kazak et al., 2015). However, studies highlight the

importance of conducting an assessment to meet the needs of these children and their families, and even note this assessment as the first step to be taken (Kazak et al., 2015; Kazak et al., 2020). Additionally, since the needs of children diagnosed with cancer and their families may change during the course of treatment and follow-up process, this assessment needs to be conducted on a regular basis, not just at the beginning (Kazak et al., 2015). Given our ecological understanding of the way childhood cancer operates, it is also important that such assessments should take other microsystems and macrosystems into the account including the parents, siblings, and also broader systems, including health care providers, schools, or cultures (Kazak et al., 2015; Wiener et al., 2015).

A study by Wiener et al. (2015), focusing on the psychosocial care for children with cancer and their families, identified assessment as the first of significant standards of pediatric cancer care. Scientifically determined standards suggest the patients and also survivors should receive an assessment each year in terms of social, emotional, education or vocational progress (Wiener et al., 2015). Also, if the child has specific needs depending on his/her age, the developmentally appropriate assessment should be considered (Wiener et al., 2015). Additionally, needs of the family members should be determined and the intervention plans should be designed for the factors which cause physical, emotional or financial burden for them and influence their quality of life negatively (Wiener et al., 2015). Another important factor for the standard of care was open communication among the child, the family members and health care providers, the psychosocial providers work as a team while considering the different dimensions of the children with cancer and their family members (Wiener et al., 2015). One more standard of care for the children with cancer is school re-entry and collaboration with the school staff (Wiener et al.,

2015). The school staff should be informed about the diagnosis, treatment plan, the needs of the child by the psychosocial providers and given recommendations to support the diagnosed children and their families (Wiener et al., 2015).

When it comes to Türkiye, the Ministry of Health (2011) published a guideline, focusing on the implementation of specific health services in Türkiye between the years 2011-2023. This guideline asserted that an oncology unit is composed of a multidisciplinary team, including the professionals who can provide psychological and social services as well as the experts in the field of medicine. However, to the best of our knowledge, there is not a standardized assessment and care for the psychosocial dimension of childhood cancer. It appears that psychosocial evaluation and support for the children with cancer and their families in Türkiye is not a common implementation which is similar to the situation in many countries although there are some institutions which provide an intervention program for them (Kazak et al., 2015).

2.5 Childhood cancer in school setting

Childhood cancer is generally an underestimated issue in school settings because it is a rare situation and typically school staff, including administrators, teachers, and school counselors, do not have enough information about it (Armstrong & Briery, 2004). However, they can play a significant role in this difficult process to assist the diagnosed children and their parents (Armstrong & Briery, 2004; Klein et al., 2022).

Studies showed that the children diagnosed with cancer may experience different physical, social, emotional, and also academic problems in school settings. Some of them could continue their education in their schools, but most of the

diagnosed children suffer from long-term absenteeism due to the hospitalization and the serious side-effects of the treatment (Klein et al., 2022; Otth & Scheinemann, 2022). Thus, it is important to be aware of the special needs of the diagnosed children in school.

As mentioned before, children with cancer experience numerous side-effects because of the treatment. First observable side-effects are often related to the appearance of the children (Armstrong & Briery, 2004). Children may lose their hair, experience weight changes, or may have other physical changes due to a surgical operation (Armstrong & Briery, 2004). Other side effects which can be less noticeable but highly impactful for their schooling experience would be child's feeling tired or suffering from nausea or pain (Armstrong & Briery, 2004; Klein et al., 2022). Additionally, they may also face some cognitive problems, including related with the working memory, attention span or processing speed (Klein et al., 2022). Under this condition, going back to school is not an easy process neither for the children, nor for the parents and teachers (Klein et al., 2022; Otth & Scheinemann, 2022). All of these factors often put the diagnosed children under strain socially and academically, which requires the school staff to be aware of all these needs (Bryan et al., 2021; Klein et al., 2022).

Klein et al. (2022) emphasized that school support was an important part of the psychosocial standard of care for children diagnosed with cancer and it should include specific information about the child's diagnosis, treatment process, potential side-effects, and recommendations for the school staff regarding how to support the children in school setting. Authors highlighted that there should be ongoing communication among the medical staff, parents, teachers and the child, and the school staff should be informed about the physical, social, emotional needs of the

children under the treatment as well as the survivors. Moreover, it was recommended that school staff should be offered training about childhood cancer.

When it comes to regulations for the education of the children treated for cancer in Türkiye, the Ministry of National Education (2010) published directives for home and hospital education services. This guideline offers some regulations and rules about the children who cannot continue their education because of their special needs and health conditions (Türkiye Ministry of National Education, 2023). According to this guideline, children at preschool and primary school level are to be provided educational services at home or in hospitals. In Türkiye, some hospitals have a classroom in the oncology units, and with the approval of their parents and doctors the preschool or primary school children can continue their education in this classroom. On the other hand, children attending middle or high school are offered homeschooling services. For these children, an individualized education program (IEP) is to be collectively prepared by the counselors, teachers and administrators. Identified staff members prepare a curriculum focusing on the needs of the child and also they are expected to offer guidance for the family members about the preparation and implementation of IEP.

When these recommendations are considered, it is important to highlight the roles of school counselors to provide functional support for the children diagnosed with cancer in the school. In the next section, the roles of school counselor will be explained as discussed in the literature.

2.5.1 Role of the school counselor

Karayanni and Spitzer (1984) identified the roles of school counselor for the children diagnosed with cancer and the target groups which should be worked in this period.

According to the authors, the school counselors were regarded as a key person for the adaptation process of the diagnosed child in the school and it was stated that their counseling process for the children with cancer should include four target groups as the diagnosed child, classmates, the school staff, and the family members of the diagnosed child (Karayanni & Spitzer, 1984). Similar to this study, a study by Kaffenberger (2006), focusing on the role of the school counselors in the process of re-entering school for the children with chronic illness, emphasized six features of the school integration programs for the children with cancer. This type of integration program was recommended to include direct services to the diagnosed child, information for the classmates, training for the school staff, consulting with the family, and collaboration with the medical team with a school-based or medical team coordinator (Kaffenberger, 2006). School counselors had a key role as the coordinator of this integration program and were expected to identify the specific needs of all target groups according to Kaffenberger (2006).

As Kaffenberger (2006) asserted the role of coordination of the school counselors, Karayanni and Spitzer (1984) talked about three roles of the school counselors for the children treated for cancer. It was stated that the school counselors should be aware of the needs of children while considering their roles as coordinator, resource person and counselor. With respect to coordination, a school counselor is expected to coordinate the communication and the meetings among child, family and medical staff, which was reported to be one of the most significant parts of the school re-entry (Karayanni & Spitzer, 1984; Klein et al. 2022). As a resource person, a school counselor is expected to keep up to date information about the medical, psychosocial, and counseling needs of the diagnosed children and share them with the relevant people when necessary (Karayanni & Spitzer, 1984). And also school

counselors are seen responsible for monitoring children's functioning both inside and outside the school and are expected to provide individual or group counseling (Karayanni & Spitzer, 1984).

In addition to these above-mentioned roles, advocacy is identified as another role of the school counselors (Herlihy & Corey, 2015). Most of the diagnosed children and their parents in this period are not aware of their needs or rights in educational setting, and it can be said that the school counselors have a key position to bridge that gap and advocate for these families' needs to be met and rights to be protected (Armstrong & Briery, 2004).

In Türkiye, the school counselors are expected to be part of a student's chronic illness process either through School Risk Maps and IEPs. School Risk Map is an evaluation form offered by the Türkiye Ministry of National Education and it aims to determine the risk status of students such as chronic illnesses, mental disorders, poverty or family problems. School counselors are responsible for the implementation of the risk maps, and they collect necessary information from the administrators, teachers, or parents so that they can navigate the process of preparing and implementing an effective individualized education program (IEP). As introduced in the above section, IEPs are intended for middle school or high school students in need and school counselors are responsible for examining the developmental and special needs of these children and offering guidance and counseling for them and their parents. However, how these required processes are implemented with respect to children and adolescents with cancer and to what degree school counselors are familiar with childhood cancer appear to be a topic that needs further attention.

In conclusion, it can be seen that the school counselors have a vital position for the integration of children with cancer in the school setting. Childhood cancer is not a well-known disease in the school setting. The children and the parents may not be aware of their educational needs and rights (Armstrong & Briery, 2004; Klein et al., 2022). And also, the teachers and the other school staff may not know how they lead the process with these children and their families (Klein et al., 2022). Therefore, it is very crucial for the school counselor to recognize their potential roles and own the responsibility in order to be able to offer a comprehensive intervention program for the children with cancer and their families (Bryan et al., 2021; Kaffenberger, 2006; Klein et al., 2022). School counselors as an important aspect of the school microsystem have the potential to be a great resource for the parents whose children are undergoing cancer treatment, which would directly benefit the student.

All in all, the current study aims to investigate the lived experiences of parents of children and adolescents with cancer in Türkiye. Based on the findings of the previous studies, the parents of children diagnosed with cancer encounter some physical, social and emotional challenging experiences and they have special needs to overcome these challenging experiences. From this respect, sources of support have become a significant issue for the parents, and friends, family members, NGOs, and religion were important sources of support for them. If they reach enough support they are able to apply coping strategies and they might experience some important perspective changes in their lives. Also, the roles of counselors and their implementation might be an important resource for the well-being of parents of children and adolescents with cancer.

CHAPTER 3

METHOD

In this section, information about the research design, participants, instruments for the data collection, and procedure for the data recruitment, data analysis, and the identity of the researcher will be introduced.

3.1 Research design

In the present study, a qualitative approach was utilized in order to investigate the experiences of parents whose children are going through cancer treatment in Türkiye. According to Hammarberg et al. (2016), qualitative design is a suitable method when the researcher aims to determine the experiences of people and their meaning making process about a phenomenon, and in-depth interviews can be used to understand experiences and the issues from personal perspectives. It provides researchers to understand how individuals subjectively respond to a specific concept and classify the written or oral materials that emerged from these personal experiences, their differences and similarities (Creswell, 1998; Creswell, 2007). For this reason, qualitative design is determined as a better suited approach to understand the lived experiences of parents of children and adolescents diagnosed with cancer and make the unique and similar experiences of them visible.

3.2 Participants

For the present study, the parents of children and adolescents diagnosed with any type of cancer and under treatment for at least three months were chosen as

participants. Because adjusting to diagnosis takes at least three months, parents of children diagnosed with cancer in less than three months were excluded (Kearney et al., 2015). In order to prevent confounding factors and to ensure homogeneity, the parents of school-aged children and adolescents aged between 6 and 17 were included for the study because infancy and early childhood periods have different characteristics, developmental needs and special care requirements. Other exclusion criteria to prevent confounding factors and ensure homogeneity are as follows:

- parents whose children's active treatment period is over and currently only having follow-up meetings with their health provider,
- parents whose children are in remission,
- parents whose children have had one or more relapses with cancer,
- parents whose children are in palliative care and continue their treatment just at home,
- parents whose children have a concurrent disease with cancer, and
- parents who have other family members having a chronic illness.

Participants of the study were reached via snowball sampling which is known as non-probability chain referral sampling (Johnson, 2005). This sampling method allows researchers to reach a group of people having specific characteristics by using their social networks (Noy, 2008). Based on the above-determined criteria, the current study was conducted with ten parents of children and adolescents receiving active cancer treatment. The data collection ceased once the content provided by the participants' started to repeat itself and it was deemed that data saturation was reached (Saunders et al., 2018). Participants consisted of two fathers and nine mothers. The age range of the diagnosed children of participating parents was 7-17, and they were under treatment between four months and two years. The participants

were anonymized in order to ensure confidentiality and they were called with their participant numbers (i.e., P2) in the study. Table 4 summarizes the characteristics of the participants. Then, the participants of the current study are introduced individually, and their demographic information is shared.

Table 4. Demographic Information of the Participants

Participant	Parental status	Age of the diagnosed child	Sex of the child	Diagnosis	Stage	Receiving psychosocial support
P1	Father	12	Female	ALL	N/A	No
P2	Mother	17	Female	Hodgkin Lymphoma	3	No
P3	Father	7	Female	Medulloblastoma	4	No
P4	Mother	11	Female	Ewing sarcoma	3	No
P5	Mother	17	Male	Osteosarcoma	4	No
P6	Mother	16	Male	Osteosarcoma	4	Yes
P7	Mother	16	Male	Osteosarcoma	2	No
P8	Mother	10	Male	Osteosarcoma	N/A	No
P9	Mother	12	Female	Soft-tissue sarcoma	N/A	No
P10	Mother	14	Male	Osteosarcoma	N/A	No

Participant 1 (P1) is a father. He has three children aged 15, 12 and 8. His 12-year-old daughter was diagnosed with Acute Lymphoblastic Leukemia (ALL) two years ago and she has been treated with chemotherapy and radiotherapy since then. He reported that they were not informed about the stage of the disease. During the treatment process, the diagnosed child received psychological support from the psychologist of the hospital. He and his wife did not receive specific psychosocial support for themselves. Per his preference, the interview was conducted in the hospital cafeteria on a day when they came to the hospital for his daughter's blood test. During the interview, he seemed calm and talkative; he tried to give detailed answers to the asked questions.

Participant 2 (P2) is a mother. She has four children aged 23, 18, 17 and 12. Her 17-year-old daughter was diagnosed with stage III Hodgkin Lymphoma (HL) and she has been treated with chemotherapy and radiotherapy for seven months. She

preferred to interview in the hospital, thus the interview was conducted in the hospital cafeteria on a day when they came to the hospital for her daughter's radiotherapy session. During the interview, she expressed her experiences and feelings willingly. At some moments of the interview, she seemed very sad and she cried. She said she did not receive psychosocial support for this period.

Participant 3 (P3) is a father. He has four children aged 3, 5, 7 and 10. His 7-year-old daughter was diagnosed with stage IV Medulloblastoma and she has been treated with chemotherapy and radiotherapy for eight months, and she also had a surgical operation in the first month of the diagnosis. He preferred to interview at home, because he was working and did not have time for an interview at work. Thus, he invited the researcher to their home which was very close to his workplace. The interview was conducted in the living room of the house and there was no one in the setting besides the participant and the researcher. During the interview, P3 seemed in a hurry and gave short answers to some questions. He also mentioned he did not receive psychosocial support during the treatment period.

Participant 4 (P4) is a mother. She has four children aged 12, 11, 10 and 7. Her 7-year-old daughter was diagnosed with stage III Ewing Sarcoma and she has been treated with chemotherapy and radiotherapy for eight months, and she also had stem cell transplant a month prior to the interview. She preferred to interview in the garden of a cafe close to her home. Because of her daughter's stem cell transplant, she said they were very careful about the infection; her daughter had to stay at home for a while and they could not accept a visitor to their home. During the interview, she seemed very calm and relaxed, and she was generally smiling. She mentioned she did not receive any psychosocial support.

Participant 5 (P5) is a mother. She has three children aged 21, 17 and 9. Her 17-year-old son was diagnosed with stage IV Osteosarcoma, and he was treated with chemotherapy for six months and he also had a surgical operation in the third month of the diagnosis. She expressed she was about to divorce and was living apart from her husband due to the marital problems that started before the diagnosis. She stated these marital problems were not related with the child's illness. She had to move from Bursa to Istanbul because of the lack of treatment options in their hometown. The interview was conducted in the hospital cafeteria on a day her child was receiving inpatient chemotherapy. During the interview, she seemed very tired, and she cried a few times. She also said she did not receive any psychosocial support.

Participant 6 (P6) is a mother. She has three children aged 16, 11 and 5. Her 16-year-old son was diagnosed with stage IV Osteosarcoma, and he was treated with chemotherapy and radiotherapy for two years and he also had a surgical operation in the fourth month of the diagnosis. She had to move from Malatya to Istanbul because of the insufficient treatment services for childhood cancer in their hometown. In the first year of the treatment, she stayed with her diagnosed child in a family house that was offered by an NGO, which works with the children diagnosed with cancer and their families, and her husband and other children stayed in Malatya. Then she rented a house with the support of another different NGO, which also works with the same targeting group, and started living with her whole family in Istanbul. She expressed that she and her diagnosed son received a weekly one-to-one counseling session and also attended some psycho-educational group studies offered by the clinical psychologists of the former mentioned NGO when they were in the family house. She preferred to be interviewed in the hospital and the interview was conducted in an available quiet room in the hospital on a day when her child was receiving inpatient

chemotherapy and there was no one in the setting besides the participant and the researcher. During the interview, she generally looked calm, but at some moments she was very sad and she cried. The interview was interrupted twice by a phone call from the diagnosed child because of his needs.

Participant 7 (P7) is a mother. She has four children aged 26, 24, 18 and 16. Her 16-year-old son was diagnosed with stage II Osteosarcoma, and he was treated with chemotherapy and radiotherapy for a year and he also had two surgical operations in this period. The interview was conducted in an available quiet room in the hospital on a day when her son was receiving inpatient chemotherapy and there was no one in the setting besides the participant and the researcher. During the interview, she looked very sad, depressed, and also physically tired, and she cried a few times. She expressed she did not want psychosocial support and has not received it until now.

Participant 8 (P8) is a mother. She has three children aged 14, 10 and 2. Her 10-year-old son was diagnosed with Osteosarcoma, and he was treated with chemotherapy for five months. He also had a surgery in the second month of the diagnosis. She had to move from Malatya to Istanbul with her whole family because of the insufficient treatment services for childhood cancer in Malatya. The interview was conducted in an available quiet room in the hospital on a day when her child was receiving inpatient chemotherapy and there was no one in the setting besides the participant and the researcher. During the interview, she was talkative and sometimes she seemed frozen and irritable. While talking about her diagnosed child and also other children, she cried and looked overwhelmed. She expressed that she did not receive psychosocial support. She said she did not share her experiences and feelings

about her son's disease with anyone before, and it was the first time she shared her story.

Participant 9 (P9) is a mother. She has two children aged 18 and 12. Her 12-year-old daughter was diagnosed with undifferentiated soft tissue sarcoma, and she was treated with chemotherapy for ten months and she also had a surgery in the first month of the diagnosis. She said they did not get information regarding the stage of the disease. The interview was conducted in an available quiet room in the hospital on a day when her child was receiving inpatient chemotherapy and there was no one in the setting besides the participant and the researcher. During the interview, she looked comfortable and talked about many different coping strategies that made her feel better. While mentioning the physical changes of her daughter, she got teary, but she kept smiling. She expressed that she did not receive psychosocial support.

Participant 10 (P10) is a mother. She has three children aged 27, 25 and 14. Her 14-year-old son was diagnosed with Osteosarcoma, and he was treated with chemotherapy for four months and he was going to have surgery soon. She moved from Düzce to İstanbul with her diagnosed child and husband because of the insufficient treatment services for childhood cancer in Düzce. The interview was conducted in an available quiet room in the hospital on a day when her child was receiving inpatient chemotherapy and there was no one in the setting besides the participant and the researcher. During the interview, she looked calm, shy and also smiling. She gave relatively short answers to the questions. She mentioned she did not receive psychosocial support.

3.3 Instruments

For the data collection, the demographic information form and semi-structured interview protocol were used. The detailed information about these instruments were provided below sections.

3.3.1 Demoghraphic information form

The demographic information form was used to obtain personal information of participants. It included the parental status (i.e. being the mother or the father), total number of the parent's children, ages of their children, diagnosis of the child, stage of the diseases, child's age at the time of the diagnosis, the type of treatments the child were received, whether the parent receive psychosocial support or not. (See Appendix A for the English version of the demographic information form and Appendix B for the Turkish version of the demographic information form).

3.3.2 Semi-structured interview protocol

In this study, in-depth interviews were conducted with the participants in order to understand their personal experiences. The semi-structured interview protocol was prepared based on the existing studies regarding the experiences of parents of children receiving cancer treatment. The interview questions aimed to address the experiences of parents of children and adolescents receiving cancer treatment and how they cope with that situation and consisted of 12 main questions and 10 sub-questions.

The first part of the interview consisted of the questions about being a parent of a child diagnosed with cancer, their story and what they experienced when they first received the diagnosis. Second, questions related to changes in their lives after

the diagnosis, specifically what they experienced as challenges in the diagnosis and treatment process and what kind of support would make this process easier, were asked to participants. Third, the parents were asked their sources of support and how they cope with their child's diagnosis and treatment process. The last part of the interview included a question aiming to identify how their perspective has changed in this period.

Before conducting the interview with 10 participants, the pilot study was conducted with two participants that met the mentioned eligible criteria in order to examine whether the interview questions (1) were understandable for the participants, and (2) suitable to gather the answers that would address the established research questions. After the interview, it was observed that the questions were understandable for participants. However, the questions focusing on the resources were generally answered as only financial support. Therefore, the sub-question "If you think about social, emotional and financial support, what kind of resources have helped you?" was divided into two sub-questions as "If you think about social and emotional support, what kind of resources have helped you?" and "If you think about financial and functional support that makes your daily life easier, what kind of resources have helped you?" to understand the resources of parents more broadly (See Appendix C for the English version of the interview protocol and Appendix D for the Turkish version of the interview protocol).

3.4 Procedure

Before the data recruitment, the lead researcher applied to the Bogazici University Ethics Committee for Master and PhD Thesis for Social Sciences and Humanities (SOBETIK) with the research information and the informed consent form. Data

collection, including the pilot study, started only after the official permission was granted by SOBETIK in November 2022 (See Appendix G for the permission from the Bogazici University Institute for Graduate Studies in Social Sciences Ethics Sub-Committee).

For the data collection, a flyer, containing the information about the research and researcher's contact information, was posted in social media accounts (e.g., Linkedin and Instagram). In addition, the same flyer was also sent to the Non-Governmental Organizations (NGOs) which are in the researcher's personal network and work with the children with cancer and their parents.

The researcher first contacted the volunteering parents via phone. The volunteers who met the established criteria were invited to a face-to-face interview. The participants were asked where and when they preferred the interview to be conducted, and the interviews were arranged according to their preferences. Generally, participating parents did not want to meet at their home, and preferred to meet on a day when they had to be in the hospital or to meet at an available place that was close to their home.

Before the interview, all participants were informed verbally about the purpose of the study, confidentiality, data collection and storage procedures, and their rights as a participant. Then they were provided with a hard-copy of the consent form (See Appendix E for the English version of the consent form and Appendix F for the Turkish version of the consent form).

After parents agreed to sign the consent form, first the demographic information was obtained, and then the interviews were conducted. All participants gave permission for audio-recording. Interviews were conducted in Turkish. Each participant was interviewed once, and interviews lasted between 35 and 50 minutes.

At the end of their interviews, the participants were invited to reach out to the researcher via phone or email in case they would have any questions about the study afterwards; however, none of the participants initiated contact with the researchers following the interviews. All interviews were conducted by the main researcher in December 2022 and January 2023.

After the data collection, interviewed parents were given a participant number (i.e., P8), and their identity was kept confidential. The recorded audio files were named with their numbers, and they were transcribed verbatim. All audio-recorded and transcribed data were saved in an encrypted USB, and this USB was only used in the researcher's personal computer.

3.5 Data analysis

In the current study, the data were analyzed with content analysis, which is one of the methods that enables condense phenomenon into different categories or themes (Shava, 2021). Content analysis provides researchers to infer from the idiosyncratic experiences or perceptions of individuals, and it is mostly utilized in the field of social sciences (Krippendorff, 1989).

After the data on the experiences of the parents of children with cancer were obtained, all of the data were transcribed verbatim. The raw data were categorized under the research questions of the current study and then divided into small meaningful units by coding. Then, based on the similarities of the expressions of the participants, the main categories and subcategories were identified by the researcher under the supervision of the thesis advisor. The emerged categories and subcategories were reviewed several times by the researcher and the thesis advisor.

To ensure the validity of the findings, member checking was conducted by the researcher. Member checking allows researchers to compare their understanding with what participants really meant about their statements (Doyle, 2007); and hence it provides researchers with an opportunity to evaluate and confirm credibility or trustworthiness of the findings of qualitative studies (Chase, 2017). It is a technique that can be done in different ways (Chase, 2017). While the literature does not provide direct instructions to complete member checking, it can be done by returning transcripts or analyzed data to the participants (Birt et al., 2016; Doyle, 2007)

In the current study, verbatim transcripts were returned to the participants. Only eight of the participants could be reached again for member checking and they were asked to provide feedback and confirm that transcribed data reflected their thoughts and statements. When one participant stated she could not read the transcript due to being illiterate, the researcher read her the summary of her interview transcript over the phone. All of the eight participants verified the accuracy of the transcribed statements. When the researcher asked them if they wanted to add something new, none of the participants gave a new statement about their process and the member checking process was completed.

For the data analysis, no software program was used, and the data was analyzed manually. Lastly, all of the findings in Turkish were translated into English before included in this thesis study.

3.6 Identity of the researcher

The identity and role of the researcher is a significant part of the qualitative studies since the researcher is a part of both data collection and analysis and the process of the study is shaped by the researcher's perception (Denscombe, 2010). Therefore, the

reason for choosing the research topic, the professional background of the researcher, and his/her personal interests and experiences are often explained in qualitative studies.

The reason why I am interested in this topic as a researcher was shaped by my personal experience and professional approach. As a childhood cancer survivor, I am familiar with the experiences of both family members of a child receiving cancer treatment and how the process is complex and challenging. When I was fifteen, I was diagnosed with Non-Hodgkin Lymphoma (NHL), and I was treated with chemotherapy for 2 years and completed the treatment in 2011. And after the treatment, I was also in contact with my oncology doctor for follow-up-visits for 5 years. In this period, my mother took care of me and led the treatment process in a different city because of the lack of the pediatric hematology-oncology services in the city we lived in. As a patient, I experienced the difficult physical, social and psychological side effects of the cancer treatment. And also, I could observe what my mother went through as a caregiver of a child with cancer. Moreover, I had the opportunity to work with children with cancer and their parents as a volunteer in different projects. That is to say, I witnessed the many different challenging and sensitive parts of cancer treatment from the lens of a person suffering from cancer.

Additionally, as a person in the field of psychological counseling, I aim to understand the needs of the disadvantaged and vulnerable populations to be a part of a preventative intervention plan before developing any clinical outcomes. My past personal experiences and the stories of other patients and their caregivers that I encountered in the hospital made me reflect on both what these people need and how this process influences their lives, and how I can play a role to prevent health disparity by understanding these children and their families as a psychological

counselor. Therefore, I decided to focus on this issue and make the experiences of the children diagnosed with cancer and their parents visible.

As a researcher, I was aware of my own personal experiences, beliefs, and biases, and I tried to be just a researcher not a cancer survivor, both during the interviews and throughout the data analysis. I was not familiar with any of the participants before the data collection process, and they did not know I was a cancer survivor.

CHAPTER 4

FINDINGS

In this section, findings emerged from data analysis will be presented under 6 categories based on the research questions, which are (1) description of being a parent diagnosed with cancer, (2) challenging experiences of parents of children with cancer, (3) unmet needs of parents of children with cancer, (4) sources of support of parents of children with cancer, (5) coping strategies of parents of children with cancer, and (6) changes in perspective of parents of children with cancer. It is important to note that all given names of children, parents, doctors, or institutions are pseudonyms in this study. Table 5 shows the list of emerging categories and subcategories.

4.1 Being a parent of children with cancer

Under this section, the participants were asked how they could describe being a parent of a child diagnosed with cancer. All of the 10 participants stated that what they have encountered has been very hard and they have followed up with a depiction of various challenges that they have experienced. The challenges they have shared were analyzed under the research question about their challenging experiences. Four of the participants depicted a portrait about what being a parent of a child with cancer looked like for them and their answers were presented under the categories of (1) hardship and (2) standing tall.

Table 5. The Categories and Sub-categories

Categories	Sub-categories
Being a parent of children with cancer	
	Hardship
	Standing Tall
Challenging experiences of parents	
	Process until the diagnosis
	Adaptation to diagnosis and treatment
	Lifestyle and daily routine changes
	Financial problems
	Family related problems
	Emotional distress
Unmet needs of parents	
	Financial needs
	Information needs
	Practical needs
	Psychological needs
Sources of support for parents	
	Religion
	Extended family and friends
	Health care professionals
	School
	Diagnosed child
	Spouses
	NGOs
	Official institutions
	Other parents whose children with cancer
	Workplace
Coping strategies of parents	
	Appraisal-focused coping
	Emotion-focused coping
	Problem-focused coping
Changes in perspectives of parents	
	Shift in attributed importance
	Changed attitudes towards children
	Awareness about the importance of family
	Awareness about the cancer
	Learning that people may not be who you expect them to be

4.1.1 Hardship

Two of these four participants referred to a very different world for the experience of being a parent of a child with cancer and tried to describe the hardship of this experience with a metaphor. For instance, Participant 6 answered this question as follows:

> What to say to that? The day I heard it, I really crossed to another world. Until today, my troubles were not small. But I was not aware that I did not suffer from anything. I mean I did not have any problems. I mean, when I think about these, it's a very heavy thing, you can't see the end. You are in the darkness in a tunnel, but you can't see any light, you don't know the result. (P6, Appendix H, 1)

Similar to Participant 6, Participant 11 utilized a different metaphor to describe her experience and she said “I was cut off from the world, my wings were cut. I mean, I was cut off from everything.” (P10, Appendix H, 2).

4.1.2 Standing tall

While describing being a parent of a child with cancer, two of four participants stated that it was an experience required standing strong. Participant 6 highlighted this point as following words:

> It's really hard to be a mother. As an experience, you have to stay strong when you're with him [the diagnosed child] all the time. So even if you cry, you should not show it because he notices everything, he notices when you're sad. So we have to be strong, we are used to the process already because it has been our second year in the treatment process. I don't know right now, because I am very tired both at home and here [hospital], but we have to stand. (P6, Appendix H, 3)

Similarly, Participant 1 reported that being a father of a child with cancer was a very difficult experience. This parent used the phrase of “standing up” to reflect what appeared to be the same sentiment as Participant 6. His words can be found below:

> Hard, that is hard. Learning that your child has leukemia and walking back and forth on the line of losing your child is really difficult for both the mother and the father. Life goes on, you have to fight, you have to stand up. (P1, Appendix H, 4)

In the end, all parents were describing a significant shift in their ways of seeing the world and living through their day-to-day life. While Participant 6 and Participant 11 emphasized the hardship they have faced, Participant 1 and Participant 7 added on the necessity to stay strong in this period.

4.2 Challenging experiences of parents

The participants were asked what their challenging experiences were in the diagnosis and treatment process of their children. Based on their answers, the challenging experiences of parents of children diagnosed with cancer were presented under six categories, which are (1) process until the diagnosis (2) adaptation to diagnosis and treatment (3) lifestyle and routine changes (4) financial problems (5) family problems, (6) emotional distress. Table 6 summarizes the sub-categories of these challenges.

Table 6. Challenging Experiences of the Parents

Challenging experiences		f
Process until the diagnosis		10
Adaptation to diagnosis and the treatment		10
	First reactions	10
	Thought of losing the child	10
	Informing the child about his/her illness	5
	Witnessing the side-effects of the treatment	10
Lifestyle and daily routine changes		10
	Moving	4
	Work-related changes	4
	Isolation	5
	Losing family routines	3
Financial problems		9
Family related problems		9
Emotional distress		10
	Managing the uncertainty and related fears	9
	Symptoms and syndromes	10

4.2.1 Process until the diagnosis

When asked about their story, all of the 10 participants reported going through a very complicated and challenging process until their children were diagnosed. Each participant stated they had to visit a number of different doctors and hospitals until the diagnosis was given which took a long time. Shared stories highlighted long waiting periods facilitated through getting numerous testing done which could provide uncertain results and seeing different providers who might be delayed in coming to a conclusion or disagree with other providers.

One example could be provided from Participant 4 who shared how unbearable it was for her to wait for the disease to be diagnosed while her child was suffering without a way to help the child. An excerpt is shared below:

> It was very difficult. In other words, the child cries, shouts, cannot eat because the pain comes in the form of attacks. We take the child [to the hospital], there is nothing. We explain where the pain is, the emergency services do nothing. Helplessness was a very bad thing. Maybe knowing what it was and starting the treatment gave us some relief. (P4, Appendix H, 5)

An example of the delays experienced in the process of being diagnosed can come from Participant 6. The quote below speaks to her experience with the third doctor they have seen during their process:

> He [the doctor] said "Take him to the university hospital." Then I took my child to the university hospital. We lingered at the university hospital for 1.5-2 months. They were suspicious but the exact diagnosis could not be made. The process was a little late. (P6, Appendix H, 6)

After sharing that, Participant 6 continued by indicating that they had a number of other doctor and hospital visits in different cities beyond what she mentioned in the quote above. Likewise, Participant 7 gave a similar example and complained about the late diagnosis because of the delays and perceived doctor's error. She said:

> It was a very difficult process. This is what happened to us anyway, let me tell you first: When his leg first ached, when we took him to the doctor, we would have acted early if we had known the diagnosis, but we suffered from the doctors' mistake. We went back and forth for 2 months, 2,5 months in vain. In that process, of course, the mass began to grow, and our 2.5 months passed like that. (P7, Appendix H, 7)

When all interviews were considered, it was observed that all of the 10 participants mentioned the diagnosis took several months and they gave many examples about the different doctor and hospital visits and delays. However, only Participant 4 and Participant 7 expressed the difficulty of this process directly. Other participants indirectly relayed this challenge through statements about medical visits and delays.

4.2.2 Adaptation to diagnosis and treatment

When participants were asked what they experienced when they learned their children's diagnosis, they talked about how they reacted and what challenged them while adjusting to diagnosis and treatment. Four sub-categories were determined in accordance with the participants' answers. These are (1) first reactions, (2) thought of losing their child, (3) informing the child about their illness, and (4) witnessing the side-effects of the treatment.

4.2.2.1 First reactions

When the participants were asked what they had experienced when their child was diagnosed with cancer, all of the 10 parents expressed that it was a very difficult time and they were in deep sorrow. Five of the participants responded that they were shocked and they experienced a breakdown. For instance, a mother expressed her first reactions as "When I first learned, I could neither sleep, nor do anything. It was like the world had collapsed on me." (P6, Appendix H, 8). Similarly, another mother mentioned her first moments and experiences when her son was diagnosed with this unexpected disease and said "The hospital collapsed on me. That was something I never expected." (P10, Appendix H, 9).

Additionally, 3 of the participants referred to denial as well as shock and disappointment. A mother participant stated how acceptance of the diagnosis was difficult for her and denied it as follows:

> It was too bad because we did not experience anything like that before. There is no something like that in our family, in our lineage. In other words, there is no such disease! I couldn't accept it anyway, I said that was not! I said it was not! But life has become very difficult. (P9, Appendix H, 10)

One of these three participants pointed to the difficulty of saying the name of disease as part of the denial:

> I could not say it; I could not even say it to myself! I said “that disease”, or I said “bad disease”. I don’t know. What was the name of “that disease”? I couldn't put it together with my child. (P2, Appendix H, 11).

The last participant who mentioned the denial of the disease reported that they experienced denial as a family:

> I was devastated the first time I heard it. As a family, all of us… I, my husband's family, my own family, my children… When we heard that, we were in a very difficult process… In fact, you can't accept it. I don't know, it was difficult.
> (P7, Appendix H, 12).

Two of the participants also mentioned they felt anger and blamed themselves for the disease when they asked what they experienced after they learned the diagnosis. One of the mothers expressed her anger and guilt feelings and she said that “It was very exhausting. I pushed myself so hard. How did I become so blind? How could I not see? How could I not feel? So I'm so mad at myself.” (P2, Appendix H, 13). Similar to Participant 2, Participant 9 pointed out that the first months were challenging and blamed herself and said that “The first 2 months were very difficult for me. I constantly fought with myself.” (P9, Appendix H, 14).

In conclusion, all of the participants stated that learning the diagnosis was a very difficult experience. Five of them gave specific and direct expressions about how they were shocked and three of them stated they did not accept the diseases and denied it. Devastation, anger, and blaming themselves were other reactions that were expressed by the parents in the beginning of the process.

4.2.2.2 Thought of losing the child

Another significant sub-category that was highlighted by all of the 10 participants is the fear of losing the child diagnosed with cancer, especially in the beginning of the process. Parents stated that cancer meant “death” for them and losing their child was the first thing that came to their mind. As an example, one of the father participants said that “The adventure of the first 6 months was very difficult for us. So it's been really hard. If I am not mistaken, I faced the possibility of losing my daughter 4 or 5 times.” (P1, Appendix H, 15).

Another mother participant also expressed the difficulty of this thought and how she was overwhelmed because of it. Her statement can be seen below.

> You know, the fear of losing! Even the thought of it is crazy. Even that idea! If the fear of losing is that bad, what happens when you actually lose? You know, going crazy is a luxury for a mother. If I go crazy, I'll get rid of it! (P2, Appendix H, 16)

Participant 5 gave another example to the struggle. She expressed her first experiences in following words:

> When I learned that, I was very upset because he is very small and he could not stand those pains, those things. I suddenly thought that he would die. I do not know why. When I heard it, I came out of the hospital, I waited outside for 10-15 minutes, I was very bad. (P5, Appendix H, 17)

Some of the participants did not mention directly their fear of losing their child but they indirectly implied they had the similar thoughts. For instance, a father participant gave an example about how Prophet Mohammed lost his children and said:

> I thought that God gave seven children to our prophet [Prophet Muhammad], he buried six of these seven with his own hands… I mean, he didn't ask us when God gave the child. He won't even ask when he takes her from us. Thank God. I'm always grateful, but it's not an easy process.” (P3, Appendix H, 18).

Moreover, Participant 10 expressed her fear of losing her child very similarly. Her words can be seen below:

> I passed out. I thought, "My God, take my life, give it to the child". I just want to take care of the child. Sometimes I sit next to him and hold his hands. His father says it's like he's going to run away or go somewhere. (P10, Appendix H, 19).

In short, all of the participants mentioned they thought about the possibility of losing their children. Eight of them expressed their fears directly. Three of them indirectly expressed that they thought about this possibility.

4.2.2.3 Informing the child about his/her illness

One of the highlighted challenges that parents experienced while trying to adjust to the diagnosis and treatment is informing the children about their illness. Five of the participants directly expressed that they did not know how they could tell the children what their diagnosis is and what they would experience because of cancer and its treatment. One of the mother participants, whose 17-year-old daughter was diagnosed, expressed her confusion about how she told the child about her diagnosis:

> It was found it was malignant. That process was bad! How could I tell the child? I told the doctor that I could not tell her. In fact, I did not want to tell. I said not to telling! I told that she would be treated without knowing it. The doctor said no. She said "She should know because she is not a small child, she will observe the procedures, she will witness the chemotherapy. She will search for herself and surely learn.". (P2, Appendix H, 20)

After her statement above, Participant 2 talked about what she experienced and how difficult it was to convince her daughter to be treated when she learned of her illness. Referring to her daughter, Participant 2 added the following:

> She said "I do not want to be treated. I do not want my hair to fall out. I want to go home. Let's go home!" She started to cry. I was also crying. She had no choice but to be convinced! That is how our process started. (P2, Appendix H, 21)

Similar to Participant 2, Participant 4 also mentioned that she was not sure about how to tell her 7-year-old daughter the diagnosis, and how to prepare her for the treatment process. She explained how she informed her child with the following words:

> How will we tell Sena in this process, how will we tell her, will she be afraid? We talked a lot about these with Feride [an oncology nurse friend of the mother], and we prepared Sena. Of course, I prepared myself first. As a family, we will explain how we will get through this process, as if nothing had happened to Sena, as if it were a normal disease, by supporting Sena in a way. Sena is a very inquisitive, very curious child and a child who wants to learn everything, a child who wants to know what is going on. We said that "It is a malignant inflammation in your waist. You will receive treatment for this inflammation, but this treatment will shed your eyebrows and eyelashes, sometimes we will go to the hospital and stay there." We told Sena these at first. So we didn't tell Sena that she had cancer. Then we saw that Sena is more steadfast than us. We told Sena the day before we were going to start the treatment … She said, "What about cancer? I can beat it, I'm not afraid of cancer!". She said "My only problem is why my hair is falling out, why are my eyelashes falling out? I don't want it to fall out!". Believe me, the only thing with which we struggled was that. (P4, Appendix H, 22)

On the other hand, another mother participant expressed a similar challenge but she preferred to go another route and did not tell her 17-year-diagnosed son that he had cancer. The child was in the sixth month of treatment when the interview was conducted, and the mother expressed her strain in following words:

> I brought the child here [hospital], I did not tell him that he had that disease [cancer] or there was such a thing. I just told him that he had a tumor in his foot and that the tumor had to shrink. So he had to undergo chemotherapy. When the time came, his hair would fall out, he would be sick to his stomach, he would be weak, his blood values would fall, all of these… He would go through like these things, but we hoped we would get better after it was over … When he comes here [hospital], he asks the mothers here, "What is your child's diagnosis?". When they say leukemia, he says "Oh, cancer patients also receive chemotherapy here." … Sometimes he thinks too much, he thinks too deeply. It feels like he's learned, but then I'm surprised when he says some things and I think "Oh he still does not know!". Now I don't know if he knows or not … If only he had met someone [a mental health professional], I would have understood if he knew about it. I can't ask him, I can't say if you know about this disease. If I tell, maybe he will start investigating, it will be worse. For this reason, I'm afraid to elaborate and that's why it's so hard. (P5, Appendix H, 23)

One more mother also stated she could not tell her 14-year-old son his diagnosis, and the child figured it out after searching for the name of the disease by himself. In this case, the mother said her son's attitude made it easier for her to go through that part of the process. You can find her words describing that moment below:

> We didn't say anything, he went online and learned it himself. He said "Mom, no, look, that's what it is." He was saying that with a smile, pinching my cheek. He is stronger than us, very strong. If he wasn't like that, if he was troubled by something, I'd probably go crazy. (P10, Appendix H, 24)

In the end, five of the participants directly mentioned how difficult it was initially to talk to their children about the illness. Although the diagnosed children are at different ages and parents' preferences of informing the children about their disease are different, the participants stated that they experienced a similar difficulty while talking to their children about the diagnosis and its treatment.

4.2.2.4 Witnessing the side effects of the treatment

One of the most highlighted challenging experiences of parents in the adaptation process is witnessing the changes of their children in treatment. All of the 10 participants mentioned that it was difficult for them to see their child's experiences due to the treatment. Because cancer treatment has a number of side effects and creates physical changes on a patient's body, such as hair loss or weakening, participants stated that it was difficult to observe their children while adjusting to the treatment. Additionally, participating parents also emphasized that it was very uncomfortable for them to see their children in pain. One mother expressed what she experienced when her daughter's hair was falling out in following words:

> It was also very bad for us that her hair started to fall out. It was also a trauma for both her and me. She got chemotherapy and her hair started to fall into her hands. I hide it from her and collect it secretly from the pillow so that she will

> not see it, so that she will not be upset. It lasted for 2 days, on the 3rd day, heaps of hair started to fall out. I said “Dilan, please let’s cut it now.”. She said “No!” at first. Then she realized it would not be like that, because as it fell into her hands, it started to get very bad. (P2, Appendix H, 25)

Another mother participant addressed the same point, emphasizing how she could not bear to see her daughter’s head without hair:

> For instance, her hair… I bought her a colorful bandana. For example, even at night, even at home, she always wears a bandana. I didn't want to see her bare head. I said “We always cover your head, my daughter”. For example, when we go to bed at night, it's hot weather, but I said “Let's cover it up” because it's so painful to see it. (P9, Appendix H, 26)

Hair loss was not the only point highlighted by parents under this sub-category. Two of the participants talked about the difficulty for them to see that their child was not physically able to move the way they did before the treatment. One of the mother participants exemplified about this point by stating:

> He was very active, but now he can't stand up, can't walk. He would turn on the lights with his feet, now he can't even wear his shoes. He has a few videos, for example, he lifts his foot and turns on the lights. He turns on the lamp at that height, at that height! [She points to a height of about 1.5 meters with her hand.] Now, we cannot wear shoes for two years. (P6, Appendix H, 27)

Additionally, the participants identified seeing their child in pain as one of the challenges they had to endure throughout the treatment process. Four of the participants directly expressed the helplessness they felt when they watched their child go through treatment and experience side-effects. One of the mother participants expressed what she experienced about her son in pain as follows:

> You can't sleep at night when the pain hits, you wait for it for hours. When he cries, we cry as a family, we are turned upside down. We sit until the mornings; our routine is broken. we all get up. You don't know what to do. There is a feeling of uneasiness, what should I do, how will the pain stop? That is like that. And the pain is not just like a normal headache. It is not like that. If you have pain, you take painkillers and it goes, but this does not go away. It is triggered once every minute, the boy's yelling as if something is gouging out his bones. (P7, Appendix H, 28)

While talking about her own challenging experiences, another mother reported that it was very difficult to even talk about the difficulties experienced by her son. She said "If I count the pain that the child has experienced, I would faint and die here" while crying (P8, Appendix H, 29).

In conclusion, all of the participants mentioned the difficulty of witnessing their child's experiences because of the disease and its treatment. Participants exemplified their challenging experiences under this subcategory as hair loss (n=5), limitation of physical movement (n=2) and pain (n=4).

4.2.3 Lifestyle and routine changes

In line with the purpose of the present study, the participants were asked what changed in their lives after their children were diagnosed with cancer and the answers were classified under the category of lifestyle and routine changes. All of the participants stated they experienced noteworthy changes in their lives, and these changes were divided into four sub-categories as (1) moving, (2) work related changes, (3) isolation, and (4) losing family routines.

4.2.3.1 Moving

Four of the participants expressed they moved to a different city as a family because of the lack of healthcare services and treatment options in their hometown. Participants revealed that moving brought on a number of challenges including struggling with settling into a new place and building a new home, leaving all or most of personal belongings behind, suffering from poor housing conditions or other housing problems, and missing out on amenities and/or social interactions to which they had access before. Moving the family to a new town did not mean staying

together either. One participant identified family members' living at different places as another and an emotionally-charged challenge.

One of the mother participants shared how she was informed about the necessity of moving in detail. She expressed how their challenging experience around moving unfolded through the following words:

> The doctor called and said that Ahmet needs to go out of the province, there is no treatment here. He said that he needs to receive chemotherapy first and then radiotherapy; I can give radiotherapy, but we do not have that treatment here, we do not have a pediatric oncology unit. He said it was only in three provinces. I took my child, I got up and came [to İstanbul]. My older child said "I want my siblings; I want a home environment.". We did everything to make him happy. We started from scratch … It is very difficult to get it together, to make a house a home. (P6, Appendix H, 30)

Participant 6 also reflected on moving. She mentioned how adapting to a new city has been socially hard for her and her children:

> You move to a different place, everything changes. Even though it wasn't like there, everything, my whole life has changed. Where children play. For example, they are in a prison right now. For example, in our hometown, every apartment has a playground, they have parks. The children would go out and play. But it's not like that here, there isn't even a proper park here for children to come out and play. Let me say that the children cannot go out at all, they are trapped in the house. For example, there are always familiar people there. But there is no one here. (P6, Appendix H, 31)

In a similar way, Participant 8 also talked about how she suddenly moved to a different city. She also added although she moved with her whole family members, they had to live different places in this period:

> The doctor there [hometown] said that you need to go to one of the big cities, there is no pediatric oncology here. That's how we started. We just took our suitcases and came on the road with slippers. Then our stuff came. We rented a furnished house from here. That's how we go … As a family of five people, we have now moved to three different locations. I am here [hospital], they [husband and the bigger child] are at home, my little one is in the home of my sister-in-law. We are divided, we are shattered. (P8, Appendix H, 32)

As a conclusion, four parents mentioned their experiences of moving to a different city because cancer treatment, especially pediatric cancer treatment,

requires specialized units and services. Since this opportunity was not available in small cities, it was inevitable for participants and their family members to move to a metropolitan city.

4.2.3.2 Work related changes

During the interviews, work related changes were mentioned among the challenges that parents have experienced in this period. In particular, four of the participants expressed that either themselves or their spouse had a change with respect to work. Out of that four participants, three of them talked about quitting jobs, and two of them expressed they could no longer work in their own business. One of the mother participants expressed her experience of quitting her job as follows:

> Because I couldn't work, I was fired because of the child. When she was sick and then I couldn't go, they fired me. I couldn't go anyway; I was in the hospital during this process. My [older] daughter started to work. (P2, Appendix H, 33)

Depending on the child's age and symptoms, presence of one parent may not be enough, requiring both parents to devote their time to the medical process. Participant 8's statements can be an example for such situations as she stated her husband could not work to be able to attend to the needs of the child that participating mother could not meet by herself:

> My husband was working [in hometown]. Now he [husband] can't work, he is at home … We come two days a week. Actually, my husband is hardworking, he can't work. We come all the way from Tuzla, the child cannot walk either, and I cannot bring him. We bring him from there, so it's a hassle. (P8, Appendix H, 34)

Larger family needs are also a consideration. One of the father participant stated that he led the entire hospital process for treatment and his wife took care of their little children at home and thus he could not work in his own business:

> When needed, I went to the hospital every day. After that, when the chemotherapy started, we were staying in the hospital for one night … I have some financial problems because I cannot work. (P3, Appendix H, 35)

In summary, four of the participants expressed that work related changes is another challenging experience that parents encountered in this period. Two of them mentioned they or their spouses had quit their jobs, and others stated they could not work because of the busy schedule of the treatment process.

4.2.3.3 Isolation

Another challenge highlighted by participating parents that can be categorized under lifestyle change is isolation. Six of the participants mentioned physical isolation. Five of the six participants directly stated the fear of getting infected created a social restriction for them. One of these six participants also pointed to a different dimension of social isolation and she stated she preferred not to communicate with people who were not part of their day to day process because she thought their agendas were different and they could not understand her.

Participant 4 whose daughter had a stem cell transplant mentioned social isolation. Before the interview, she expressed she could not accept the researcher in her house because of the risk of being infected and she could only meet with the researcher somewhere in an open area. In the interview, she said “We have already restricted others coming to our home, that is, we talked when we met outside, we talked on the phone [with big family members and friends] (P4, Appendix H, 36). Participant 7 gave some examples about how she experienced isolation as follows:

> When I intended to go out, I would go out. I used to spend more time with the little girl when she was at home. We used to walk around together, go to cafes. I don't have many friends, but I spent more time with the children. Now they are all restricted. There is none anymore. Even she says “Mom, we used to go out before”. Now, no! Hospital-home. I do not even meet anyone. Just on the phone. We don't have a social life anyway, it's over … You cannot

> let anyone come into your house. So it is forbidden … You are afraid that your child's immunity is falling. What if someone comes and the child gets an infection. (P7, Appendix H, 37).

Participant 9 mentioned the necessity of physical isolation as the above-mentioned parents highlighted. She also pointed out she did not prefer to have any contact with outside people because she believed that they could not understand her experiences:

> Of course there were daily changes. I could not go for a walk; I could not be in a crowded place. Even though I entered a crowd, Ceyda did not. Also this pandemic [COVID -19] has affected. We have kept away from crowded places for 2 years. Oh, we're going to work again, we have to go to work. But we didn't go into social environments too much. (P9, Appendix H, 38).

She continued her speech and rationalized why she did not prefer to communicate with other people as follows:

> There's no point in having too much of a crowd anyway. I have many people, I have relatives, I have acquaintances. I have been surrounded by many people, but being surrounded with many people is of no use to anyone. If you are in trouble, if you are short of money, if you are sick, it does not matter if you have billions of friends, no one will even accept you. So, this is the philosophy of life, we learned it. I don't trust anyone, there are 1-2 people I trust. I don't say to everyone, "Let's go there, let's go here", I do not go! Because there is no reason to go, they gab, they talk nonsense. What do I do? It is in vain, there is no need … Someone who doesn't lose a loved one and doesn't see his/her illness can't understand me very well anyway … The person who did not experience it does not know it. If he/she knows and does not understand me, I get angrier with them too. There is a person who understands me best, a friend. 1-2 of my friends. We talk to each other. I usually live inside myself. (P9, Appendix H, 39).

In the end, six out of 10 participants reported that they were socially isolated because they had to protect their children from getting an infection. One of these six participants mentioned her family members were also isolated because of infection; but she also preferred isolation for one more reason since she believed nobody could not understand her experiences and thus communicating with others was unnecessary.

4.2.3.4 Losing family routines

Losing family routines have emerged as another challenge for parents whose children undergo cancer treatment. Three out of 10 participants gave examples about how their family routines were changed after the treatment. They talked about how they had spent their holidays before this process and what they were deprived of for now. Participant 7 exemplified this situation as follows:

> For example, we used to go on a vacation in the summer as a family, we used to go to the seaside on the weekends. None of them exist anymore. For example, if you take the child, even the [diagnosed] child does not want to go, he cannot walk. What happens when he can't walk? It is a big obstacle for you. You want to take him, but when he doesn't want to go, you don't want to go either. I mean, we're fastened to the house actually. (P7, Appendix H, 40).

Not being able to go to the seaside for a vacation was also mentioned by Participant 9 who added that as a family they dream of going back again come next summer. Participant 8 also gave an example about their routines which they used to have before they moved to a different city and she said "We were close to our village [in hometown], we used to come and go [with family members]. Thank God, it was good." (P8, Appendix H, 41)

In the end, three of the participants talked about activities as their family routines they had before their children were diagnosed. Not being able to engage in past routines was identified as one of the challenges that parents experience as their children go through cancer treatment.

4.2.4 Financial problems

Financial issues are one of the most mentioned challenges by the participating parents. Nine out of 10 participants reported that they were struggling financially. When participants' answers were examined, it is seen that financial strain stems from

two main reasons for them. All of these nine participants highlighted that cancer treatment is expensive itself because their children may need medicines, other special medical products, and also special care. The details of the expense of the treatment process will be elaborated in the heading of "Financial needs". Additionally, four out of these nine participants also implied that current economic fluctuations in Türkiye have affected their treatment process prominently.

Participant 5 stated that her son needed special medicines and she had to spent large sums of money in a limited period of time as follows:

> Conditions are not easy in normal life either, so I had a hard time financially. For example, an injection here, we use allergy injections. Those have been very difficult for me. The money I paid in just the last 15 days exceeded 1500, 2000 Turkish Liras, that's only cost of the medicine. It gets very challenging when such [expenses] occur. (P5, Appendix H, 42)

Participant 6, who stated her son experienced physical movement difficulties and could not walk because of the location of the disease, also talked about the cost of transportation as well as the cost of special medicines:

> For example, it would be easy for us if there was not the cost of going back and forth [to and from the hospital]. Transportation. I was a tenant there [hometown], I am still a tenant here. We are having a lot of trouble going back and forth. He needs extra medicines. He has some [personal] requests. (P6, Appendix H, 43)

One of the participants mentioned the high cost of special surgical operations that her son had and how their costs were increasing day by day:

> Now, as we get into it, it gets deeper and deeper. We came to XXX [a specific hospital] and left with 70 billion [bill]. We had him operated here, and we gave 90 billion to Prof. YYY [a specific doctor]. Now, he [husband] can't work, he's at home. I feel sorry for him [husband] on the one hand, and Ali [the child] on the other. I think about debts. (P8, Appendix H, 44)

Four parents stated that besides the expense of the treatment and medical necessities, they were also affected by the inflation. Participant 3 gave an example about how he experienced this economic fluctuation as follows:

> The examination fee was 700 Liras. I do not know how much it is now. I am sure it has reached 1000 Liras now. When we started it was 400-300 Liras. There has been a huge increase in bed costs and hospital expenses. There was an increase in everything, not just there. (P3, Appendix H, 45)

Likewise, Participant 4 also gave an example about the sudden increase of the costs and she said:

> When we started, the bed cost was 150 Turkish Liras per day. Can you believe it was 500 when we were discharged? We started with 150 Turkish Liras, the daily bed cost in April, then it suddenly became 500 Liras. (P4, Appendix H, 46)

All in all, most of the participants (n=9) directly mentioned that cancer treatment requires special expenses, and it is costly itself, and thus they experienced some financial difficulties. Moreover, four of these participants also expressed that many things they needed had been over-priced suddenly and this condition added to the challenges they have been facing.

4.2.5 Family related problems

Most of the participants mentioned that they have experienced challenges with their nuclear families. Nine out of 10 participants expressed that their other children were also influenced by this process and this created an additional struggle for them. It was stated that siblings had experienced emotional or psychological difficulties, and also their academic performances were negatively affected from this process. Participant 1 mentioned what his other children experienced in his diagnosed child's treatment process. He said his other children often fell ill during the treatment period:

> Her youngest sister is 8-year-old now. She was younger at that time, and she could not perceive anything. She was a little bit devastated psychologically because she was away from her mother, because their mother was always here [hospital]. I think that her three-month sickness period was due to sadness, both her and her big brother sickness period due to sadness. (P1, Appendix H, 47)

Participant 2 also talked about her experiences with her other children. She shed some light onto how different siblings may react to the illness in their own way.

> Of course I neglected my other children because I have four children. I didn't care much about what happened to those at home. Others have found a place to escape. For example, his eldest sister did not even come close to the event. Maybe it was a self-preservation instinct. She didn't accept, she didn't stand next to me, she couldn't. But, I would like her to do so. She talked more with her friends. I said to her "Yelda, I would like you to stand by me, share my pain". She chose not to talk. For example, we never spoke during this process because she ran away. Another older sister, now 18. That time she was 17 years old. She tried to be with me more. Later she said it herself "Mom, I was always trying to meet my friend, I was not coming home, I was actually trying to escape. (P2, Appendix H, 48)

Similarly, Participant 4 mentioned, "Of course they [the other children] were influenced. Their teachers said they always talked about us … Their behaviors, of course, changed during this period". (P4, Appendix H, 49). Participant 6 reflected on what her younger child experiences emotionally in relation to her mother's absence. She shared how her child tries to hold onto the mother when she has to go back to the hospital:

> Sometimes, I cannot take care of them [other children], but God bless, they [the sisters of the mother] take care. The younger one is struggling a little bit, she is longing. She is getting used to it now … For example, she cries. When I leave, she holds the door and says "Do not go!". For example, when I go home to get something, she says "Mom, do not go.", she says "Let's sleep together tonight". So, the child is very much impacted. But she gets used to it after I leave. (P6, Appendix H, 50).

Participant 7 highlighted that her other children complained that she did not spare time for themselves, and they experienced academic problems in this period:

> For example, all my children are struggling psychologically … For example, I can't take care of my other children, they say "Mom, we exist too." But I don't know, I can't do anything for them, I can't spare time for them. For example, the one, who is older than Arda, had very good grades. Last year, after Arda's disease, there was a regression in her classes and her hair fell out. The children were very impacted. Her brother also has the same thing. (P7, Appendix H, 51)

The participants did not make a special statement about having relationship problems with their partners due to the disease. Only one of the participants reported that she had a disagreement with her husband about sexual intercourse and said “I don't want to do anything private [sexually] with my husband. He [the husband] says “it [disease] is different [condition]”. He says “I have rights too”. (P8, Appendix H, 52). However, she did not mention a problem with her marriage during the entire interview and spoke highly of her husband. Additionally, two of the participants expressed that they were in the process of getting a divorce due to relationship problems. When the researcher asked if the divorce process was related to the disease, they stated that it started before their children were diagnosed and they did not have any statements about the disease worsening their relationship or contributing to the divorce process.

4.2.6 Emotional distress

Emotional distress was another category that emerged when the participants were asked what their challenging experiences in this process were. All of the participating parents gave examples of psychological distress as well as related physiological changes. Struggles related to uncertainty including the fear of the unknown future appeared to be the underlying theme and hence it was explored under a sub-category. Rest of shared experiences were grouped under the sub-category of “symptoms and syndromes”.

4.2.6.1 Managing the uncertainty and related fears

Fear of losing one’s child, not knowing whether it is the treatment outcome or side-effects, witnessing the declining health or death of other children were identified as

the major sources of uncertainty and fear. These points will be explained below along with direct quotes from the participants.

As it was mentioned in the adaptation to diagnosis and treatment sub-category, the first thing that parents think when their child is diagnosed is the possibility of losing their child. They experienced a big fear because of the disease and this creates very high levels of stress for them. However, their fears are not limited to the process of learning about the diagnosis. Especially the fear of losing the child is one of the major stressors for parents throughout the treatment process as well.

In the present study, although all of the participants mentioned their stress sources, what creates stress for them and how they experienced it differs. Ten of the participants refer to uncertainty existing throughout the process and they talked about the stress that the uncertainty caused. A father participant, whose daughter's treatment is about to end, gave examples about the uncertainty in the different stages of the treatment:

> Morally, it is the fear of losing your child. So in every chemotherapy she received, every spinal tap [lumbar puncture], every biopsy … I wonder if she will wake up from the narcosis or will something happen in there? Those fears… We have been still experiencing… (P1, Appendix H, 53)

Furthermore, he continued her expressions and referred to the fear of relapse and late onset side-effects and the uncertainty that comes with it:

> Even if our daughter has problems from time to time and we come here [hospital] once in a while, thank goodness her general condition seems good. But leukemia is a relative concept. We don't know what tomorrow will bring for us. We do not know whether it left any damage or not, either. (P1, Appendix H, 54)

Another mother also exemplified how she had experienced the discomfort of uncertainty. She said the following words:

> Our minds are not comfortable at all, I mean my mind is not at all comfortable at all. You know, if there is no such disease, you can do your job comfortably and you will have a peace of mind. If you would go somewhere, you would go; you can do your work comfortably. What if she gets a fever, what if she gets sick, what would we do then? So, my mind is not at ease. (P9, Appendix H, 55)

Six of the participants highlighted the hopelessness and fear that they have felt when they witnessed other patients in the hospital whose treatment process went poorly or when they heard the news of another patient passing away. This situation inevitably became a source of stress for them. A mother expressed this distress as follows:

> Actually the hospital environment is so bad; you get to relax a little at home. For example, when you come to the hospital, you see those who suffer from the same problem. Because they have new relapses or something, you say that if they have it, I will also, for instance. I see that people whose pathology results were 100% [clear] are suffering right now; suffering a lot. They have relapses in various different parts. (P5, Appendix H, 56)

Similarly, another mother also stated witnessing the patients in the hospital impact her mood and said “You don't see anyone when you go a little far from here [hospital]. Inevitably, seeing the people here makes you feel more depressed. I'm getting depressed, I feel sadder when I see them.” (P7, Appendix H, 57).

One more direct example referring to this point was stated by another mother. She highlighted an array of negative feelings she has felt, including fear, as can be seen in the following quote:

> I am actually very grateful for my condition, thank God it will be fine, but when I see [these patients in the hospital], I feel very bad. Thank goodness our child is fine. But other mothers say that this came out here of my child, that came out there, I feel very sorry then. I feel afraid too. (P8, Appendix H, 58)

Participant 6 stated that witnessing patient deaths was very hard for her. She added how she tried to prevent her child from learning about the deaths:

> Always afraid of death. It's always that fear. Because a lot of people died, you say, I wonder if we would too. For example, the child asks “Mom, where is

> that person, why is he/she not coming?". In fact, he/she passed away, but I say that the treatment now could be received in their hometown now, they went back there. So he does not know the truth. A lot of the people passed away. And all were the people we stayed with, people with whom we stayed at the foundation, stayed in the family home. Children would die and families would leave all of a sudden, they would go quietly. We wouldn't even see it. (P6, Appendix H, 59)

4.2.6.2 Symptoms and syndromes

In addition to the above-mentioned uncertainty-based fears, all of 10 participants gave examples about how they experienced these stressors and mentioned an array of psychological or physical symptoms of anxiety and depression. Loss of interest (n=3), feeling restless (n=3), feeling disconnected from others (n=2), freeze (n=3), sleep problems (n=3), forgetfulness (n=1), loss of appetite (n=1), weight loss (n=1), low sex drive (n=1) were significant highlighted points by participants as a result of the emotional distress.

Participant 2 talked about how this process influence her emotionally and implied many different depressive symptoms as follows:

> I disconnected from people. For instance, I realized that I'm not smiling anymore. I cannot help it; I am not aware of it. In a crowded place, where 3-4 people are sitting, I would normally be the one to start the conversation. I was the funniest person there. Now, when I entered the environment, I realized that I was frozen. I can't adapt to the situation. Even if someone comes, it's like I'm not there, like I'm in a void. I can't get into that thing again. It's not like it used to be. It started to improve a bit, but I still don't want to communicate with anyone. I don't want to meet anyone. I don't want to talk to people, chat, or share. I have no desire. I feel in a void space. I cannot fully adapt to anything. I used to cook with love and devotion in the past. I don't want to do it now. I just want to pass it off like let's fill our stomachs, that would be enough. I don't enjoy anything. I became intolerant. And I realized that I was very easily offended. (P2, Appendix H, 60)

Likewise, Participant 7 also talked about how this process affects her emotionally. She mentioned her forgetfulness and sleep problems:

> I live disconnected, it's like I'm disconnected from everything. Now I put something somewhere, then I can't remember where it is, where did I put it. Sometimes I think, where did I put this? It did not come to my mind! I have

> become like this. I don't have a sleep pattern anyway, like normal people do. For example, when I put my head on the pillow before, I fell asleep because there was no problem. Now, the biggest problem! I cannot sleep, I can't sleep when I put my head down, it's like that disease is coming, it's eating my brain. I have become this. Not a minute goes by without thinking about it. How will it be, will it end, will this disease go away, will it leave my child? You always have a contradiction. (P7, Appendix H, 61)

Participant 8 also talked about the loss of the interest and how she experienced these emotional strains similarly:

> I don't want to do anything. In the past, they used to build garbage houses abroad. I watched it on TV. I used to say what kind of people these are. Now our house is close to being a garbage house. I do not want to do anything. This is my house where I live! Excuse me if this is a pile of garbage, I don't feel like cleaning at all. I don't want to go out, I don't want to see anyone. (P8, Appendix H, 62)

Participant 8 also expressed having experienced weight loss because of this situation and she said “I was 72 kilos when I heard. I fell to 67 or 68 kilos.” (P8, Appendix H, 63).

In summary, participating parents expressed a number of cognitive, emotional, and physical symptoms that appear to be associated with anxiety and depression. Ten of the participants referred to the uncertainty and mentioned at least one of the emotional difficulties in these processes and stated some physical or psychological symptoms related to stressors.

4.3 Unmet needs of parents

When the participants were asked what kinds of support would make their process easier, they highlighted their unmet needs in the diagnosis and treatment process. Participating parents expressed they had financial, psychological, information and practical needs. Table 7 summarizes the sub-categories of unmet needs of parents.

Table 7. Unmet Needs of the Parents

Unmet needs	f
Financial needs	6
Informational needs	3
Practical needs	2
Psychological needs	1

4.3.1 Financial needs

Six out of 10 participants expressed that they had financial needs because cancer requires long, regular, and special treatment procedures and their financial needs has been true for every step of the process. During the interview, all of these six participants stated although they were supported financially by different sources, they had to afford numerous costs including constant doctor visits and special tests or medical imaging. It was stated that some of these costs were not covered by their health insurance which increased their financial burden. Additionally, when the diagnosed child suffered from physical limitations or their weakened immune systems were considered, they may need to use private vehicles. In this situation, the cost of transportation between home and hospital has been identified as another and often hidden factor that adds to the financial burden. And as mentioned under the "Challenges" section, moving to a new city for treatment and building a new home from scratch can be considered another hidden cost.

Participant 2 exemplified her one of the unmet needs as financial need and she said "If I had financial support, I would not have had a hard time. I mean I am trying to meet the needs of home; I am trying to cover the hospital expenses." (P2, Appendix H, 64). Similarly, Participant 4 reported that they requested from the hospital's foundation that some expenses would be kept fixed for the patients of the oncology unit because of the rapid price inflations, but their request was denied:

> Let them fix it, at least 200 (Turkish Liras). Let it be at a certain level. They had no support. They could have been closer to us, at least by keeping the oncology department separate. We have completed the deficiencies with a

> friend's support, because we pay a certain part of the cost of an MRI, and the government [insurance] does not cover all of them. You know, the others are paid. (P4, Appendix H, 65)

Participant 7 stated very similar thing. Her word can be found below:

> If you go to a hospital, a doctor's examination is 2 billion, 3 billion [meaning 2000-3000 Turkish Liras], so this is how it is. I suffer a little from that aspect as well. It should have been different. Because this disease is a serious disease. I would like the health care providers to be paid less, because the higher amounts are challenging people. So you can't afford it at a certain point. (P7, Appendix H, 66)

4.3.2 Informational needs

Three out of the 10 participants reported they suffered from lack of information about the treatment process. They reported that they did not have enough information before the diagnosis about cancer and its treatment and they needed someone who was familiar with that disease. Participant 9 expressed this need in following words:

> You don't know anything. A disease has come, the most terrible disease, the worst disease, and you do not know anything about that disease because there is nobody who has experienced or known it in your surroundings. In no way. Zero information. (P9, Appendix H, 67)

4.3.3 Practical needs

Two of the participating parents reported they need someone who could help them with practical matters. They stated they needed a little break to meet their daily needs and if someone could help them, they would take this break. Participant 5 expressed her practical needs in following words:

> I wish I had someone in my family who could help me. For example, I wish I did not stay here for 15 days, but I could rest 1 day out of 15 days. I would like someone like that, but unfortunately there is no such person … For example, sometimes my feet have been swollen, I have tried to go back and forth with pain in my feet all day long. I would like to have someone who can take care of him, even if it is 24 hours, so that I could take care of my daily needs, take a bath, change my clothes, wash my clothes or something. I would like someone like that but there isn't. (P5, Appendix H, 68)

Similarly, Participant 2 expressed she did not want to leave her child with a different person, but she needs someone to help her because she was tired:

> I wish someone would take her [to the hospital]. Actually, I want it and I also don't want it. I do not want to leave her either, but I'm very tired, due to constantly going back and forth to the hospital. (P2, Appendix H, 69)

4.3.4 Psychological needs

One of the participants stated they needed professional psychological support from a psychologist or psychiatrist but these needs could not be met in this process. Participant 2 expressed this need was not provided by the health care professionals:

> I would also like to get psychological help. It was not provided. Rather than being an optional thing, such mothers and children should already be known. I think that from the moment the child is diagnosed, after the process begins, just as the oncology-hematology doctor is always with her [diagnosed child], a psychologist or psychiatrist should always be with her in parallel. There should be no need for me to request it. (P2, Appendix H, 70)

4.4 Sources of support for parents

In order to understand supportive experiences of parents, the participants were asked what helpful support was present for them in this period. In answer, the participants exemplified their sources of support and identified how these resources helped them socially, emotionally, financially or practically. All of the participants mentioned at least one of their resources. Based on their answers, their sources of support were divided into 10 categories as (1) religion, (2) extended family and friends, (3) health care professionals (4) school, (5) diagnosed child, (6) spouses, (7) NGOs, (8) official institutions, (9) other parents whose children diagnosed with cancer, and (10) workplace. Table 8 summarizes the sources of support for the parents.

Table 8. Sources of Support for the Parents

Sources of support	f
Religion	10
Extended family and friends	10
Health care professionals	10
School	5
Diagnosed child	5
Spouses	5
NGO	4
Official institutions	4
Other parents whose children diagnosed with cancer	3
Workplace	1

4.4.1 Religious support

All of 10 participants mentioned their religious belief as a part of their resources in this period. Nine of these 10 participants directly stated that their religious belief was the most important source of support and if they did not have their belief, they could not stand their situation.

In response to the question "What was helpful support for you in this period?", Participant 4 reported that the only resource was her religious belief although she mentioned many different sources of support when answering the previous questions during the interview. She expressed her religious belief as following lines:

> It's really just faith. So nothing really exists because you are helpless, there is nothing. You know the drug is poison. Okay, it helps your child, but it also kills. It kills all blood values. Imagine that you accept that they give poison to your child. I said, my Mawla, the drugs given, chemotherapy is poison, but it is your cure, so there is nothing to do. (P4, Appendix H, 71)

Similarly, Participant 1 reported that the most significant resource for him was his religious belief. He expressed trust, surrender and prayer as important parts of his faith:

> Alhamdulillah, we are Muslims. Nothing more than that. We begged the Mawla. We opened our hands. We trusted our teachers [doctors], we surrendered. There is no greater faith than that, what I see. So, my Mawla reciprocated, I think. (P1, Appendix H, 72)

Participant 3 mentioned the life story of Prophet Mohammed [who is the pioneer of Islamic religion] as a resource. He reported that reflecting on how the Prophet himself lost and buried his children gave him strength to carry on.

> As I said that I took our prophet as an example for myself … 7 sons were given to him and he buried 6 of them in the ground. It has been a great source of strength for me. It's always the life of our prophet. There is no other, I did not take anyone as an example. Our only example. (P3, Appendix H, 73)

Participant 9 stated that relationship with God made her psychological condition better and it was the biggest resource for her. During the interview, she gave a number of different coping behavior examples related to her religious belief, which are also analyzed under the coping style section. One example statement from Participant 9 that highlights how much of her belief is integrated with her psychological wellness can be read below:

> I think that whoever is at peace with God is also at peace with [their own] psychology, because that's life, there is nothing we can do. Let's do our best, the rest is in the hands of the divine." (P9, Appendix H, 74).

As it was stated, all of the participants reported that their religious belief was a very important resource for them. They gave numerous different examples about their religious practices and thoughts. It was observed that religious support made it easier for them to cope with their children's cancer treatment. Religion also seemed to influence the coping strategies that the participants utilized, and how the participating parents applied religion as a coping strategy will be explored in the next section.

4.4.2 Support from extended family and friends

All of the 10 participants reported that they received moral support from their extended families and close friends. They stated their families and close friends' gentle and helpful attitudes have become an important resource for them.

Additionally, five of the participants stated they were financially supported by their extended family members and friends. For instance, Participant 1 expressed different ways in which they were supported by their neighbors as he said:

> May God bless our neighbors a thousand times. Fortunately to our neighbors, thanks to our friends, especially my neighborhood. They still call us; they ask how we are. They always support us. They support not only financially but also morally; God bless them a thousand times. They never leave us alone. I would say our neighbors are in the foreground. (P1, Appendix H, 75)

Likewise, Participant 5 gave a similar example:

> Thank God my family is with me financially and morally. For example, he [the diagnosed child] had an operation, we had him operated on his foot for 150,000 liras. I didn't have that amount, so my family gave me 100,000 liras. I owed other amounts as well. Then, they paid for those too, God bless them. (P5, Appendix H, 76)

Participant 8 also mentioned how they were supported by their extended families:

> Of course there are good things as well, not everything is bad. My husband's family gave money for the surgery. My mother-in-law collected it. Also my family. There is support coming from everywhere … Fortunately, they say "Do not think about it". They say "If you ask again, we will send again". Both my own family and my husband's family are good in that respect. They always have our back, they are supporters, God bless them. So it's not all bad, thank goodness … I have cousins, who are my aunt's daughters. They send walnut, grapes. These also count as financial [support] as well. Moreover, the house has been built here again, and they sent everything we need God bless. Some gave this kind of support, some gave money, and some prayed. (P8, Appendix H, 77)

Moreover, four of the participants stated they were supported by their families in practical ways. They reported that their relatives took care of their other children and helped with their chores. Participant 6 exemplified this type of support as she mentioned her sisters as care-takers for her other children:

> As I said, the aunt takes care of the children. She comes and takes care. I can say aunts rather than aunt. One of them is here. When one of them goes to work, another takes care [of the children]. That's how we manage. At times I cannot take care [of my children], but God bless them they look after [the children]. (P6, Appendix H, 78)

Participant 7 also mentioned that her husband's sisters helped her for domestic work as follows:

> He [the diagnosed child] has an aunt. She comes when I go to the hospital. She has no children, never had. She comes and stays with us. And the boy wants to stay with her aunt very much. When we get back home, he wants to see his aunt a lot. Just her; there is no one else besides her anyways. She comes and stays, many thanks. For example, sometimes she cooks our food, I cannot do it all. [Even] my underwear, she takes care of it all. (P7, Appendix H, 79)

Participant 9 and Participant 10 also shared that her relatives and friends provided moral and financial support. Unlike other participants' examples of moral support, they said that their relatives and friends engaged in religious practices including saying prayers and hearing about these practices made them feel stronger. Participant 10 expressed this resource in following words:

> They always talked to us. They called and said, "Don't be afraid. This disease will pass. Okay, it is a hard disease. There is a treatment for it, but it takes time. Don't be sad, don't worry.". While we are on the road, the phones start to ring. They say "We are reading the Quran and praying for you." I do not know, when a person hears that, it gives you a power. (P10, Appendix H, 80)

In general, all of the participants reported their extended families and close friends are a significant source of support for them in this process. It was observed that they benefit from their support in a number of different social, emotional, financial and practical ways.

4.4.3 Support from the healthcare professionals

The participants were asked how their experiences with healthcare professionals have been. Participants' answers revealed the support from healthcare professionals as a very important resource for the parents. All of the 10 participants reported that they were supported by their health care professionals, including doctors, nurses, caretaker and cleaning crew, in different ways. All of them stated the caring and

understanding attitude of the healthcare professionals was a significant resource for them. Four of participants used the word “family” as they refer to their healthcare providers or providers' attitudes towards them. Participant 1’s following words would be an example to the sentiment shared and reported by others:

> So God bless them [healthcare professionals] a thousand times. I mean, how can I tell you, they say from the smallest to the biggest. From the cleaning person to the caretaker. From the smallest to the biggest, they are perfect. That I say. They saw us not only as an unworthy patient but as their family. It's not just for me, it's the same for everyone. So I really like this side of them. (P1, Appendix H, 81).

Participant 9 also stated her appreciation of the healthcare professionals’ attitudes. She emphasized that providers at the hospital has been aware of their unique and difficult circumstances and behaved accordingly:

> They take care of children. I mean, how can I say, there wasn't much scolding, they take care of children. Well, our psychology also deteriorates from time to time, but they behave nicely and do not resent it. They are also aware that these are children with cancer, and the mothers’ psychology is also important and it's already broken here. Many mothers are upset, they can be angry, but they [healthcare providers] act accordingly because they are aware. That also was a thing [in terms of a resource]. They are also conscious after all. They are behaving nicely. (P9, Appendix H, 82).

In addition to the caring and understanding attitude exemplified above, availability of the healthcare professionals came up as another significant point that makes parents’ experiences better. Two of the participants reported that being able to reach their doctors was a source of relief. Participant 2 expressed this experience as follows:

> Ms. Sinem [the oncology doctor] takes care of every aspect, day and night. She gave us her phone number and she is a woman who can say “You can call day and night or weekend. Does not matter. If you have any problem, call me”. She is so in love with her job, she respects us so much, God bless her. Imagine that, this woman actually does what psychology or psychiatry needs to do, both that and that [referring to oncology care]. She does not have to. That's why, as a doctor, it was more than enough for me, well-qualified. I wasn't expecting this much. It is a great chance for us to come across a good doctor, we are glad we came across her. (P2, Appendix H, 83)

Similar to Participant 2, Participant 5 also talked about the availability of their doctor:

> Doctor Sıla [the oncology doctor] is a really good doctor. For example, I can call her at 2:00 am, in the middle of the night and she answers. I don't think there is such a doctor around. She answers. God bless her, she may not, she has no such duty. She does not have to answer me at 3:00 am at night. (P5, Appendix H, 84)

Furthermore, while talking about the experiences with the healthcare professionals, one of the participating parents, Participant 3, mentioned receiving financial support from their doctor. The fact that her daughter's oncology doctor was flexible about the examination fee made it easier for the father to carry out this process. He expressed this support as follows:

> Thank God I was very satisfied with that hospital. Prof. Sinem and her team. So they were interested in us. In other words, if Prof. Sinem had obeyed the financial rules of the hospital, I would have had a hard time. God is the witness. They were very flexible with us, both in the examination fee and in the analysis. I don't know if it was for us or for all her patients, but sometimes she didn't get an examination fee from us every 2 months or 3 months. (P3, Appendix H, 85)

In conclusion, participants' answers show that healthcare professionals are significant parts of the parents' sources of support. It was observed that although what helped the parents might differ, the caring, understanding and flexible attitude of the healthcare professionals has become an important resource for all participants.

4.4.4 Support from school

When the participants asked if they were supported by their school administration and counseling and guidance unit, five out of 10 participants exemplified receiving support from their children's schools. Based on their answers, support from school included home tutoring assisting the children with passing their exams and giving

motivation. Participant 1 highlighted the support they received from the counseling units of her daughter's school in following words:

> Thanks to the school guidance, they always show their care and interest at the school which she attends now. If we had asked for special education [home tutoring] even this year, they would have still given special education this year. (P1, Appendix H, 86).

Similarly, Participant 4 reported her daughter's school had also become a source of moral support through their care and attention in addition to providing the child with a way to continue her education:

> Her teachers were always supportive. Both the school principal and the vice principal said, "We are ready to support Sena as much as we can, both financially and morally". They directed Sena to distance education because Sena wanted that so much, she was a successful student in her classes so she wouldn't fall behind. They called Sena and asked about her condition. For example, her primary school teacher. I mean, they all became supporters, thank you very much, they all gave their support together. They were very good to Sena. (P4, Appendix H, 87).

Participant 5 reported that school teachers provided a facility for the child to pass the exams more easily. She expressed that this was a noteworthy support for her and her son:

> Fortunately, they made it easy for us by saying that "He can study for only certain things [predetermined topics], we can give the exam online, many thanks. God bless the teachers. They also created a group, a WhatsApp group. They sometimes talk to him and ask how he is doing. So it is. Thank goodness, they are good, God bless. Of course, it was a great support, we do not want his education to be interrupted. (P5, Appendix H, 88).

All in all, according to five participants, guidance and counseling units, the school administration, and teachers supported the diagnosed children in different ways. Support received from school has been a resource for both children and their parents.

4.4.5 Support from the diagnosed child

When the participants were asked what was helpful for them in this process, five out of 10 participating parents mentioned their diagnosed children made the process easier for them. They reported that their child behaved maturely and appeared strong, and such positive attitude of the child had become a resource for the parents. For example, Participant 3 expressed how his diagnosed daughter made the process easy for him and said "Thankfully, my process went smoothly. I didn't need much. So my process went smoothly. Beril is also a very strong girl. Thanks to her, we were very strong while going through this process." (P3, Appendix H, 89). Similarly, Participant 4 also mentioned how her diagnosed daughter's attitude gave her strength:

> During the treatment process, Sena did not cause us any difficulties. She was very upset only because her hair was falling out, her eyelashes were falling out, her eyebrows were falling out. She hugged me and cried, I hugged her and cried. I can say that we had an easy time by supporting each other, thank Goodness, Alhamdulillah. But as I said, because Sena was strong, it gave me strength as well. (P4, Appendix H, 90)

Likewise, Participant 8 stated how her son behaved matured and she said the following words:

> I'm fine, thank God. He is such an understanding, big boy on my side. He is like 15-16 years old even though he is 9 years old. Sometimes I cry and I try not to let him know. He says "Mom, don't cry. I'm fine". He's thinking about me. (P8, Appendix H, 91)

In sum, some of the participants (n=5) reported that their diagnosed child's attitude played a significant role as a resource for them. The mature and strong stance of the children appears to have eased the participating parents' process.

4.4.6 Support from spouses

When the participants were asked what was helpful for them, five out of 10 participants said that their spouses helped them in certain ways. Four out of five indirectly stated that they had a division of labor with their spouses but they did not exemplify it as a resource. When it comes to the division of labor, based on the statements of five participants, it was observed that one of the partners tends to accompany the diagnosed child, while the other takes care of the outside business. For example, a father participant stated his wife was always with his diagnosed daughter and he took care of other special procedures himself and said "As I said, in that process, fevers, blood draws, blood donations, blood irradiations etc. I rushed to these … Since the father [referring to himself] was out anyway, the whole burden was on the mother." (P1, Appendix H, 92). Likewise, Participant 4 stated she and her husband had division of labor and her husband took on the logistic and financial part of the treatment:

> Thanks to my husband, he took her [the diagnosed child] to the hospital and took on the hospital expenses. We gave him that burden … I always stayed with Sena [in hospital]. I mean, thanks to my husband, he took care of everything financially. (P4, Appendix H, 93)

4.4.7 Support from non-governmental organizations (NGOs)

Based on the participants, it was observed that non-governmental organizations have become a resource for parents. Three out of 10 participants reported they were supported by a NGO psychosocially or financially. For example, Participant 1 said "ABC [a NGO]. Thanks to ABC, they never left us alone financially and morally." (P1, Appendix H, 94).

In addition, Participant 6 stated they were supported by two different NGOs. While obtaining her demographic information, she reported that she stayed in a

family house of a NGO for a while when she moved to a different city for the treatment. Participant 6 also reported that while living there, she and her diagnosed child got some psychosocial help including one-to-one sessions with psychotherapists and psychoeducational information sessions. When she had to leave the family house of the NGO and rented a house, she was also supported by one of the NGO working with the oncology units of the hospital. She shared the following words.

> When I left the family house, I had nothing, I had nothing. I had a quilt and a pillow. I had nothing. After that, I told the oncology association here, they gave me everything. God bless them a thousand times. They helped both for the disease [treatment] and financial things. (P6, Appendix H, 95)

All in all, when the four participants' answers were examined, NGOs came up as a source of support for the parents of children in cancer treatment.

4.4.8 Support from official institutions

When the participants were asked what has been helpful for them, four of the participants mentioned financial support from official institutions. Three of them reported that the government provided them a monthly care allowance for their children when they were diagnosed. Participant 3 said about this benefit paid to the person who takes care of the child "My wife, her mother, is now receiving care allowance because she has a report." (P3, Appendix H, 96). One other participant, Participant 4, mentioned that they have received support from the municipality of the district in which they live. Details of the support they have received can be seen in the quote below.

> We talked to the municipality and the municipality helped. They said that they will continue, even today Sena will receive a computer from our municipality. They asked what she wanted in this process. I said "She will attend a training but she does not have a computer. She would be happy if she did". Thankfully, they are sending the computer today, which was also what

> they wanted. Mr. Sedat, the deputy mayor, is still calling and asking “Do you need anything, what can we do in this process?”. Fortunately, they also give support. (P4, Appendix H, 97).

4.4.9 Support from other parents whose children diagnosed with cancer

Three out of the 10 participants reported that other parents of children diagnosed with cancer had become a resource for them. They expressed that when they saw other parents, they did not feel alone. These participants highlighted being a resource for one another. Participant 2, for instance, qualified this source of support as the most important one.

> The only sincerity I believed in, who made me feel better here, were the mothers of the patients who were hospitalized in the same ward like me. They understood me, I understood them. We were supporting each other. I was taking that power from them. I'm sure they got it from me too. Because we were wounded in the same place, our wounds were the same. Only the wearer knows where the shoe pinches. (P2, Appendix H, 98)

In a very similar way, Participant 6 expressed that she did not feel alone thanks to other mothers of diagnosed children. She highlighted the importance of recognizing that her family was not the only one suffering. And she said:

> For example, there was a friend here [hospital]. You listen to her story. I mean, it feels good to me when people get support from each other. I'm saying I'm not the only one, there are other mothers. So it is a little good to me. I'm not the only one, there are many people like me. (P6, Appendix H, 99)

Likewise, Participant 10 made a reference to other mothers and their stories being a resource. She particularly highlighted how hearing stories of recovery was helpful for her:

> We had a neighbor, his/her child was more sick. Her child got better, so s/he is fine now. S/he is gallivanting around mixed with other children. I thought about it, I considered it. This gave me morale. Seeing other patients, seeing their mothers, hearing about them gives a morale boost. (P10, Appendix H, 100)

In sum, other parents of children diagnosed with cancer were one of the sources of support for some of the participants (n=3). It was observed that sharing the similar story and suffering from the same disease prevented parents from feeling lonely and increased their morale.

4.4.10 Support from workplace

One of the participants reported being supported by their co-workers. She stated her boss and colleagues helped her financially by raising money for their needs in this period. She also added. There were people who sent money from my husband's workplace." (P2, Appendix H, 101).

4.5 Coping strategies of parents

In order to understand parents' coping strategies, the participants were asked how they cope with their child's cancer diagnosis and treatment. While common coping strategies emerged for all participants, there were also behavioral differences. The category of coping strategies will be examined under three sub-categories as (1) appraisal focused (2) emotion-focused, and (3) problem-focused coping behaviors based on those mentioned in the literature. Table 9 summarizes the coping strategies of parents.

4.5.1 Appraisal-focused coping

Based on the participants' answers, it was observed that every participant used at least one appraisal-focused coping behavior to overcome their child's cancer diagnosis and treatment. Their behaviors as appraisal-focused coping include believing in God (n=11), maintaining hope (n=3), making comparisons (n=3), living

in the present (n=1), purposefully finding joy in small things (n=1), letting go (n=1), and recognizing impermanence (n=1).

Table 9. Coping Strategies of the Parents

Coping strategies		f
Appraisal-focused coping		10
	Believing in God	10
	Maintaining hope	3
	Making comparison	3
	Living in the present	1
	Finding joy in small things	1
	Letting go	1
	Recognizing impermanence	1
Emotion-focused coping		7
	Being strong	5
	Crying	2
	Avoidance	2
Problem-focused coping		7
	Seeking external support	5
	Moving	4
	Arrangement related to work	4
	Planning ahead	1
	Avoiding sharing experienced with other people	1
	Changing scenery	1

4.5.1.1 Believing in God

As it was mentioned in the section above, religion came up as an important resource for all of the participants when they were asked about the resources they have received during the diagnosis and treatment of their child. Consistently, religious beliefs were mentioned again when participants were asked how they cope with their child's cancer diagnosis and treatment. All of the participants reported that trusting God made it easier to cope with this very difficult process. For instance, Participant 5 mentioned that believing in God and praying for her son was the only useful behavior to cope with the diagnosis and treatment and she said "So I just prayed to God. I am a person who does my prayers. I also believe in the power of prayer. He's the only one good for me. I only ask God for help." (P5, Appendix H, 102).

Additionally, Participant 4 expressed they trusted their doctor while leaving the process to God and this strategy made her process more bearable:

> The first thing is to surrender to God, then trust the doctors. I mean we kept them together in this period. It is unbearable, truly unbearable without faith. But we said, he [God] is the one who gives and God is the one who takes. We said that there is nothing we can do, healing is from my Mawla, doctors are means to that end. In other words, we got through this process with the two things, with our prayers. (P4, Appendix H, 103)

In a very similar way, Participant 9 mentioned she also abides by doctors' directives while leaving the process to God. And this attitude made her more comfortable as follows:

> I do everything I can. The doctors say come, we come. They say go, we go. They say do this, we do it. They say get an injection, we get it. I mean, I'm doing everything for my child in the best way. But even if things go wrong again, if it spreads, or if God forbid she dies, there is no discomfort in my conscience, that's God's will. I think it's more comforting to admit that. (P9, Appendix H, 104)

Participant 6's following words also reflect how hope and belief are intertwined. She also highlights how her faith facilitates acceptance of what will be.

> I'm telling you, I'm used to this process now. So even if you cry, it won't change, whatever it is, it will be. Whatever God has said will happen. If it is predestined for him, it [healing] will happen; if it is predestined for him, I believe it will get better. I believe in hope, it will get better, I have hope. (P6, Appendix H, 105)

Likewise, Participant 5 also mentioned she had hope because of her faith. She said, "We have hope. We are people who have such faith, we know that the sick does not die, the one who comes at the appointed time dies." (P5, Appendix H, 106)

In summary, religious belief appeared as one of the most important coping methods of the participants and all of the 10 participants acknowledged it as a frequently utilized coping behavior. It was observed that leaving the process to God provided relief for the parents and their faith also contains acceptance and hope in it, that are other forms of appraisal-focused coping behaviors and would be further explored in the following subsections.

4.5.1.2 Maintaining hope

As it was mentioned in the above part, hope is another coping strategy utilized by the participating parents. The statements about hope which are contained by the religious beliefs of the participants were given above. Except for the hope tied to religious belief, two of the participants directly stated they maintained hope and dreamed about the future to cope with their child's cancer diagnosis and treatment. However, it may be important to note that one of these two participants, Participant 6, mentioned her hope for the first time while talking about her religious belief as highlighted above. Following her statements that link her belief and hope, she separately expressed that hoping has been a helpful coping strategy for her as part of conversation on how she dreamed her son to have a good life:

> What's positive? At least, you think positively. Like, when a person wakes up to a new day, s/he thinks that it will be beautiful. So I say, I have hope. I hope it will be good. He [the diagnosed child] has his dreams, he has his own tastes too … I've never lost my hope. The only thing [I want] is my children to be healthy, my children to rise in the world. (P6, Appendix H, 107)

In a very similar way, Participant 9 mentioned her expectations and dreams about the future. Unlike other participants, she appeared very energetic and happy while talking about her hopes and dreams in the interview. Her statements were as follows:

> But we'll be fine, have a nice day ahead. I have absolute faith in this, we will not always deal with the disease, my dear! We will be a little better, we will travel, we will go gallivanting around. So we're even willing to take out a loan! We will travel, we will go gallivanting around. It is not always good, so it won't always be bad. But what happens, for example, when we go to the hospital for the treatments, we find a place, we sit down immediately. I say to my husband, "Let's sit down and have a look. Okay, we have sadness in our pocket. Let's take a look and open ourselves up". … We will go to the sea, take a vacation, and go to a place with a pool. We have dreams, so we are trying to get through this disease better with those dreams. (P9, Appendix H, 108)

All in all, it was seen that hope is another coping strategy that makes it easier for parents to be more positive and dream about their children's future.

4.5.1.3 Making comparisons

Three of the 10 participants reported that as a coping behavior they compared themselves with the patients in worse conditions. They reported that such comparisons allowed them to see their condition, and specifically their child's health status, in a better light. Participant 3 explained a similar sentiment in the following quote:

> What I saw when I was in the hospital was a great support for me. Our disease is still good, there is a paralyzed person there. S/he suffers from the same disease, but s/he also has a plus, s/he is paralyzed, cannot use his feet, cannot speak. There were children who passed away that we had met, who started their treatment after us. Our situation is very good now, thankfully. (P3, Appendix H, 109)

Similarly, Participant 9 expressed comparing herself with the people worse off than her to keep her mental health stable. She said, "You should always look at those who are worse than you are in life. When you look at those who are doing better than you, your psychology will break down." (P9, Appendix H, 110). Likewise, Participant 4 reported the same way of coping in the following statement:

> I've seen people worse off than me. I also saw children who were in a more difficult situation than Sena. Now that there is worse, so you are thankful for your situation. So you say, your child also has cancer, but you say, "Thank God for that!" because there are so many bad varieties and metastases! (P4, Appendix H, 111).

4.5.1.5 Additional appraisal-focused coping strategies

Our interviews revealed a number of additional appraisal-focused coping strategies which were all mentioned only once. In this section, we intend to highlight these strategies. It may be important to recognize that most of these strategies came from

Participant 10 who gave a very rich answer to our question about coping strategies and when analyzed, appeared to utilize appraisal-focused coping in numerous ways.

One appraisal-focused coping strategy that was highlighted by only one participant was living in the present. Participant 6 reported that her son was alive for now and awareness of this made her feel relieved. She expressed this coping strategy in the following words: “My child is at least safe. It's what comforts me. That is, living in the moment, living in the moment.” (P6, Appendix H, 112)

Another appraisal-focused coping strategy that emerged was purposefully finding joy. Participant 9 talked about how she tried to enjoy small things and used activities that gave her pleasure in day to day life:

> For example, I'm feeling low, I'm making a cup of coffee, I like Turkish coffee. I am drinking tea. So that's what I'm doing now. What should I do if it's low, will we die? It cannot die. You know what they say, "Life is like water in a cracked glass, it will end whether you drink it or not, it will end even if you don't." Whether you live or not. If you're not dying, if you can breathe, then we have to try to live well. Why should that life be poison to us? (P9, Appendix H, 113)

Participant 9 also talked about letting go. She reported she recognized one’s loneliness in the world and invited herself to let go of caring for life or others in the following words:

> You know, because we have a problem, the world stops and says, "Oops, this woman has a problem too." it doesn't say. Nobody cares, everybody lives their own life. That's why we shouldn't get stuck in this short world. You shouldn't pursue everything. (P9, Appendix H, 114)

Related to these, Participant 9 also stated she recognized how everything was transient. She reflected on how the hurt subsides in time.

> Everything comes and goes in this life. Even the biggest, unbearable pains are not like the first day, everything is temporary. The pain and sadness of the first day is not on us now; we are used to it. If the pain and sadness would stay as it was like the first day, I would go crazy. (P9, Appendix H, 115)

4.5.2 Emotion-focused coping

When the participants were asked how they coped with their child's cancer diagnosis and treatment emotionally, seven out 10 participants gave examples for emotion-focused coping strategies that they have utilized to handle the overwhelming emotions of this process. These strategies included being strong (n=5), crying (n=2) and avoidance (n=2).

4.5.2.1 Being strong

Five out of 10 participants reported they tried to stay strong to cope with their child's cancer diagnosis and treatment and lead the process. They stated that they had to be strong because they believed that they could support their children only in this way. For example, Participant 4 expressed that she tried to be strong to keep this process stable as can be seen in the following lines:

> We talk and sometimes they say to me, "Oh Hacer, you are so strong, mashallah you are not crying, you are holding yourself back.". So I said, I'm not really strong, but we have to be, because when that bar is broken, I know it's very difficult to pick up. I said it has to happen in a way. If you think of a mother who constantly cries next to her child like that, she is devastated and worse. It will affect that child badly; you have to be strong. As I said, once that bar is broken, it will be very difficult to collect it. I try not to break it as much as I can, both for Sena and for the other children because there is not one, there are others. As I said, weeping and whining. The same goes for my husband, if I kept weeping and whining for him, it would be very difficult for him to manage this process. My children would also get worse psychologically. So I can't think of myself alone in this situation. "Oh, I'm crying, I'm wasted, I'm damned!". I couldn't do it! I didn't have that luxury, I still don't. (P4, Appendix H, 116)

Likewise, Participant 9 stated very similar sentiments. She expressed her related belief that the mothers should have been strong to care for their children and lead the process.

> I think the pillar of the house is the mother. If the mother collapses, the whole system collapses. Mothers need to be strong. That's very important. You know, there were times when I was sick. For example, I got sick once or twice, my blood pressure rose, I got sick myself. I looked around: I was sick;

> the child was sick. I said “Oh, this won’t do, I should never be sick” so that I can take care of that child because there is no one else to take care of … That child needs care and attention. (P9, Appendix H, 117)

Similarly, a participating father was in agreement with above-provided examples. Participant 3 reported that the adult who leads the treatment process in the hospital had to be strong to be able to handle the process:

> In this process, parents, especially the person who runs the hospital business, cannot cope if s/he releases herself/himself. S/he even forgets what s/he knows. The first thing you have to do is to be strong. If you can't be strong, you can't lead the treatment of the child anyway. (P3, Appendix H, 118)

4.5.2.2 Crying

When the participants were asked what they do to cope with this process emotionally, two out of the 10 participants directly answered that they cried to cope. Participant 10 answered this question by directly saying that she cried. In her statement, it was seen that she combined crying with staying strong strategy that was identified above.

> I cried in the corner, I cried, then I came back to the child, I laughed and had fun. First I poured out, then I sat next to the boy as if nothing had happened. So that my child will not be sad. (P10, Appendix H, 119)

Participant 8 stated that her only two coping behavior were crying as well as praying to God. She shared how she intentionally facilitated her crying to feel the relief that came with crying.

> I'm not doing anything; I'm praying to God. And I told you for the first time, as a foreigner. I'm not picking up anyone's phone. Cry, pray, that's all … I'm constantly looking for an excuse to cry. Sometimes I hear a song, I listen to that song over and over again. After that, I found quotations related to religion. Just to make myself cry, I open it again and again and cry. It feels like it's good when I cry. (P8, Appendix H, 120)

All in all, crying appeared to be another emotion-focused coping behavior that participants (n=2) used to regulate their overwhelming emotions. We would like

to highlight that there were other participants who mentioned crying in the different parts of the interviews. These statements were not counted as coping since these statements were more so an indication of their emotional state, instead of a coping strategy they utilized.

4.5.2.3 Avoidance

Another emotion focused coping strategy that was mentioned by two participants was avoidance. One of the participating mothers stated that she avoided asking doctors about their son's condition because of the fear of hearing bad news. She expressed this way of coping behavior as “For example, when I ask the doctors something, I am afraid if they will say something bad. I don't even have the courage to ask anymore. I don't want to hear it.” (P7, Appendix H, 121). Another participating mother talked about her other types of coping strategies but she also reported that her husband applied his work to avoid this process and said “His father threw himself into work. He did not see anyone for a month, he closed himself at home. He didn't talk to his friends or neighbors.” (P10, Appendix H, 122).

4.5.3 Problem-focused coping

The participants were asked what they did to solve problems that they encountered through the diagnosis and treatment of their child. Seven out of 10 participants gave at least one example for problem-focused coping strategies. Their problem-focused behaviors included seeking external support (n=5), moving (n=4), arrangements related to work (n=4), planning ahead (n=1), avoiding sharing experiences with other people (n=1), and changing scenery (n=1).

4.5.3.1 Seeking external support

As it was mentioned in the "Sources of Support" section, all of the participating parents were supported in different ways by their relatives or friends. It was observed that five of participants actively sought support to meet their emotional, financial, informational or practical needs and they gave examples about how they sought external support. For example, Participant 4 reported she requested financial support from the municipality of their place of residence. Similarly, Participant 6 mentioned that she requested financial support from a foundation which worked with the children with cancer and their parents. Additionally, Participant 10 reflected on a different kind of support, and reported that she shared her experiences with the parents who experienced similar things and so that she gathered information about the disease and received support from them. Quotes from these participants can be found in the "Sources of Support" section.

Moreover, two of the participants reported that they consulted different professionals from their surroundings about various topics in the treatment process. For example, Participant 1 reported that he shared his daughter's test results with his doctor friend and this made him feel relieved:

> My daughter's school friend's father is also a doctor; his specialist is different. I always consulted with him, Dr. Enver is working at XY [a private hospital]. I used to send it to my Dr. Enver every time it came out. Thank God, thank God. He would show it to his oncologist friends, too. Thankfully. He would say "It's going well, Mehmet [referring to himself], is going well." (P1, Appendix H, 123)

Additionally, Participant 4 talked about a consultation about a different issue. As it was mentioned in the sub-section titled "Informing children about their illness", Participant 4 could not know how to tell her daughter the diagnosis and she consulted her oncology nurse friend about this point. Her exact statement can be seen under that section.

4.5.3.2 Moving and work related arrangements

As it was mentioned above, the participating parents reported their experiences about moving (n=4) and work-related changes (n=4). When asked their coping strategies, they did not talk about moving and work-related changes as a coping strategy. However, these decisions were made for offering better treatment options for their children when they encountered a problem of limited healthcare options. Thus, these actions can be also considered as problem-focused strategies.

4.5.3.3 Additional problem-focused coping strategies

As in the above section titled "Appraisal-focused coping", Participant 9 talked about different problem-focused coping strategies that were not highlighted by the other participants. Her other problem-focused coping strategies are gathered under this section. Firstly, she reported that she thought about what she could do in this situation. She expressed her strategy as "Ok, this happened to me, but how do I get over it well? So what can I do to alleviate it a little more?" (P9, Appendix H, 124). She also reported that when she felt overwhelmed, she left the situation, took her precautions and went outside which was recognized as changing scenery. Her words would shine light onto how she used this strategy to cope better:

> I go somewhere, I go out, we go to the market. I say walk Ceyda [the diagnosed child], let's wear masks, let's go to the market. We go, we come around. We do not close ourselves at home. Okay, if you're sick, you are sick anyways, it's happening. It is like an overprotected eye always gets sand in it. If it's going to happen, it's already happening. If the weather is nice, if it's available, I say come on, let's take a walk. A short walk, you know, isn't too long so that she doesn't get tired. (P9, Appendix H, 125)

Moreover, Participant 9 also reported that in order to protect herself from difficult feelings, she actively avoided sharing her experiences with the people who

could not understand her. She expressed this particular type of avoidance in following words:

> Anyway, life is bad now, people don't care about each other's problems. They say ok, ok, so that this time you get angry. It's best if I don't tell anyone, but I live it anyway. The person who will understand me is already approaching me, s/he says I came, what should I do, what should I do, what can I do for you. Or s/he says “Tell me I'm listening.”. In other words, the person who will understand me is already approaching me that way. (P9, Appendix H, 126)

4.6 Changes in perspectives of parents

In this category, the participants were asked what changed in their perspective, both positive and negative, in this process. Their answers were grouped under five sub-categories as (1) shift in attributed importance, (2) changed attitudes toward children (3) awareness about the importance of family (4) awareness about cancer, and (5) awareness for people’s true character. Table 10 summarized the changes in perspectives of the parents.

Table 10. Changes in Perspectives of the Parents

Changes in perspectives	f
Shift in attributed importance	3
Changed attitudes towards children	3
Awareness about the importance of family	2
Awareness about the cancer	2
Learning that people may not be who you expect them to be	2

4.6.1 Shift in attributed importance

When the participants were asked what had changed in their perspectives after the disease, two of the participants reported that they understood what was really important and what was not after the disease. Both two participants stated that what they had perceived as difficulties in the past were not real difficulties. Two of these three participants also expressed that health was the most important thing in life. For example, Participant 2 reported recognizing that the things she cared about in the

past were actually not as important. She said “I was obsessed with too many unnecessary things. Like “s/he did this, s/he said that".” (P2, Appendix H, 127)

Participant 5 also mentioned she learnt the importance of health after this process. She expressed her concern about that the people cared about what she perceives to be little and/or unnecessary:

> I mean, I see people getting upset over such simple, unnecessary things! When I saw them - I have never been like that, actually, I'm not a person who gets upset about such simple things. I solve it if I can; if it doesn't [get solved], I don't leave it that way anyways. There are people who get upset over their husbands’ making a salad. I don't feel sorry for such simple things. When I look at them, I see how heavy their experience of the world is, how much they care about the world. Turns out, it shouldn't have mattered at all. Nothing happens without health, I have learned that. (P5, Appendix H, 128)

4.6.2 Changed attitudes towards children

When the participants were asked what had changed in their perspectives after the disease, three of the participants reported they regretted how they had treated their children until the disease. They stated they wanted to behave in a different way now and mentioned making some decisions about their attitudes towards their child. For instance, Participant 2 reflected on the time she spent with her children. She identified her newly developed awareness of the importance of prioritizing her children as a significant gain of the disease. She said:

> I was spending less time with my children. As if such a disease would never happen to us, as if we were not going to die. I would say more "me", I was selfish. "I" means selfishness. But I can admit it. … I understood the value of my children better, I realized that I would never be able to breathe without them. They're on top of everything right now, they already were, but I wasn't aware of it. It was good in that sense, as if it shook me a little. (P2, Appendix H, 129)

Participant 6 reflected on expressions of love and care. She shared her regret for not showing affection to her son as openly and frequently as it can be seen in the following lines:

> So I make up for it, for example, I do what I didn't do before. I wish I had done what I didn't do earlier. For example, my child was a very active child, he would do something, like kissing, hugging tightly. But now I'm doing the same thing, but I feel a little guilty. I wish I told him I loved him. I used to say I loved him, but not often like this. You love your child, but you love your child inside. Think about it, you cannot express it to the outside. There is something in our hometown. So how can I say, it is perceived as shameful. You know, you love your child, but you do not want them to know because it's a shame, they laugh at me. I wish I had done it earlier. So my child already knows that I love him, I am always next to him. He knows, but I don't know, sometimes I blame myself. I wish I had done this. I wish a person did not say "I wish…", s/he would have done what s/he wanted to do before. I'm very sorry, I couldn't show my love to my child. (P6, Appendix H, 130)

Participant 6 further elaborated on this matter. She gave an example about her more blaming, less supportive attitude towards her child before the disease:

> For example, something would happen, there would be a fight. I always blamed my child because he was active. I would say that you did it for sure. I mean, I would say that whether he is right or wrong, I would say that he does not stop. All mothers behaved like for example she (the other mothers) knew that he (their children) had done wrong, but she still supported it. I wasn't like that. My child was active, for example, I would say that. For example, I would say he did it. (P6, Appendix H, 131)

In a very similar way, Participant 8 also mentioned her regrets around the way she treated her children. She shared her newly found perspective around corporal punishment and the decisions she made after the diagnosis:

> For example, I was doing things to my children sometimes, Especially my eldest daughter, I was doing things to her occasionally, I was beating. She entered puberty, it was pushing me a bit. After that, I am thinking I decided not to even hit [touching her own arm softly] like that. Hopefully I will implement it. The most precious and precious thing in the world is a child. I understood that it was the most hurtful thing. The son. Nothing is that painful. (P8, Appendix H, 132)

4.6.3 Awareness about the importance of the family

When the participants were asked what had changed in their perspectives after the disease, two of the participants drew attention to the importance of their family. They highlighted that now they recognized the most important thing as family and their

relationship with family members has been stronger after the disease. For example, Participant 1 expressed the strengthening of their familial bonds in following words:

> It has changed positively. As a family, we are not a detached family anyway. May God be pleased with my wife, she is not a person who has such character, she is not a person who has such a nature. It keeps me afloat, it took all my pains, it still does. Within ourselves, that is, this did not happen, there was never a rupture. We are more connected. Already a nuclear family, a family of 5, we are more connected. We cared (each other) more. So, I am a father who is fond of children. (P1, Appendix H, 133)

Similarly, Participant 9 stated she has experienced many shifts in her perspective about life. She made a unique point that other participants did not express as she stated that through this experience she got to love not only the close family members but also herself more Her statements as follows:

> A lot has changed, both positive and negative. Especially during this disease process, many things have changed … I love myself more, but of course the family is also very important. I love my family more than anything. My family, my husband, and my children are very important. The rest are all outsiders; they stay outside when the door is closed. Friend, neighbor, relative... They all stay outside. Family is very important. Husband and wife, your children are very important. So, the others are inconsistent. (P9, Appendix H, 134)

4.6.4 Awareness about cancer

When the participants were asked what had changed in their perspectives after the disease, two of the participants reported that as a result of this process, they gained awareness about the cancer, which they framed as an important positive gain of this disease. Participant 3 expressed this outcome as:

> It has made this a little positive in my life. For example, we did not know what kind of disease such patients were experiencing before, that is, we knew the name of it, but we did not know what kind of process, what they were going through, what those patients were going through, what difficulties they had. They just said blood cancer, brain cancer or lung cancer... It just seemed that simple to us. But when a person experiences it personally, this time it is different, so you see what kind of difficulty it is. Now you can guess what that patient went through, you know. There is a big difference between knowing it and hearing about it. (P3, Appendix H, 135)

Likewise, Participant 4 expressed awareness of what cancer truly is as a significant positive outcome. She also stated her recognition for the need for blood donations to blood bank operated by “Kızılay”, which is the Turkish Red Crescent.

> It has changed in a very positive way because you don't understand anything when it doesn't happen to you. Well, of course we heard about LÖSEV, blood cancer etc. In this process, we have become more aware of the need to give blood to Kızılay. Blood is needed, there is no blood in Kızılay. No donors. You know, I said to the people around me, "You know, it could not be known if it was experienced, but for the sake of God, donate blood to Kızılay, because it's really hard". Platelets are needed but no; donor is needed, no, no donor! (P4, Appendix H, 136)

Two participating parents did not have too much information about the cancer before the diagnosis. They did not know the experiences of the patients and their families, and they were not aware of what they could do for that disease on the social level. With this disease, they expressed that they had become more conscious and they framed this awareness as a positive outcome of that disease.

4.6.5 Learning that people may not be who you expect them to be

When the participants were asked what had changed in their perspectives after the disease, two of the participants reported that this process helped them understand people’s true character. They stated that they learned to differentiate who was true and good. For instance, Participant 9 expressed that when their life conditions were good, people provided support and stayed close to them, but nobody would care once their conditions got challenging. She expressed her experiences in following words:

> How can I say… Every time a person falls like this, there are many who try to step on him/her more. That's why I'm used to it now, I'm not surprised by anything because this is not the first blow I've taken. It's not the first blow, so I'm used to it now. If you are good, let's go to dinner, let's go for a walk, let's go to the cafe, everyone will come. You will have many friends. But once you fall, there will be no one around. Only a select few would stay around. (P9, Appendix H, 137)

Likewise, Participant 10 made a similar point. She expressed she could differentiate between people after the disease in following words:

> For example, a person understands his/her true friend. Good ones turned out to be bad, others turned out to be good. The person who had never called or asked about us, called and the other, with whom we have always talked, did not call. So there are mixed things around us. (P10, Appendix H, 138)

CHAPTER 5

DISCUSSION

In this section, the findings of the present study will be discussed while considering the previously conducted studies about the experiences of parents of children and adolescents with cancer. Moreover, limitations of the study and recommendations for the further research will be presented.

The current study aimed to examine the lived experiences of the parents of children and adolescents with cancer in Türkiye. Semi-structured interviews with ten parents of children diagnosed with cancer were conducted. The inclusion criteria for choosing participants were determined as being a parent of a child or adolescent aged 6-17 who has been diagnosed with any type of cancer at least three months ago. The data from the interviews was analyzed through the content analysis.

When the findings of the current study were examined, it was observed that the parents of children with cancer have shared many of their experiences. Yet, there were also differences, particularly with respect to their parenting experiences and coping strategies. These findings will be discussed in line with the research questions and the theoretical background of the present study.

5.1 Discussion of findings

In this section, findings of the currents study will be discussed under the headings of (1) being a parent of a child diagnosed with cancer, (2) challenging experiences of parents, (3) unmet needs of parents, (4) sources of supports for parents, (5) coping strategies of parents, (6) change in perspectives of parents, (7) exploring similarities

and differences among participants, (8) experiences of parents from the lens of ecological system approach, and (9) implications for counseling.

5.1.1 Being a parent of a child diagnosed with cancer

Findings of the current study indicate that the experience of being a parent of a child diagnosed with cancer has many different physical, social, and psychological aspects. It was observed that all of the participants had to deal with both the requirements of the treatment of the disease and the significant changes in many different areas of life. When the participants were asked how they described being a parent of a child diagnosed with cancer, all of them asserted that it was a very difficult experience. Most of them talked about their emotional reactions and thought process in the beginning of the interviews as we invited them to reflect on their experience. Then, they also mentioned other challenges that they have experienced. We are to discuss the identified challenges in detail under the heading of "Challenging experiences of the parents".

Portraits of being a parent of a child diagnosed with cancer were identified. Being a parent to a child with cancer was described as living in an alternate reality. It seemed that parents were to adapt to a brand-new world about which they did not have any information. And this new world appeared to be full of new people, contexts, and routines, along with the feeling of uncertainty, which was unlike any experience the parents had in the past. Consistent with what Khoury et al. (2013) highlighted, this process meant not only fighting a disease, but also managing numerous changes that came with the disease.

5.1.2 Challenging experiences of parents

Findings of the current study showed that the parents of children receiving cancer treatment experienced a number of challenges in different areas. It was found that parents started to experience challenges with the first signs of the disease. The diagnosis journey and the process after the diagnosis were the first times that they faced a wide range of emotions as they navigated through uncertainty. Parents had to adjust to their new life and deal with emotional burden, financial strains, and changing family dynamics. These findings were consistent with the studies conducted in different countries. As in Türkiye, the parents of children undergoing cancer treatment in Croatia reported experiencing mental, physical and social changes (Džombić & Bezić, 2022). In a study conducted in Iran, Taleghani et al. (2012) highlighted the devastation that the parents faced. Just like their counterparts in Iran, our parents from Türkiye had to deal with the psychological and financial burden of cancer.

Beyond the general picture that seemed consistent across countries, sub-categories have emerged in our analyses. The findings of this study about their challenging experiences will be discussed separately as (1) before the diagnosis, (2) after the diagnosis, (3) emotional impact, (4) changes in lifestyle and routines, (5) financial burden, and (6) family dynamics.

5.1.2.1 Before the diagnosis

As it was mentioned above, the challenges for parents started when their children started to suffer from the first signs of the disease. During the interviews, all of the participating parents pointed to the difficulty of the diagnosis process. They experienced a long and overwhelming process with several visits of healthcare

professionals. Until their children were diagnosed with a conclusive disease, they had to struggle with the uncertainty and fear caused by the unclear feedback of the healthcare professionals and the slow progress of this process.

A study by Maillie et al. (2020) conducted in Tanzania emphasized that delay in diagnosing pediatric cancer arises from the patient delay and the referral delay. Based on the interviews, all of the participants took actions when they faced the first signs of disease and sought support from the professionals about it. They asserted that these symptoms were different from those they were familiar with before. Although most of them did not know what cancer looked like, they realized that something was wrong. Thus, at least for our participant the length of the diagnosis process cannot be attributed to the lack of awareness or delay on the part of parents. It seems the referral delay component of Maillie et al.'s (2020) findings are more reflective of our participants' experiences. A cancer diagnosis requires special tests and procedures such as biopsy and imaging. Both getting an appointment for these tests and procedures and then getting the test results take time; parents and children have to visit healthcare providers multiple times as well to facilitate the process and each step has its own waiting time. Participating parents specifically talked about the delay in referral by the healthcare professionals and also delay in appointments for the doctor visits and medical procedures. Participants shared that each aspect contributing to the delay added to their stress. Especially after receiving the diagnosis, parents seem to question if the treatment process could be smoother should they have received the diagnosis sooner.

Another study by Fermo et al. (2014) that was conducted in Brazil highlighted that the cancer diagnosis of children may take a long time and parents suffered from the feelings of fear, sadness, and concern in this period. And the study

also asserted that these delays are caused by the public health system and the lack of awareness of the doctors. In the current study, only one participant referred to the wrongful decision of the doctors, which can be considered as an example to healthcare professionals' lack of awareness. However, all of the 10 participants mentioned the delays about the medical appointments that are related to the public healthcare system in Türkiye. Given how the healthcare system works differently across countries, it is expected that systemic contribution to the delay in diagnosis would differ from country to country. However, it appears that in Türkiye, as in Brazil, the healthcare system slows down the process and these disruptions add onto the parental distress.

5.1.2.2 After the diagnosis

Our results suggest that the cancer diagnosis itself brings on an array of challenges for the parents and this finding was consistent with the studies conducted in foreign countries. Whether they are from Australia (Schweitzer et al., 2012), Sweden (Carlsson et al., 2019), or Türkiye (Günay & Özkan, 2019; Uzun, 2016), parents report their initial reaction to the diagnosis is shock and disbelief. Parents report experiencing difficulty accepting the diagnosis and denying it in the beginning months. Parents also report blaming themselves and feeling guilty for their children's disease. The strongest thought underlying these reactions appear to be the possibility of losing their child which was highlighted by all of the participants of the current study as well as other studies conducted internationally (Gårdling et al., 2017; Schweitzer et al., 2012; Taleghani et al., 2011). It can be said that the type of the disease and the stage of it did not prevent this thought and cancer meant death for the parents.

Another significant challenge for the parents with the diagnosis was talking to their children about their illness, as it was stated in literature (Tan et al., 2022). Five of the participating parents said that they had a hard time telling their children that they were diagnosed with cancer. The age range of the children of these five parents was 7 to 17 and their diagnoses were different. It was observed that parents had different preferences about telling the diagnosis to their children and some of them could not tell the diagnosis to them. There were parents who did not tell their children about the diagnosis and tried to keep it as a secret although they have been in treatment for several months, and they appeared to have a hard time. It seemed keeping such a secret may create an additional burden for the parents. For instance, Participant 6 stated that she did not know whether her 17-year-old son knew the diagnosis or not and she wanted her son to talk to a professional so she would learn if the child knew the diagnosis because she could not talk to her son about cancer. It is clear that informing the children about their illness is another significant step and challenge for both the parents and the children. Gibson (2019) emphasized that parents may experience difficulty while communicating with their diagnosed child about the illness; not only did they not know how they could manage this process, but also, they felt the fear of burdening the children by telling them about their diagnosis.

When the previous studies and the emerging findings of the current study are considered, it can be said that the parents need to be supported and guided about how they can communicate with their children about cancer developmentally age appropriately. Korones (2016) can be a useful guide as the author identifies specific steps about informing the children about their cancer diagnosis and alerted adults to the necessity of paying special attention to this process.

Another challenging factor that the parents experienced while adjusting to the treatment process was to witness the physical and emotional changes that children experience as side effects of the cancer treatment. Parents expressed that they were frustrated and felt helpless while observing these changes. Changes such as hair loss, fatigue and pain were most mentioned by the participating parents. These findings were consistent with the literature. Warman (2021), for instance, highlighted the struggle that Latina mothers experience while watching their children in treatment. That study highlighted the helplessness that the mothers have felt when they saw their children in pain, when they faced the children's physical limitations, and as the children's physical appearance changed due to the treatment. Similar findings related to how stressful it was for the parents to witness these side-effects were also asserted in a study conducted in Türkiye (Ay & Akyar, 2020).

5.1.2.3 Emotional impacts

Throughout the interviews, the participants talked about the emotional outcomes of the process of their child being diagnosed with and treated for cancer. They mostly reported their fears informed by the uncertainty of the whole process along with the possibility of losing their child. It was observed that this particular fear existed not only in the beginning stages of the process when the child was first diagnosed, but also throughout the later periods of treatment. As the previous studies emphasized and also revealed in this study, cancer treatment may require different and hard medical procedures and it has some significant side effects, thus the parents were anxious about their children's life and well-being and they felt overwhelmed by this uncertainty (Ay & Akyar; 2020; Džombić & Bezić, 2022; Eyigor et al., 2011; Gibbins et al., 2012).

Additionally, the parents also reported that they felt hopeless when they encountered the patients whose disease was getting worse and those who died. Although some of the parents stated they compared themselves with those who were worse off as a coping strategy by thinking their condition was not too bad, witnessing this situation was a very important contributor to their distress. A study by Džombić and Ogresta (2020) that was conducted in Croatia asserted that being in the hospital was a big issue for the parents because they had to witness other patients' suffering, and even dying. And they recommended children with cancer to be accommodated by their health status and diagnosis to minimize such exposure to potentially triggering cases (Džombić & Ogresta, 2020).

Participating parents of the current study reported some physical, psychological, and cognitive symptoms that can be related to anxiety and depression. They talked about loss of interest, feeling disconnected from others, sleep problems, weight loss and forgetfulness as a result of this process. These findings were also consistent with the previous studies conducted in Türkiye and other countries. It was emphasized that parents of children receiving cancer treatment may experience the symptoms of depression, anxiety, PTSD and also physical health problems (Karadeniz Cerit et al., 2017; Khoury et al., 2013; Moğolkoç, 2014; Ovayolu et al., 2014; Taleghani et al., 2013).

The diagnosis and treatment process may create uncertainty and fear and makes parents more vulnerable to experience the symptoms of anxiety and depression. It is important to note that although the parents suffered a lot from the emotional distress, it was observed that they did not search for psychiatric or psychological support. Only one of the participants reported she took psychosocial support as individual therapy that was offered by an NGO which they reside in.

However, other parents did not mention receiving any professional support for their mental health. One of the participants talked about her concern regarding the side effects of the psychiatric drugs. Following lines express her fear about how using psychotropic medication may interfere with her childcare responsibilities:

> What will you do if you go crazy? Come on, okay, you're very upset, you're depressed, you're crazy, you took pills, I don't know what you did! What will you do? Those pills also have a lot of side effects. Those psychology pills have so many side effects. You can't quit when you say enough, it cannot be. Either I have to be useful to my child, I have to be good! (P9, Appendix H, 139)

When their expressions about their needs are considered, which will be discussed in the next parts, parents appear to be aware of their need for psychological support but they did not utilize these services. Quote above gives an example of an emotional reason, yet there are also financial and logistic reasons (Gibbins et al., 2012; Pohlkamp et al., 2020). Therefore, it might be a good idea that mental health professionals and their guidance will be a part of regular psychosocial support for these children and their parents.

5.1.2.4 Changes in lifestyle and routines

In this study, findings pointed out that the parents experienced many big changes in their lives. The major changes which they highlighted were moving to different cities, work related changes, isolation and losing their family routines.

Firstly, four of the parents reported they had to move to a different city because pediatric cancer treatment is offered by special institutions that are mostly located in the metropolitan cities. Fluchel et al. (2014) emphasized that geography could create a burden of care for the families of pediatric cancer patients and the families living far from the treatment center might experience additional challenges to reach the institutions because these centers are mostly in urban areas. When we

think about the pediatric cancer treatment centers in Türkiye, most of them are located in metropolitan cities, especially İstanbul, Ankara and İzmir (Türkiye Ministry of Health, 2023). Thus, the families of pediatric cancer patients need to move to these big cities. Such a move also causes some additional problems like housing, job related problems, and lack of communication with their close friends or relatives.

Although the parents did not move to a different city, they may still experience work related changes because they had to navigate the treatment process. They generally highlighted that they or their spouses had to quit their jobs because they had to take care of their children and navigate the whole steps at home and hospital. One of the parents reported he could not work enough in his own business because of the medical appointments. These findings were consistent with the results of the previous studies (Džombić et al., 2020; Gibbins et al., 2012).

Isolation was another highlighted point by the parents in the interviews, but the reason for it changed among the participants. Because cancer treatment causes weakening of the immune system, the parents were afraid of their children getting an infection. Thus, they isolated themselves to protect their children. This point was also emphasized in the previous studies (Khoury et al., 2013). In addition to this, one of the parents reported that she did not prefer to communicate with outside people because she believed that they could not understand her experiences. This data was also consistent with the existing studies. The study by Ovayolu et al. (2014) emphasized that the parent may experience social isolation and withdrawal because of the burden of the process. Džombić and Ogresta (2020) highlighted the similar thing and stated that the parent might avoid contact with other people because their agenda was different.

The last change stated by the parents was about losing their family routines or rituals after the treatment. While they were able to go on vacation or to their hometown before the treatment process, they could not go anymore. Additionally, some of the parents talked about how their family was divided because of the hospitalization and the family members had to stay in different places. Although the participating parents did not mention losing their domestic rituals or leisure time activities it can be speculated that they may lose their special routines because they stayed in different places.

5.1.2.5 Financial burden

Most of the participants stated they experienced financial difficulties because cancer treatment may require special medical procedures, medicines, products and long hospitalization and all of these were costly for them. When the above-mentioned work related changes are considered, quitting a job created one more financial challenge for them. These findings were similar to the previous studies (Džombić et al., 2020; Gibbins et al., 2012; Khoury et al., 2013). Another point that led to additional financial burden for the parents was the economic fluctuation and rapid price changes of the services and products in Türkiye. It could be suspected that these rapid changes and big fluctuations are important stressors and create uncertainty and parents could not know how to deal with the situation financially. There are studies that mentioned the effects of inflation on the cost of cancer treatment in the literature. These studies mentioned the cost of treatment that has changed over the years due to inflation (Savage et al., 2017). However, the parents talked about the rapid changes in a few months in the Türkiye context. Financial burden of the parents of children treated for cancer due to this type of rapid economic fluctuation is not a commonly mentioned issue in the literature.

5.1.2.6 Family dynamics

Other findings from the interviews were related to the difficulties in the nuclear families. Most of the parents stated that their other children were affected by the treatment process. Siblings of the diagnosed children experienced emotional challenges, academic difficulties, and showed some behavioral changes in this period. They reported that these children might be jealous of their diagnosed sister or brothers in this period because the parents could not spend a long time with them in their diagnosed child's treatment process. All of these findings were consistent with the studies conducted before both in Türkiye and other countries (Ay & Akyar, 2020; Ay Kaatsız & Öz, 2020; Cheung et al., 2020; Young et al., 2021).

Literature on the challenging experiences of parents in their family also highlighted the relationship problems between couples. (Çınar et al., 2021; Taleghani et al., 2012; Young et al., 2021). However, the participating parents of the current study did not mention marital problems which they experienced after the diagnosis. Only one of the mother participants stated her husband has sexual demands from her and he said the disease of children was a different condition and it was not an excuse for that, but the mother did not want sexual intercourse. However, she did not describe this as a problem and did not mention any marital problems; in fact, she praised her husband during the interview. Two of the participants reported they were in the process of divorce that began before the diagnosis. They stated the divorce was not related to the disease, and they did not mention the contribution of the diagnosis in this process. Thus, marital problems due to the diagnosis was not a specific point that was directly highlighted by the participating parents.

5.1.3 Unmet needs of parents

Existing literature appeared to infer parents' needs through exploring the challenges they have faced. In this study, in the spirit of giving parents a voice, we have asked them what was missing in the diagnosis and treatment process that should it be there it would make their process easier. Their responses allowed some of their unmet needs to be identified. Reported unmet needs, which can be categorized as financial, informational, psychological and practical, were discussed in relation to the existing literature. Our inferences from the rest of the collected data are also shared.

As it was stated above, the financial burden was an important challenge for the parents. When they were asked what would make their process easier, most of the participants mentioned their financial need again. Although there were parents who were supported by their relatives or close friends, they reported that since the treatment was long term, it had constant costs leaving families in a financial need for, at least, the duration of the treatment. Financial drawback of the cancer treatments is a significant struggle that was stated by the parents of children receiving cancer treatment all around the world (Bretones Nieto et al., 2022; Borrescio-Hega & Valdés, 2022), including Türkiye (Çınar et al., 2021; Eyigor et al., 2011).

Based on the data, another important issue for the parents was information about the illness, as it was also emphasized in the previous studies (Altay et al., 2014; Ay & Akyar, 2020; Džombić & Ogresta, 2020; Pohlkamp et al., 2020). When they were asked about their unmet needs, participating parents did not state directly they needed information. However, they reported that they did not have any idea about cancer and its treatment and they looked for someone to ask about this process and get some advice. The lack of information about the treatment process led to uncertainty again, and made them more anxious. One of the participants reported that

she did not know anything and she researched the disease on the internet and this attempt made her emotionally worse.

> I'm researching on the phone about his illness. As I mixed this, other things came out, it was more tiring for my brain and I quit. I won't see, I won't look because I couldn't sleep at night and I couldn't take care of my child. I spent my day crying all the time. (P6, Appendix H, 140)

Studies in other countries (Bretones Nieto, et al, 2022; Pohlkamp et al., 2020) and in Türkiye (Altay et al., 2014; Ay & Akyar, 2020; Çetinkaya & Sonay Kurt, 2010; Eyigor et al., 2011) identify informing parents about the treatment process as a very important part of the process. Its presence or how it is done has direct implications for parents' wellness. It can be speculated that if parents are to be provided with comprehensive information about the disease and its treatment process, they may be less inclined to seek information from unreliable sources, and avoid being unnecessarily triggered.

When the findings were considered, it can be seen that parents did not know what they could do, how they navigated the process and how to tell the diagnosis to their children. These points indicated that they can benefit from being informed about and guidance through the process, in addition to clinical mental health support (Schweitzer et al., 2011; Wiener et al., 2015).

Throughout the interviews, it was observed that participating parents experienced an array of psychological difficulties. Emotional difficulties and utilizing a number of coping strategies were expressed by every single participant. However, when asked about their needs, only two of the participating parents directly stated that they needed psychological support from professionals. Studies focusing on the experiences of parents of children with cancer also highlight that the parents suffer psychologically and they need professional support in their child's diagnosis and treatment period (Altay et al., 2014; Bretones Nieto et al., 2022; Davies &

O'Conner, 2022). One of two parents who mentioned the need of psychological support in this study stated mental health professionals should be a part of the treatment process as oncology-hematology doctors, as it was also recommended for the psychosocial care of children with cancer and their families both in international studies (Davies & O'Conner, 2022; Wiener et al., 2015) and in Türkiye (Altay et al., Ay & Akyar, 2020). This expression points out the existing lack of standardized psychosocial assessments for the needs of children with cancer and their families in Türkiye (Ay & Akyar, 2020). If these children and their parents are to be routinely supported by the mental health professionals, the parents could have an easier time handling the process psychologically (Ay & Akyar, 2020; Kazak et al, 2015). When the low number of participants expressing this need is considered, it could be speculated that parents' lack of awareness or expression of this need might be a reflection of the lack of such routine implementations.

Another unmet need that was directly highlighted by two of the participants was about their functional needs. Parents stated that they needed someone who could help them and so that they could take a break to meet their personal needs and take time for self-care. The practical needs which were highlighted in this study were also consistent with the previous studies (Gibbins et al., 2012; McGrath, 2001). Overall, it appeared that participating parents were not as verbose when it comes to answering a question about their needs versus their challenges or how they cope with these challenges. For instance, as it was highlighted in the headings of "Challenges faced by parents", all of the participants experienced emotional difficulties and gave some examples about the syndromes and symptoms related to the emotional distress which they suffered, but except two parents, the rest of the participants did not mention the needs of psychological needs. On the other hand, our findings showed

that the practical and informational needs were other important unmet needs when their challenges were considered, but their disclosure around these needs were limited. Studies conducted in US (Rini et al., 2008) and in Türkiye (Altay et al., 2014; Yildirim Sari et al., 2013) emphasized that the parents might not be aware of their needs for their self-care or emotional well-being, and they put these needs behind their child's treatment needs. When we thought that financial need was directly related to assuring and maintaining the qualified treatment for their child, it is not surprising that this need was emphasized by most of the participating parents. Therefore, it can be said these findings were also consistent with the previous empirical studies.

5.1.4 Sources of supports for parents

Our findings suggested that the parents received both moral and financial support from different resources. Based on the interviews, their sources of support can be listed as religion, extended family, healthcare professionals, school, diagnosed child, spouses, NGOs, official institutions, other parents of children diagnosed with cancer and workplace. Patterson (1988) proposed a model to understand the experiences of families going through health related issues. Based on this model, the resources of the parents of children diagnosed with cancer were divided into four categories namely child resources, family resources, community resources and health-care system resources (Patterson 1988; Patterson et al., 2004). Below the findings will be discussed in the light of Patterson's (1988) model.

5.1.4.1 Child resources

Patterson et al. (2004) pointed out that diagnosed children tend to be a distinct source of support for their parents. A very similar pattern was evident in our sample. Most of

the participating parents of the current study also mentioned that their children behave maturely, accept the situation and appear strong, and their demeanor made them strong throughout the cancer treatment process. It was observed that the diagnosed children displayed active support for their parents; they were using humor and giving feedback about their condition, ensuring the parents that they were okay.

5.1.4.2 Family resources

Patterson et al. (2004) categorized family resources as another distinct source of support for the parents of children diagnosed with cancer. Marital relationship, sibling support, support from the extended family were identified as different kinds of support that were grouped under family resources. Religious belief was also included in family resources in the mentioned study (Patterson et al., 2004). The parents in the current study also talked about receiving similar support from their families. The nuclear family, specifically the spouses, were named as a source of support. Participating parents indicated both their spouses' attitudes and the labor of division that they have established as a couple made the process easier. In addition to support from the spouse, religion was directly emphasized as a resource by all of the parents. Most of them stated the biggest source of support was believing in God, and they mentioned how they applied their religion as coping strategies, which will be discussed in the next section.

Extended family or relatives were other resources for the participating parents. They stated that their family members and relatives supported them socially, financially and functionally. These kinds of support mostly included covering some of the treatment cost and giving emotional support by asking their needs with a caring attitude. Also, it was stated that there were relatives who shared their home to meet the need for shelter of the moved families, and those cared for the siblings of

the diagnosed child. While extended family support is recognized in the literature, this specific form of help through providing shelter or child-care was not commonly highlighted in the literature. It can be speculated that this unique kind of extended family support is a reflection of Turkish culture. Relationship among relatives is seen as important in Türkiye context and the way boundaries are established allows, maybe even encourages extended family to make accommodations as it was also stated in previous studies in our country (Altay et al., 2014; Ay & Akyar, 2020; Eyigor et al., 2011; Ovayolu et al., 2014).

Another diversion from the literature was that sibling support did not emerge in the current data as a specific type of family resource (Patterson et al, 2004). When mentioned, siblings' presence appeared to be a cause of distress (due to their unmet needs) or disappointment (for not helping out the parents as much as they hoped they would). This result seems at odds with Turkish culture and might be explained through generational differences. Families do expect older siblings to be contributors, however, older siblings may not have internalized these cultural expectations, and as a way of managing the challenges that pediatric cancer brings onto the family, they may be prioritizing their own needs. Additionally, some of the parents stated their family members had to stay in different locations due to moving. This point may cause parents to interact less with siblings in this period (Ay & Akyar, 2020); and thus their support may be perceived less by parents compared to the other family resources.

5.1.4.3 Community resources

Patterson et al., (2004) identified community resources as another distinct source of support for the parents of children with cancer. When it comes to the community resources, parents of the current study named their friends, co-workers, other parents

of children diagnosed with cancer, school staff, NGOs and official institutions as specific sources. They stated their close friends and co-workers provided moral and financial support. Sharing experiences with the other parents of children with cancer helped them feel understood and supported. Especially, if the other parent's child had the same type of cancer and the diagnosed child was either getting better or successfully completed their treatment, advice and comments that came from their parents had higher valence.

In the current study, the participants were specifically asked whether they were supported by their child's school administration or counseling services. Five of them mentioned receiving some kinds of support from their school's staff, including home-tutoring, online education, support for the child in passing their exams, and moral support for the child. During the interview, four of these five participants appeared satisfied and happy while talking about the support from their schools. They seemed to perceive the school as part of their support system. However, one of these five participants reported her child took home tutoring from the teachers of their school but she stated the teacher could not understand the child's experiences, nor provide the needed support.

> Teachers are coming home. They come home for 3 days, Monday, Tuesday, Saturday. Coming home for 3 days. I told Ceyda it was just for this year. I said you will go to school again next year. This year it will be like that so that she does not get infected. So I can fix Ceyda's psychology best. What will the teacher understand? I would not say what they will understand, of course they are also teachers. But you know, there is not anybody saying "Let's take care of it too. Do you need any support?". I'm telling you, no one cares, so I fix everyone's psychology. (P9, Appendix H, 141)

This quote illustrated the difference between presence and support. Receiving visitations of a school personnel may not translate to the sense of being supported for the families. In addition, it is important to note that six of the participants did not mention any support from their school. In response to our questions, one of these six

participants reported that school staff were not interested in their condition and they could not get any support. She stated her experience with the school in following words:

> No support from the school! Once I went to school to meet the principal to ask what will happen to her academic life. He said what's wrong, he did not even know which student [the diagnosed child] was. I was shocked. I told the principal, "The child has not been in school for 1.5 years, sir.". He does not know which student, whose parent I am, why she did not come, what her illness is. Her teachers learned from her friends, but no one called to say get well soon or is there anything we can do. None of them cared. (P2, Appendix H, 142)

Remaining participants did not report making a request of support from their schools, nor having any such expectations. Two of them knew the requirements to get support but the school support was not their first priority in this period. School support and roles of counselor in facilitating school support is an important issue and it will be discussed in another section below.

Non-governmental organizations were another source that was named by the participating parents. NGOs' support has become an important resource for many needs, such as financial, psychological or shelter for the participating parents. The participants also reported they got social support from the official institutions of the government. Some of the parents expressed they received a monthly care allowance from the government with a medical board report. They regard this support as an important resource, as their financial needs are long-lasting. Additionally, one of the participants mentioned the municipal administration of the residence they lived in as a resource which provided the diagnosed child with a computer for the child to continue her lessons online.

All in all, our findings show that parents of the current study named their friends, co-workers, other parents of children diagnosed with cancer, school staff, NGOs and official institutions as specific sources. All these types of community

support were consistent with the previous studies (Džombić et al., 2020; Patterson et al., 2004).

5.1.4.4 Other health care resources

Patterson et al., (2004) identified health care resources as another distinct source of support for the parents of children with cancer. Health-care system support included support from the health care professionals and all of the participating parents in the current study mentioned their positive experiences with the healthcare professionals. They reported that caring attitudes and competence of the healthcare professionals positively contributed to their wellness. They felt confident and comfortable while asking their doctors or nurses something about their children's treatment. Also, one of the participants stated that sometimes their oncology doctor did not charge inspection fees, and this financial ease also translated to appreciation of the provider. It is important to note that although all of the participants reported having positive experiences with the healthcare professionals in oncology units, two participants reported that the professionals in other fields of medicine could not understand their needs, and their attitudes were not as good as the healthcare professionals in the oncology unit. For instance, a mother expressed her experiences with other professionals below:

> Other places [other units] are not like that [as the staff of the oncology units]. For example, my child had a blood check recently. They didn't do anything when I went there. How can I say, they have been getting too big for their boots, they behave like that? (P6, Appendix H, 143)

It can be speculated that the health professionals in the field of oncology and hematology are more aware of the unique needs and experiences of the children with cancer and their needs compared to other fields. Their compassionate attitude seems as important as their professional competence for the parents. Thus, when the

parent's emotional distress and information needs are considered, attitudes and competence of the healthcare professionals can easily turn into a strain for the parents in this vulnerable period. This finding also appears to be consistent with the existing literature. Studies conducted in Türkiye (Altay et al., 2014; Eyigor et al., 2011; Günay & Özkan, 2019) and in other countries (Davies & O'Connor et al., 2022; Khoury et al., 2013; Schweitzer et al., 2011; Tan et al., 2020) emphasize that the attitude of healthcare professionals was an important factor which influenced the stress level of the parents and lack of support or empathy provided by the professionals exacerbate parents' hardship as they try to adapting to the diagnosis and treatment process.

5.1.5 Coping strategies of parents

In this study, the coping strategies of the parents of children with cancer were also examined. When it was inquired, all of the participating parents named strategies to cope with the challenges that pediatric cancer brought. Their coping strategies were examined under three main categories of coping strategies, namely appraisal-focused coping strategies, emotion-focused strategies, and problem-focused strategies.

During the interviews, it was observed that the most commonly used coping type which was highlighted by all of the 10 participants was appraisal-focused coping strategies. Parents tended to deal with the situation through shaping the way they think and religious beliefs appeared to be a common factor that guided parents' appraisal-focused coping. This was consistent with the existing studies on parents of children with cancer, which recognized religious belief and spirituality as important components of coping with challenges brought by cancer (Dolan et al., 2021; Günay & Özkan, 2019; Patterson et al., 2004; Picci et al., 2015; Usluoğlu, 2018). A recent

study conducted in Philadelphia by Dolan et al. (2021) highlighted that religion played an important role in managing psychological distress for the parents of children diagnosed with cancer. Another study which was conducted in Türkiye by Günay & Özkan (2019) highlighted that the parents believed the disease came from God, which was parallel to reports of our participating parents. It was also observed that believing in God facilitated acceptance for their child's disease and gave parents opportunities to foster hope through praying for their child's health. It was speculated that the appraisal-focused coping strategy of believing in God facilitated acceptance and hope for the future in itself, which are also types of appraisal-focused coping strategies.

As appraisal-focused strategies, making comparisons and living in the present were other ways of coping reported by participating parents, which were also highlighted in literature (Patterson et al., 2004). Enjoying small things, letting go and recognizing impermanence were other appraisal-focused coping ways that were reported by only one participant. These specific forms of appraisal were not commonly mentioned in the literature exploring the coping strategies of parents of children with cancer. Hence, it was meaningful and enriching to hear these examples of appraisal-focused coping as part of the parents' experience.

The second most used coping strategies reported by the participating parents were problem-focused strategies, which can be listed as seeking external support, moving, work related arrangements, planning ahead, avoiding sharing experiences with other people, and changing scenery. When the parents were asked what they did to solve the problems they encountered in this period, they did not directly mention seeking support behaviors, moving, or quitting their job as a way of coping. Yet as the interviews were analyzed, it became clear that the participating parents were

actually solving their important problems through these actions. Hence, it was deemed important to highlight these problem-focused coping behaviors in relation to the coping strategies that parents of children with cancer utilizes.

Among the identified problem-focused strategy, seeking external support was most commonly noted. They reported that they sought support from their extended families, professionals and official institutions to meet their needs in this period. Additionally, the participating parents reported that they moved to a different city and experienced some changes related to their work, like quitting their job, all done to overcome barriers to a better treatment process for their child. Additionally, planning ahead was another problem-focused strategy that was reported by only one participant in the current study.

These findings were consistent with the previous studies (Lyu et al., 2019; Patterson et al., 2004; Usluoğlu, 2018). Lyu et al. (2019) emphasized that the parents of children receiving cancer treatment avoided discussions with their friends or other family members because of two reasons. First, the parents did not want to worry their friends or relatives. Second, the parents wanted to protect themselves emotionally from the attitudes of their relatives or friends because parents thought they did not know the process exactly. One of the participants of the current study shared the exact sentiment as she stated that she did not talk about her experiences with others because she did not want to get angered by their attitude. While this finding was similar to the findings of the study by Lyu et al. (2019), this was not a commonly highlighted coping strategy in studies in Türkiye. Other problem-focused coping strategies, which were moving, work related arrangements and planning ahead, were another highlighted type of strategy in other countries (Miedema et al., 2010; Patterson et al., 2004) as well as Türkiye (Usluoğlu, 2018).

Participating parents also reported utilizing emotion-focused coping strategies, which were being strong, crying, and avoidance. Most of the parents who used emotion-focused coping strategies stated that they had to be strong to lead the treatment process and meet the treatment needs. It was also reported that they cried to relieve their difficult emotions. These two emotion-focused strategies were emphasized in studies both conducted in Türkiye (Usluoğlu, 2018) and other countries (Miedema et al, 2010; Patterson, 2004). In the current study, overworking or avoiding to hear from the doctors were also mentioned as forms of avoidance by the participants. This strategy was also stated in previous studies (Miedema et al, 2010; Picci et al., 2015; Usluoğlu, 2018).

Studies in other countries (Miedema et al, 2010; Picci et al., 2015) and also in Türkiye (Günay & Özkan, 2019; Usluoğlu, 2018) stated that substance use like cigarette, alcohol or drug was commonly applied by parents of children with cancer as a form of emotion-focused coping strategy. In this study, the participating parents did not report that they used substance to cope emotionally. However, one of the parents mentioned the use of substances among the parents and she said:

> Friends [other parents in hospital] sometimes smoke, I am going near them. I've never smoked in my life, sometimes I say let's start! … There is Mehtap from Kayseri, I don't know if you've ever seen her, she says "I started after my child's illness". I'm trying hard not to start smoking." (P8, Appendix H, 144).

Thus, it can be speculated that although our participants did not talk about substance use, smoking exists as an emotion-focused coping mechanism among the parents of children treated for cancer.

5.1.6 Changes in perspectives of parents

During the interviews, the participants were asked what has changed in their perspectives due to their child's diagnosis and ongoing treatment. Their answers suggested significant shifts in their awareness and attitudes.

While there were a limited number of studies exploring parents' change process through the disease or the positive outcomes of this taxing process, still there were consistencies between our findings and the existing literature (Schweitzer et al., 2011; Usluoğlu, 2018). Parents tend to experience a strengthening in their family ties, and they give more importance to family units after the cancer diagnosis and through the treatment (Schweitzer et al., 2011; Usluoğlu, 2018). Parents get to learn what cancer is and its prevalence in society, and they perceive that as a significant gain of the disease. Additionally, they get more aware about the importance of life and a person's health. Small problems which they have encountered in daily life no longer appear as important as they did before (Schweitzer et al., 2011; Usluoğlu, 2018).

Moreover, two different dimensions of change that were expressed by the participating parents were not commonly mentioned in the previous studies. One of these changes was parents' report of how their attitudes towards their children, including the diagnosed one and others, has changed after the diagnosis. They said they regretted not showing their love to their children enough and they wanted to behave differently now. A study conducted in China by Siyu and Sang (2020) highlighted that parents started to behave differently and show more affection to their child more after the diagnosis. Researchers explained that parents spent more time with their children and tried to have fun with them during the treatment process to make the treatment process easier for their children through diverting the children'

attention. However, in our case, our data pointed to a more general perspective change, not a behavioral change to facilitate or ease up the treatment process. It appeared that this increased appreciation for the child and willingness to show love was associated with a shift in perspective towards life and living too.

Another finding was that the participating parents reported they gained awareness about the people's true character and understood who their real friend was and who was not. Parents stated that they could not get support from the people from whom they expected to receive help; on the other hand, people, whom they never expected to help them, did. Parents pointed out that this understanding was something they have gained through the process of their child's diagnosis and treatment. This type of an outcome of the process did not seem to be recognized in the literature.

We suggest that it is important to look at parents' experiences from a more comprehensive perspective. As difficult as it can be for them to go through their child's cancer diagnosis and treatment, this period fosters change and growth. While we cannot speculate whether these changes are long-term changes, presence of these growth in parents' journeys is noteworthy.

5.1.7 Exploring similarities and differences among participants

While there are many common experiences of parents of children with cancer, there are also differences in their experiences in this period. In this section, their experiences will be compared in terms of being a father or being a mother, their child's age, type of cancer and stage of the disease.

First, it is important to note that the numbers of the mother and father participants in the current study were not close to each other and most of the

participating parents were mothers, which will be recognized among the limitations of the study. However, participants made a number of references to the experiences of their family members which allowed us to make certain inferences.

In this study, there seemed to be a clear difference between mothers and fathers with respect to their involvement in cancer treatment. It was observed that it was mothers who generally led the diagnosis and treatment process of the children in the hospital and they were more in control of the process. Both participants, including one participating father, and the referred fathers who declined to participate in the study suggested that mothers were more heavily involved in the process.

Most of the mothers stated that the fathers had to spend their time with work while the mothers took care of the children. Also in the data recruitment process, most of the referred fathers declining participation stated that the mother of the child knew more about their child's process and that the researcher should have interviewed their wife instead of them. Although there are limited number of studies focusing on the fathers of children with cancer all around the world, this point seems consistent with the existing studies conducted in Türkiye (Ay & Akyar, 2020; Eyigor et al., 2013; Günay & Özkan, 2019) and in other countries (Mogensen et al., 2022; Nicholas et al., 2009). In a study focusing on the quality of life of parents of children with ALL in Denmark, Finland and Sweden by Mogensen et al. (2022), mothers were primary caregivers of these children and they were more in control of the treatment process compared to fathers because the fathers generally spent time at work. In another study conducted in Canada by Nicholas et al. (2009), the mothers were first parents to meet the diagnosed child's daily needs, and the fathers were responsible for the long-term influences of the process. Studies conducted in Türkiye also emphasized that mothers took more care of their child and spent more time with

them in the hospital and fathers were often indirectly involved in process (Ay & Akyar, 2020; Eyigor et al., 2013; Günay & Özkan, 2019). Based on these findings, it can be speculated that differences in gender roles of mothers and fathers for caring for their child with cancer is observed in Türkiye as well as other countries.

The target group of the current study was the parents whose child in cancer treatment was of school-age. Ranging from 7 to 17, we have covered different developmental stages. Neither parents' reports, nor our analysis of the data did not suggest differences for the participating parents' experience based on their child's age. Neither challenges they faced, nor coping mechanisms they have utilized appeared to be different for those who have younger or older children. Consistently, previous studies showed that experiences of children and adolescents with cancer were rather similar (Darcy et al., 2019; McLoone, 2021; Vena & Copel, 2021). In that vein, it is not surprising that parental experiences of children and adolescents with cancer are also similar.

Another variable that can differentiate parental experiences can be children's diagnosis, particularly the type and stage of the disease. The diagnosis of the children of participating parents were osteosarcoma (n=5), acute lymphoblastic leukemia (ALL, n=1), lymphoma (n=1), medulloblastoma (n=1), ewing sarcoma (n=1), soft tissue sarcoma (n=1), meaning half of the participants' children were diagnosed with osteosarcoma while the other half was a cumulation of different types of cancer. All of the participants stated their child received chemotherapy treatment. Except the parents whose children were diagnosed with lymphoma and ALL, all parents mentioned the surgical procedures were part of their child's treatment, which was observed to be a cause of additional stress for the parents. During the interviews. participating parents also talked about different medical procedures that added to

their distress. For example, one of the parents whose children were diagnosed with ALL talked about the procedure known as spinal tap [lumbar puncture] and how worrying it was for them to get this procedure done. There are limited studies in the literature on the effect of specific treatment procedures on parents. However, a study conducted in the US by Mangurian et al., (2018), focusing on the effects of bone marrow transplants on parents, and another study in Türkiye by Karadeniz Cerit et al. (2017), focusing on the effects of cancer surgery on parents, pointed at the stressful nature of these procedures and suggested that going through such procedures may cause severe distress for the parents. Thus, it can be speculated that the type of the disease might be a factor that can differentiate the parent's experiences, especially as the type of the disease dictates which surgical or medical procedures would be conducted. Each procedure might bring on different needs and burdens for the parents.

In this study, the stages of the four children's disease were not identified since the participating parents reported not being informed about it. One child's disease was in the second stage, and the rest of them were in the third or fourth stage. Based on the findings and researcher's observation during the interviews, it can be said that the prognosis of disease is another factor which influences the parents' experiences because some of the parents appeared hopeless and gave less examples about their coping strategies while some of them expressed that they were quite hopeful about the future. This finding also seems consistent with the existing literature. A study conducted in Australia by Muscara et al. (2015) suggested that the severity of illness and process of hospital stay were important factors which influenced parental stress regardless of the stage of disease. Another study in Türkiye also supported these findings and highlighted that the symptoms of the diagnosed children related to the

illness in the treatment process was one of the factors influencing the parents' quality of life. How the treatment is unfolding appears to affect parents' stress level (Muscara et al., 2015).

5.1.8 Experiences of the parents from the lens of ecological system approach

It would be essential to examine our findings from the lens of Bronfenbrenner's ecological system approach, which had laid the theoretical foundation for the current study. Studies emphasized that the ecological systems theory was useful to understand the complexity of childhood cancer for all family members (Davies et al., 2022), and it may also offer researchers an approach to reduce the health disparity (Reifsnider et al., 2005).

As it was stated in the literature review, the ecological system model includes five sub-systems, which are microsystem, mesosystem, exosystem, macrosystem and chronosystem, and these systems form a nested structure (Bronfenbrenner, 1979). In this study, the findings will be elaborated while considering the parents in the center of the system.

According to Kazak et al. (2009), chronic illnesses can also be considered as a concept in microsystems both for the children and their parents. When we look at the microsystem level, there are reciprocal relationships between the parents and children and they form each other's microsystem (Kazak et al, 2009). This means diagnosis of children may directly influence the experiences of the parents (Kazak et al, 2009; Steele & Aylward, 2009). Current study provides examples for this conceptualization. For example, our findings showed that witnessing the side-effects of the treatment was a difficult experience for the parents. On the other hand, it was also observed that diagnosed children supported their parents emotionally with their

strong stance as a response. This situation may be an indicator of this reciprocal relationship between the children and the parents at the microsystems level.

Also, home and the hospital environment created other major microsystems of this structure and they had direct influences both on the children and the parents (Steele & Aylward, 2009). For the current study, the hospital environment had opposing effects on parents' experiences: while being in the hospital could be a source of challenge, it was also a source of support, mainly through the attitudes of the health care professionals. On the other hand, parents mentioned their spouses' and other children's attitudes. These are important examples for the microsystems and directly affect the experiences of the parents.

Mesosystem was a structure which included the interactions among the different microsystems and would also indirectly affect the individuals (Bronfenbrenner, 1979). In this study, the diagnosed child, other family members, hospital, and cancer itself were different microsystems (Kazak et al., 2009). When we look at how the interactions among these microsystems affect parents, it is possible to observe significant examples. Based on the findings, the diagnosed children were affected by the disease and its different treatment procedures. Children's relationship with the disease and their reactions to this process played a significant role in parents' experiences. For instance, some participants stated that chemotherapy causes hair loss and their child was upset about this situation, and it was a difficult experience for them to see their child was sad about this issue. This indirect effects of treatment on parents can be considered as an example of a mesosystem.

Another larger social system which may indirectly affect the individuals is the exosystem (Bronfenbrenner, 1979). When the findings were examined in terms of

the exosystem, it is possible to observe several significant examples. The participating parents mentioned their sources of support, social networks, employment situation or community services, which may be included in the exosystem of them (Steele & Aylward, 2009). Based on the findings all of these points influence the experiences of the parents negatively or positively. For instance, all of the participants mentioned their different sources of support and how these resources made them relieved. Parents also talked about the work-related problems and financial drawbacks of the process, that were the parts of the exosystem. Thus, it can be said that if the structures in the exosystem work well, it becomes easier for parents to handle this process.

The next system which includes all of the interactions among these different systems is macrosystem (Bronfenbrenner, 1979). It is more complex and composed of societal or cultural values, regulations, law and policies (Bronfenbrenner, 1979; Steele & Aylward, 2009). When the experiences of the parents were examined, there are a number of important remarks related to this system. First, all of the parents mentioned their religious beliefs and it was observed that their belief played a noteworthy role to cope with this experience. Second, the findings showed that the families had to move to different cities because there were not enough treatment options for the pediatric cancer in small cities in Türkiye, which could be considered as an experience in macrosystem. Additionally, the parents also talked about some financial burden caused by two reasons which were the expenses of the cancer treatment that were not covered by the health insurance and the economic fluctuations in Türkiye. These points are directly related with the political decisions and regulations in Türkiye and affect the experiences of both parents and children.

The last system in the ecological approach was chronosystem, which includes the transitions and historical life changes of the individuals (Kazak et al., 2009). When all the findings were considered, it can be said that cancer diagnosis and treatment had become important transitions for all family members. They experienced many changes in their lives in this period. The parents also talked about their perspective changes about life and these could be an indicator that they experienced a big transition. On the other hand, cancer treatment takes time and the results of it create many changes for all family members in the long run (Kazak et al., 2009; Steele & Aylward, 2009). However, the changes that would be experienced in the long run could not be identified in the current study because the data was collected only at one point during which the families were still in the treatment process.

In summary, when our findings were considered, it can be said that childhood cancer is a concept which should be examined from a detailed conceptual framework (Davies et al., 2022). And Bronfenbrenner's ecological system model provides us to understand the experiences of parents of children diagnosed with cancer in detail while considering their challenges, needs and resources both on an individual and societal level.

5.1.9 Implications for counseling

As this study was conducted from a mental health perspective, it is important to discuss the roles of the providers in the field of mental health counseling, specifically of counselors who are general practitioners and school counselors. When the broader literature is examined, it was seen that the team for the psychosocial support for the children treated for cancer and their families includes professionals from different

backgrounds such as doctors, nurses, social workers, psychologists and counselors are seen as an integral part of the support team. Moreover, mental health providers seem to play a significant role in the provision of psychosocial support to the families (Chaudhuri et al., 2022; Wakefield et al., 2021; Young, 2018).

However, in medical settings in Türkiye, psychosocial support is expected to be provided by psychiatrists, nurses and psychologists as informed by the regulations of the Türkiye Ministry of Health, and mental health counselors are not a part of this team. The findings of the current study have consistently reflected how counselors were out of the parents' experiences. Yet psychological counselors are fit to take part in a very significant role in support of families going through childhood cancer for a number of reasons including their values, perspectives, and skill sets.

As it was recognized in the introduction section, social justice is an important counseling value and it refers to ensuring that all individuals have the same rights, freedoms or services regardless of whether they have any individual differences (Lee, 2013). One meaningful way to promote social justice is to take steps to minimize health disparity. United States National Cancer Institute (NCI, 2023) defines health disparity as:

> A type of preventable health difference that is closely linked with social, political, economic, and environmental disadvantage. Health disparities may occur because of race, ethnicity, sex, gender identity, sexual orientation, age, religion, disability, education, income, where people live, or other characteristics (NCI, 2023, NCI Dictionary of Cancer Terms section).

Buki and Selem (2012) emphasized that health disparity was an underestimated issue in the field of counseling psychology but it needed to be looked at because counselors' values, knowledge and skills could create important resources to overcome this disparity. Chwalisz (2008) in particular reflected on the reasons counselors can play an important role to ensure social justice and prevent health

disparity for people diagnosed with a chronic illness, including cancer. According to Chwalisz (2008), counselors are equipped to carry out assessments for the needs of people experiencing health disparity and also create employment domain or community domain intervention programs for them. In addition to this, Chwalisz (2008) stated that giving voice to disadvantaged people like those having chronic illnesses was an important counseling value to promote social justice which can be facilitated especially through conducting qualitative studies. The current study stands out with respect to deepening our understanding of an important yet under-studied disadvantaged population and giving voice to their experience. Moreover, findings of the current study can be a resource for counselors to fight against health disparity and social rights of families dealing with childhood cancer.

Similarly, counseling health psychology has the potential to contribute to the field of clinical health psychology by considering wellness and prevention with holistic approaches and counseling psychologists can offer new perspectives to health psychology through the application of biopsychosocial models (Raque-Bogdan et al., 2013). From this point, it could be a good idea that counselors use International Classification of Functioning (ICF), which was mentioned in our literature review. Because ICF offers a detailed guideline to understand people's functioning based on the biopsychosocial approach, it might be used as a statistical, clinical, educational or policy tool (WHO, 2001). Therefore, a biopsychosocial approach along with ICF would make it easier to understand the experiences of children diagnosed with cancer. Through this approach, it is possible to create effective prevention programs and make arrangements to meet the needs of these children in the healthcare system and policies (WHO, 2007).

Raque-Bogdan et al. (2013) also encouraged counseling psychology programs to be re-designed in a way that would facilitate their contribution to health care settings. We support this invitation and recommend the field of psychological counseling in Türkiye to be more intentional in incorporating health psychology to the program. Getting counselors equipped to reflect on, work with and conduct studies on health psychology would facilitate counseling's presence in health services and would benefit patients and their families in their health journeys.

When it comes to the school contexts, there are a limited number of studies focusing on the contribution of school counselors to the process of diagnosis and treatment for children with cancer and their families. Karayanni and Spitzer (1984) reflected on the roles that school counselors can take on to serve children diagnosed with cancer. Authors stated that the school counselors should be aware of the needs of the children and they can play three different roles of a coordinator, a resource person and a counselor. The school counselor should coordinate the communication among child, family and medical staff, and keep up to date information about the medical, psychosocial, and counseling needs of the child. In addition, school counselors are seen as holding the responsibility for monitoring and supporting the child's functioning both in and outside of the school through the treatment period.

In the current study, a few of the participants reported receiving support from the school staff, including the school counselors. Yet, most of the participants did not even mention the school context, let alone reflecting on school counselors as a source of support. It almost seemed like they did not regard school as a part of their process. However, the pediatric cancer studies highlight school support as one of the psychosocial standards of care for the children diagnosed with cancer (Klein et al., 2022). Established standards suggest that school staff, especially teachers should

have a clear understanding of the physical, social, emotional and also academic needs of these children (Klein et al., 2022). Yet school administration and teachers do not necessarily know what a crucial role they can play or how to work with these children. School counselors can be instrumental in both raising awareness and supporting administration's and teachers' engagement with the children.

In Türkiye, a recent study suggested that 698,406 children were diagnosed with a chronic illness, with the most common chronic illnesses among school-aged children being asthma, cancer, cystic fibrosis, cerebral palsy, chronic kidney failure, malnutrition, diabetes, epilepsy, autism, obesity, and attention deficit and hyperactivity disorder (Çakır & Altay, 2021). Despite the large number of school-aged children diagnosed with a chronic illness, studies focusing on the role of school counselors in supporting the chronically ill students are scarce. One study exploring the school counselors' and teachers' attitudes towards the chronically ill students indicated that school counselors and teachers did not have enough information about the needs and rights of the children with chronic illnesses (Sakarya, 2003). Since this study was conducted some years ago, there is a need for up-to-date studies on this subject. Specific studies or guidelines explaining how school counselors support the children with chronic illness and their family members appear to be lacking as well.

In schools, risk maps are known as a tool utilized by school counselors to identify the children having special needs (Tokyay, 2022). By using this tool, it is possible to determine some of the needs of children diagnosed with cancer. For instance, risk maps include items related to chronic illnesses, financial difficulties, or family related problems, which overlap with some of the common struggles of families dealing with childhood cancer. Through risk map implementation, school counselors may have an opportunity to identify such challenges experienced by these

children and their parents earlier and it may be an effective early step to create an intervention program for these children and their families.

In addition to the implementation of the risk maps, school counselors may also be a part of a unit preparing an individualized education program (IEP) for the children diagnosed with cancer based on the guideline of home and hospital education services directives by Türkiye Ministry of National Education (Türkiye Ministry of National Education, 2023). However, this guideline does not explain the specific roles of the counselor but just gives them the responsibility of preparation and implementation of IEP. From this point, it can be suggested that the roles of school counselors in Türkiye are not well identified and comprehensive studies focusing on the needs of children diagnosed with chronic illness in school and also their parents are needed. In addition, it is also needed to establish a psychosocial standard of care for the children with cancer in Türkiye in a way that acknowledges and promotes the role of a school counselor. It is regretful that the potential contributions of this very important source of support and coordination might have gone unnoticed by the parents as well as the authorities in our country.

5.2 Limitations of the study

Limitations of the current study can be grouped into four. First, findings of the current study have limited generalizability. Both the sample size and sampling method contributes to this limitation. As a qualitative study, aiming to develop an in-depth understanding of the experiences of a small group of people, we had a limited number of participants. And the snowball sampling method meant the participating parents of the current study were reached via the researcher's social network and then referral of one another. Participants knew each other through the public and

foundation hospitals at which their children were treated. Thus, their experiences in the medical setting may be similar and more reflective of their setting than their individual experiences, further limiting the extent to which findings can be generalized to the population of all parents of children with cancer. However, the convergence of our findings with the existing literature and the differences among participants do suggest that our data was rich and valid.

Small sample size also meant very limited numbers of participants for the different types and stages of the disease. Hence, the current study did not have the means to explore the ways in which parents' experiences may change based on the type or stage of the disease. In addition, the current study had a wide age-range for the participants' children. Hence, the way the child's developmental needs shape the parents' experiences could not be differentiated. Caution must be exerted when interpreting the findings.

Another limitation of the study stemmed from the imbalance between the number of women and men participants. A common limitation of studies focusing on experiences of parents of children with cancer, we were able to reach more mothers and the number of fathers was very limited. Therefore, we have limited information about what fathers of children and adolescents with cancer experience and whether their experiences differ when compared to the experiences of mothers.

Lastly, four of the participating parents preferred to conduct their interviews in a public space where others were present around the participants and the researcher. Presence of others in an earshot might have limited the way these four participants expressed themselves openly and freely.

5.3. Future recommendations

This study aimed to increase the visibility of parents of children and adolescents with cancer. Understanding the lived experiences of these parents would have implications for healthcare professionals, policy makers, and researchers. Our specific recommendations for each group will be detailed in this section.

5.3.1 Recommendations for healthcare professionals

As it was stated in the literature and also supported by our findings, the attitude and competency of the healthcare professionals is a significant issue for the parents of children treated for cancer. Providers' caring and flexible approach has become a resource for the parents. Yet the healthcare professionals outside of the field of oncology or hematology appear to be less aware of the parents' needs and vulnerability compared to the providers in the field of oncology or hematology. Childhood cancer should be approached from a multidisciplinary lens and experts in other fields should be informed about the childhood cancer and needs of families so that the relationship with healthcare professionals does not create an additional burden for the parents.

Particularly mental health professionals have key responsibilities for not only the children diagnosed with cancer but also their families. First, counselors should be aware of their role of advocacy to protect health disparity for these children and their families and promote social justice. They may be a part of preventative intervention plans for this unique population under significant distress.

Additionally, as it was mentioned before, school counselors can be a powerful resource for the families experiencing childhood cancer through providing support, leading coordination of services, and facilitating communication between the

families and stakeholders including teaching staff, administration and other students, especially classmates. The roles of school counselors for the children with chronic diseases are not well defined in Türkiye, nor is consistently covered in counselor education; hence, their personal efforts to increase their awareness about childhood cancer and take action to support such families becomes more important to bridge the existing gap.

5.3.2 Recommendations for policy makers

As it was recognized in Bronfenbrenner's macrosystem, the issue of childhood cancer cannot be considered independently of the policies and laws of the country. Findings of the current study showed that childhood cancer puts a significant burden on the parents' shoulders and yet systemic steps can be taken to ease the burden and support the families.

Based on the findings, parents have long waiting periods until their child's diagnosis in public health care services in Türkiye. These long waiting periods not only allow the disease to progress, but it also causes additional emotional burden for the parents who have to tolerate high levels of uncertainty and fear. Health care policy makers in Türkiye have the power and responsibility to minimize the waiting time caused by the systemic inefficiencies.

Moreover, as it was stated in the literature, the psychosocial assessment and support is a very important issue to protect the children and their families from negative outcomes of the cancer diagnosis and treatment process. Recognizing and implementing internationally-established standards for psychosocial care in pediatric cancer could make a difference for families going through childhood cancer.

After their child's are diagnosed with cancer, new challenging experiences await the parents. For example, those who lived in small towns need to move to a big city for better treatment options; and shelter, which is one of the most basic human needs, becomes a problem along with an array of financial, social and emotional problems for all family members. Because of this reason, the policy makers are invited to provide a comprehensive intervention plan for the families suffering from childhood cancer.

Another challenge which was stated by the participants was the lack of the support for the practical needs. To overcome this challenge, parents might be offered respite care services which would enable them to take a break and prevent very-likely exhaustion.

5.3.3 Recommendations for researchers

This qualitative study was conducted to provide an in-depth portrayal of the lived experiences of the parents of children and adolescents with cancer, and in that spirit, data was collected from a very small sample. In order to generalize findings for the larger population, studies with larger sample sizes are needed. Larger sample sizes would also allow comparisons such as whether the experiences of parents vary depending on the use of private or public health services, or type or stage of the cancer with which the child is diagnosed. Information obtained from such studies would guide the design and delivery of suitable intervention programs.

In the literature, studies focusing on the experiences of fathers of children with cancer are scarce compared to the experiences of mothers. It would be beneficial to understand what fathers experience in the process of their child's diagnosis and treatment and make their experiences and needs more visible. In

addition, the existing literature can be enriched through exploring the changes and growth experiences of parents as they go through their child's treatment process. Whether the observed changes remain long-term can be explored as well.

In addition to the experiences of the fathers, studies regarding the experiences of siblings of the children diagnosed with cancer are very limited both in Türkiye and in other countries. Based on the parents' expressions, it is clear that siblings have experienced their share of challenges in this period. These unique experiences are worth examining in the future as it would give us a more comprehensive picture of the ecological landscape of childhood cancer. Another point which is limited in current literature globally and worth investigating might be examining the experiences of family members and diagnosed children in the same study and comparing their experiences so that it can be observed how the same phenomenon can have different meanings in a family.

Moreover, there are a limited number of studies focusing on the role of psychological counselors for childhood cancer in the literature. The importance of counselors, especially of school counselors, is not well known and their roles need to be explained clearly and in detail, especially in Türkiye. Studies investigating roles and responsibilities of the counselor can make a significant contribution to the literature which would serve to inform policy-makers and healthcare providers and support the wellness of children with cancer and their parents. Counselor attitudes towards and competency with pediatric cancer is also not known. Future studies can focus on the attitudes, knowledge and skills of school counselors about childhood cancer. Counselors' training needs to increase their competency in supporting children with cancer and their parents can be established.

5.4. Conclusion

In conclusion, this study aimed to understand the lived experiences of parents of children and adolescents with cancer in Türkiye from the perspective of mental health and within the framework of Bronfenbrenner's ecological systems theory. It showed that parents experienced a number of physical, social and emotional difficulties and their lifestyle and daily routines have changed after the diagnosis. It was also observed that parents needed financial, information, practical, and psychological support in the diagnosis and treatment period.

This study also showed that parents had a number of sources of support and strategies to cope with this period. All of the parents stated religion was one of the most important sources of support for them. Extended family and friends, healthcare professionals, school, diagnosed child, spouses, non governmental organizations, official institutions, other parents whose children were diagnosed with cancer and workplace were other resources which were perceived as social, emotional, and financial support by the participating parents. Additionally, all of the parents reported utilizing at least one coping strategy in this period and they gave different examples reflecting the appraisal-focused, emotion focused, and problem-focused coping strategies.

In this study, the participating parents also highlighted that they experienced some changes in their perspective after their child was diagnosed with cancer. Shift in attributed importance, changed attitudes towards the children, awareness about the family unit, awareness about cancer as a disease, and learning that people are not who you expect them to be were among the changes which were stated by the parents.

When the findings of the current study were discussed in the light of the literature, it can be said that there were common experiences of parents of children with cancer in Türkiye and other countries. However, the results also suggested the presence of a few cultural differences and parental experiences that appeared to be unique to Türkiye.

Consistent with Bronfenbrenner's ecological approach, findings reflected the microsystems shaping parents' experiences as well as larger systems including mesosystem, exosystem, macrosystem, and chronosystem. Interaction between systems were evident in the obtained results and future studies investigating childhood cancer are recommended to continue utilizing such comprehensive frameworks to capture families' experiences.

Lastly, the findings of the current study might be informative for the mental health counselors. It made the experiences and the needs of parents of children with cancer visible and the roles of counselors and implementations for them were discussed. With this respect, it might be beneficial to understand social justice and health disparity from the lens of psychological counselors.

REFERENCES

Altay, N., Kilicarslan, E., Sarı, Ç., & Kisecik, Z. (2014). Determination of social support needs and expectations of mothers of children with cancer. *Journal of Pediatric Oncology Nursing*, *31*(3), 147-153.

American Cancer Society. *A to Z list of cancer types*. Retrieved May 11, 2023, from https://www.cancer.gov/types

American Cancer Society. *Cancer in children.* Retrieved May 11, 2023, from https://www.cancer.org/cancer/types/cancer-in-children.html

American Cancer Society. *Key statistics for childhood cancer.* Retrieved May 11, 2023, from https://www.cancer.org/cancer/types/cancer-in-children/key-statistics.html.

Armstrong, F. D., & Briery, B. G. (2004). Childhood cancer and the school. In R. T. Brown (Ed.), *Handbook of pediatric psychology in school settings* (pp. 263–281). London: Lawrence Erlbaum Associates Publishers.

Ay Kaatsız, M. A., & Öz, F. (2020). I'm here, too: Being an adolescent sibling of a pediatric cancer patient in Turkey. *Journal of Pediatric Nursing*, *51*, e77-e84.

Ay, M. A., & Akyar, I. (2020). Psychosocial status of Turkish families of pediatric cancer patients. *Journal of Transcultural Nursing*, *31*(3), 227-241.

Ay, M.A. (2019). *Kanser tanılı ve sağlıklı ergen çocuğu olan annelere uygulanan psikoeğitimin ebeveyn rolüne ilişkin kendilik algısı, stresle başa çıkma ve ruhsal belirtiler üzerine etkisi* (Unpublished PhD thesis). Hacettepe University, Ankara, Türkiye.

Bailey, K., & Im-Bolter, N. (2018). Social context as a risk factor for psychopathology in children with epilepsy. *Seizure*, *57*, 14-21.

Baytan, B., Aşut, Ç., Çırpan Kantarcıoğlu, A., Sezgin Evim, M., & Güneş, A. M. (2016). Health-related quality of life, depression, anxiety, and self-image in acute lymphocytic leukemia survivors. *Turkish Journal of Hematology*, *33*(4), 326-330.

Bennett Murphy, L. M., Flowers, S., McNamara, K. A., & Young-Saleme, T. (2008). Fathers of children with cancer: Involvement, Coping, and Adjustment. *Journal of Pediatric Health Care*, *22*(3), 182-189.

Bhakta, N., Force, L. M., Allemani, C., Atun, R., Bray, F., Coleman, M. P., Steliarova-Foucher, E., Frazier, A. L., Robison, L. L., Rodriguez-Galindo, C., & Fitzmaurice, C. (2019). Childhood cancer burden: A review of global estimates. *The Lancet Oncology*, *20*(1), e42-e53.

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member Checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, *26*(13), 1802-1811.

Björk, M., Wiebe, T., & Hallström, I. (2005). Striving to survive: families' lived experiences when a child is diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, *22*(5), 265-275.

Borrescio-Higa, F., & Valdés, N. (2022). The psychosocial burden of families with childhood blood cancer. *International Journal of Environmental Research and Public Health*, *19*(1), 599.

Braun, V. & Clarke, V. (2013) *Successful qualitative research: A practical guide for beginners.* London: SAGE Publication.

Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, *9*(1), 3-26.

Braveman P. (2014). What are health disparities and health equity? We need to be clear. *Public health reports, 129* (Suppl 2), 5–8.

Bretones Nieto, B., Pozo Muñoz, C., & Vázquez López, M. Á. (2022). Needs assessment in parents of children affected by cancer: A qualitative perspective. *Children*, *9*(12), 1957.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Cambridge, MA: Harvard University Press.

Bryan, G., Kelly, P., Chesters, H., Franklin, J., Griffiths, H., Langton, L., Langton, L., Wakefield, C. E., & Gibson, F. (2021). Access to and experience of education for children and adolescents with cancer: A scoping review protocol. *Systematic Reviews*, *10*(1), 167.

Buki, L. P., & Selem, M. (2012). Health disparities: Issues and opportunities for counseling psychologists. In N. A. Fouad, J. A. Carter, & L. M. Subich (Eds.), *APA handbook of counseling psychology, Vol. 2. Practice, interventions, and applications* (pp. 235–251). American Psychological Association.

Çakır, G. & Altay, N. (2021). Kronik hastalığı olan çocukların bakımında okul hemşiresinin görev ve sorumlulukları. *Dokuz Eylül Üniversitesi Hemşirelik Fakültesi Elektronik Dergisi, 14*(1), 55-61.

Carlsson, T., Kukkola, L., Ljungman, L., Hovén, E., & von Essen, L. (2019). Psychological distress in parents of children treated for cancer: An explorative study. *Plos One*, *14*(6), e0218860.

Castellano-Tejedor, C., Pérez-Campdepadrós, M., Capdevila, L., & Blasco-Blasco, T. (2016). Surviving cancer: The psychosocial outcomes of childhood cancer survivors and its correlates. *Journal of Health Psychology, 21*(7), 1491–1502.

Chase, E. (2017). Enhanced member checks: Reflections and insights from a participant-researcher collaboration. *The Qualitative Report*, *22*(10), 2689-2703.

Chaudhuri, T., Nandakumar, D., Datta, S. S., Husain, Z., Sukumaran, R. K., Sekhar Yadav, I., Krishnan, S., & Panda, S. (2022). Information-sharing experiences of professionals looking after children with cancer: A qualitative exploration from a specialist paediatric oncology unit in India. *Ecancermedicalscience*, *16,* 1399.

Cheung, C. K., Acquati, C., Smith, E., Katerere-Virima, T., Helbling, L., & Betz, G. (2020). The impact of a cancer diagnosis on sibling relationships from childhood through young adulthood: A systematic review. *Journal of Family Social Work*, *23*(4), 357-377.

Christensen, S. R., & Carlsen, L. T. (2022). From well-known to changed everyday family life in families with childhood cancer: A grounded theory of disrupted family dynamic. *Psycho-oncology*, *31*(2), 282–289.

Chwalisz, K. (2008). The future of counseling psychology: Improving quality of life for persons with chronic health issues. *The Counseling Psychologist*, *36*(1), 98-107.

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*, 102022.

Clarke J. N. (2006). Mother's home healthcare: emotion work when a child has cancer. *Cancer nursing*, *29*(1), 58–65.

Cornelio, S. J., Nayak, B. S., & George, A. (2016). Experiences of mothers on parenting children with leukemia. *Indian Journal of Palliative Care*, *22*(2), 168–172.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage Publications, Inc.

Creswell, J. W., Hanson, W. E., Clark Plano, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist, 35*(2), 236–264.

Cunningham, S. J., Patton, M., Schulte, F., Richardson, P. A., & Heathcote, L. C. (2021). Worry about somatic symptoms as a sign of cancer recurrence: Prevalence and associations with fear of recurrence and quality of life in survivors of childhood cancer. *Psycho-Oncology*, *30*(7), 1077-1085.

Darcy, L., Enskär, K., & Björk, M. (2019). Young children's experiences of living an everyday life with cancer – A three-year interview study. *European Journal of Oncology Nursing*, *39*, 1-9.

Davies, J., & O'Connor, M. (2022). Mothers' experiences post-childhood cancer treatment: A qualitative study. *Journal of Child and Family Studies* [Manuscript submitted for publication].

Davies, J., O'Connor, M., Halkett, G. K. B., Kelada, L., & Gottardo, N. G. (2022). Parents' experiences of childhood cancer during the COVID-19 Pandemic: An Australian perspective. *Journal of Pediatric Psychology*, *47*(2), 148-157.

Deatrick, J. A., Kazak, A. E., Scialla, M. A., Madden, R. E., McDonnell, G. A., Okonak, K., & Barakat, L. P. (2022). Advancing health equity in pediatric cancer through implementation of universal family psychosocial risk screening. *Psycho-Oncology, 31*(9), 1483-1490.

Denscombe, M. (2010). *The good research guide for small scale research projects* (4th ed.). Buckingham: Open University Press.

Desai, P. P., Rivera, A. T., & Backes, E. M. (2016). Latino caregiver coping with children's chronic health conditions: An integrative literature review. *Journal of Pediatric Health Care*, *30*(2), 108-120.

Dinleyici, M., Carman, K. B., Özdemir, C., Harmancı, K., Eren, M., Kırel, B., Şimşek, E., Yarar, C., Duyan Çamurdan, A., & Şahin Dağlı, F. (2019). Quality-of-life evaluation of healthy siblings of children with chronic illness. *Balkan Medical Journal*. Retrieved May 11, 2023, from https://doi.org/10.4274/balkanmedj.galenos.2019.2019.7.142.

Dolan, J. G., Hill, D. L., Faerber, J. A., Palmer, L. E., Barakat, L. P., & Feudtner, C. (2021). Association of psychological distress and religious coping tendencies in parents of children recently diagnosed with cancer: A cross-sectional study. *Pediatr Blood & Cancer*, *68*(7), 1-9.

Doyle S. (2007). Member checking with older women: a framework for negotiating meaning. *Health Care for Women International*, *28*(10), 888–908.

DuHamel, K. N., Rini, C., Austin, J., Ostroff, J., Parsons, S., Martini, R., Williams, S., Mee, L., Sexson, S., Winkel, G., Boulad, F., Redd, W. H., & Manne, S. (2007). Optimism and life events as predictors of fear appraisals in mothers of children undergoing hematopoietic stem cell transplantation. *Psycho-Oncology*, *16*(9), 821-833.

Džombić, A. (2020). Living "day-by-day": Parents' experiences during their child's active cancer treatment. Retrieved October 13, 2022, from https://hrcak.srce.hr/240188.

Džombić, A., & Bezić, I. (2022). "When we came home, I experienced crisis"-Caregiving experiences of parents whose children have undergone cancer treatment. *Hrvatska Revija Za Rehabilitacijska Istraživanja*, *58*(2), 118-129.

Ebob-Anya, BA., Bassah, N. (2022). Psychosocial distress and the quality of life of cancer patients in two health facilities in Cameroon. *BMC Palliative Care 21*(1), 96.

Effendy, C., Uligraff, D. K., Sari, S. H., Angraini, F., & Chandra, L. (2022). Experiences of family caregivers of children with cancer while receiving home-based pediatric palliative care in Indonesia: A qualitative study. *BMC Palliative Care*, *21*(1), 104.

Erdmann, F., Frederiksen, L. E., Bonaventure, A., Mader, L., Hasle, H., Robison, L. L., & Winther, J. F. (2021). Childhood cancer: Survival, treatment modalities, late effects and improvements over time. *Cancer Epidemiology*, *71*, 101733.

Esenay, F. I., Sezer, T. A., & Turan, S. A. (2018). Causal perceptions in Turkish parents of children with cancer. *Turkish Journal of Oncology, 33*(3), 94-101.

Evan, E. E., & Zeltzer, L. K. (2006). Psychosocial dimensions of cancer in adolescents and young adults. *Cancer*, *107*(7 Suppl), 1663–1671.

Eyigor, S., Karapolat, H., Yesil, H., & Kantar, M. (2011). The quality of life and psychological status of mothers of hospitalized pediatric oncology patients. *Pediatric Hematology and Oncology*, *28*(5), 428-438.

Fermo, V. C., Lourençatto, G. N., Medeiros, T. D. S., Anders, J. C., & Souza, A. I. J. D. (2014). Early diagnosis of child cancer: The journey taken by families. *Escola Anna Nery - Revista de Enfermagem*, *18*(1).

Fluchel, M. N., Kirchhoff, A. C., Bodson, J., Sweeney, C., Edwards, S. L., Ding, Q., Stoddard, G. J., & Kinney, A. Y. (2014). Geography and the burden of care in pediatric cancers: Pediatric Oncology Burden of Care. *Pediatric Blood & Cancer*, *61*(11), 1918-1924.

Gårdling, J., Törnqvist, E., Edwinson Månsson, M., & Hallström, I. (2017). Parents' lived experiences during their children's radiotherapy. *Journal of Pediatric Oncology Nursing*, *34*(2), 140-147.

Ghorbani, F., Iranmanesh, S., Razban, F., & Dehghan, M. (2020). Parental coping with childhood cancer and its relationship with self-construal: A survey in southeast Iran. *Health Science Reports*, *3*(3), e185.

Gibbins, J., Steinhardt, K., & Beinart, H. (2012). A Systematic review of qualitative studies exploring the experience of parents whose child is diagnosed and treated for cancer. *Journal of Pediatric Oncology Nursing*, *29*(5), 253-271.

Gibson, F. (2019). Children with cancer: Communication, an essential component of care. In: Charnay-Sonnek, F., Murphy, A. (eds). *Principles of Specialty Nursing*. Cham: Springer.

Griffiths, M., Schweitzer, R., & Yates, P. (2011). Childhood experiences of cancer: An interpretative phenomenological analysis approach. *Journal of Pediatric Oncology Nursing*, *28*(2), 83-92.

Günay, U., & Özkan, M. (2019). Emotions and coping methods of Turkish parents of children with cancer. *Journal of Psychosocial Oncology*, *37*(3), 398-412.

Gürcan, M., & Atay Turan, S. (2020). The experiences of adolescents receiving cancer treatment in Turkey: A qualitative study. *European Journal of Cancer Care*, *29*(5), e13239.

Gurtovenko, K., Fladeboe, K. M., Galtieri, L. R., King, K., Friedman, D., Compas, B., Breiger, D., Lengua, L., Keim, M., Kawamura, J., & Katz, L. F. (2021). Stress and psychological adjustment in caregivers of children with cancer. *Health Psychology*, *40*(5), 295-304.

Hammarberg, K., Kirkman, M., & de Lacey, S. (2016). Qualitative research methods: When to use them and how to judge them. *Human Reproduction*, *31*(3), 498-501.

Herlihy, B., & Corey, G. (2015). *ACA ethical standards casebook (7th ed.)*. Alexandria, VA: American Counseling Association.

Hosek, S. G., Harper, G. W., Lemos, D., Martinez, J., & Adolescent Medicine Trials Network. (2008). An ecological model of stressors experienced by youth newly diagnosed with HIV. *Journal of HIV/AIDS Prevention in Children & Youth*, *9*(2), 192-218.

Howard Sharp, K. M., Fisher, R. S., Clark, O. E., Dunnells, Z. D. O., Murphy, L. K., Prussien, K. V., Vannatta, K., Compas, B. E., & Gerhardt, C. A. (2020). Long-term trajectories of depression symptoms in mothers of children with cancer. *Health Psychology*, *39*(2), 89-98.

Inhestern, L., Peikert, M. L., Krauth, K. A., Escherich, G., Rutkowski, S., Kandels, D., & Bergelt, C. (2020). Parents' perception of their children's process of reintegration after childhood cancer treatment. *Plos One*, *15*(10), e0239967.

Johnson, T. P. (2005). Snowball sampling. In P. Armitage & T. Colton (Ed.), *Encyclopedia of Biostatistics* (1. bs). Chichester: Wiley.

Johnston, D. M., & Johnston, J. M. (2020). When childhood cancer becomes a family affair, it really hits home. *Pediatric Clinics of North America*, *67*(6), 1021-1031.

Kaffenberger, C. J. (2006). School reentry for students with a chronic illness: A role for professional school counselors. *Professional School Counseling, 9*(3), 223–230.

Kalaycı, E., & Çalışkan, Z. (2021). The quality of life and influencing factors in Turkish children receiving cancer treatment. *Journal of Pediatric Nursing*, *61*, 213-218.

Karadeniz Cerit, K., Cerit, C., Nart, Ö., Eker, N., Kıyan, G., Dağlı, T., Ekingen, G., Tokuç, G., Karaca, Ö., & Çorapçıoğlu, F. (2017). Post-traumatic stress disorder in mothers of children who have undergone cancer surgery. *Pediatrics International*, *59*(9), 996-1001.

Karataş, Z., Yavuzer, Y., & Tagay, Ö. (2020). Development of accountability scale for school counselor: Investigation of psychometric properties. *Turkish Psychological Counseling and Guidance Journal, 10*(59), 631-648.

Karayanni, M., & Spitzer, A. (1984). The role of the school counselor in the rehabilitation of children with cancer. *International Journal for the Advancement of Counselling*, *7*(3), 209-215.

Kars, M. C., Duijnstee, M. S., Pool, A., van Delden, J. J., & Grypdonck, M. H. (2008). Being there: parenting the child with acute lymphoblastic leukemia. *Journal of clinical nursing*, *17*(12), 1553–1562.

Katz, L.F., Fladeboe, K., King, K., Gurtovenko, K., Kawamura, J., Friedman, D., Compas, B., Gruhn, M., Breiger, D., Lengua, L., Lavi, I., & Stettler, N. (2018). Trajectories of child and caregiver psychological adjustment in families of children with cancer. *Health Psychology*, *37*(8), 725-735.

Kazak, A. E., Abrams, A. N., Banks, J., Christofferson, J., DiDonato, S., Grootenhuis, M. A., Kabour, M., Madan-Swain, A., Patel, S. K., Zadeh, S., & Kupst, M. J. (2015). Psychosocial assessment as a standard of care in pediatric cancer: Psychosocial assessment standard. *Pediatric Blood & Cancer*, *62*(S5), S426-S459.

Kazak, A. E., Deatrick, J. A., Scialla, M. A., Sandler, E., Madden, R. E., & Barakat, L. P. (2020). Implementation of family psychosocial risk assessment in pediatric cancer with the Psychosocial Assessment Tool (PAT): Study protocol for a cluster-randomized comparative effectiveness trial. *Implementation Science*, *15*(1), 60.

Kazak, A. E., Rourke, M.T., & Navsaria, N. (2009). Families and other systems in pediatric psychology. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (pp. 656–671). New York: The Guilford Press.

Kazak, A. E., Segal-Andrews, A. M., & Johnson, K. (1995). Pediatric psychology research and practice: A family/systems approach. In M. C. Roberts (Ed.), *Handbook of pediatric psychology* (pp. 84–104). New York: The Guilford Press.

Kearney, J. A., Salley, C. G., & Muriel, A. C. (2015). Standards of psychosocial care for parents of children with cancer: Standards of psychosocial care for parents of children with cancer. *Pediatric Blood & Cancer*, *62*(S5), S632-S683.

Kebudi, R., & Alkaya, D. U. (2021). Epidemiology and survival of childhood cancer in Turkey. *Pediatric Blood & Cancer*, *68*(2), e28754.

Khoury, M. N., Huijer, H. A.-S., & Doumit, M. A. A. (2013). Lebanese parents' experiences with a child with cancer. *European Journal of Oncology Nursing*, *17*(1), 16-21.

Klein, S., Byford, N., Ellison, S., & Jurbergs, N. (2022). Support for community school personnel working with pediatric cancer patients: A quality improvement initiative. *Continuity in Education*, *3*(1), 1-12.

Korones, D. N. (2016). Talking to children with cancer: Sometimes less is more. *Journal of Clinical Oncology*, *34*(28), 3477-3479.

Kostak, M., Semerci, R., Eren, T., Avci, G., & Savran, F. (2019). Life experiences of adolescents with cancer in Turkey: A phenomenological study. *Journal of the Pakistan Medical Association*, *0*, 1.

Koumarianou, A., Symeonidi, A. E., Kattamis, A., Linardatou, K., Chrousos, G. P., & Darviri, C. (2021). A review of psychosocial interventions targeting families of children with cancer. *Palliative and Supportive Care*, *19*(1), 103-118.

Krau, S. D. (2015). Social justice: A basis for health care delivery. *Nursing Clinics of North America*, *50*(3), xiii-xv.

Krippendorff, K. (1989). Content analysis. *International encyclopedia of communication*, 1, 403-407. New York, NY: Oxford University Press. Retrieved from http://repository.upenn.edu/asc_papers/226.

Kudubes, A. A., Bektas, M., & Ugur, O. (2014). Symptom frequency of children with cancer and parent quality of life in Turkey. *Asian Pacific Journal of Cancer Prevention*, *15*(8), 3487-3493.

Larsen, H. B., Johansen, C., Frandsen, T. L., Schmiegelow, K., & Wahlberg, A. (2020). Everyday life challenges among adolescent and young adult survivors of childhood acute lymphoblastic leukemia: An in-depth qualitative study. *Psycho-Oncology*, *29*(10), 1630-1637.

Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, *1*(3), 141-169.

Lee, C. C. (2013). The cross-cultural encounter: Meeting the challenge of culturally competent counseling. In C. C. Lee (Ed.), *Multicultural Issues in Counseling: New approaches to diversity* (pp. 13-19). Alexandria, VA: American Counseling Association.

Lewandowska, A. (2021). *Influence of a child's cancer on the functioning of their family, 8*(7), 592.

Lulgjuraj, D. (2022). *The lived experience of hospitalized children* (PhD thesis). Retrieved May 15, 2023, from https://www.proquest.com/dissertations-theses/lived-experience-hospitalized-children/docview/2688493203/se-2.

Luo, Y., Li, H. C. W., Xia, W., Cheung, A. T., Ho, L. L. K., & Chung, J. O. K. (2022). The lived experience of resilience in parents of children with cancer: A phenomenological study. *Frontiers in Pediatrics*, *10*, 871435.

Luo, Y., Xia, W., He, X., Zhang, J., & Li, H. C. W. (2021). Psychological interventions for enhancing resilience in parents of children with cancer: A systematic review and meta-analysis. *Supportive Care in Cancer*, *29*(11), 7101-7110.

Luo, Y., Yang, P., Yang, Y., He, P., Qin, M., Wang, B., Zhu, G., Jia, C., Yan, Y., Zhou, Y., Wang, R., Wang, A., Zhou, X., & Peng, X. (2019). Cognitive and psychological outcomes of pediatric allogeneic hematopoietic stem cell transplantation survivors in a single center in China. *Medicine*, *98*(39), e17307.

Lyu, Q.-Y., Zhang, M.-F., Bu, X.-Q., Zhou, X.-Z., & Zhao, X. (2019). A qualitative study exploring coping strategies in chinese families during children's hospitalization for cancer treatment. *Journal of Pediatric Nursing*, *48*, e27-e34.

Maillie, L., Masalu, N., Mafwimbo, J., Maxmilian, M., & Schroeder, K. (2020). Delays experienced by patients with pediatric cancer during the health facility referral process: A study in Northern Tanzania. *JCO Global Oncology*, *6*, 1757-1765.

Mangurian, C., Packman, W., Riano, N. S., & Kearney, J. (2018). The need to support caregivers during pediatric bone marrow transplantation (BMT): A case report. *Palliative and Supportive Care*, *16*(3), 367-370.

Maryam, D., Wu, L.-M., Su, Y.-C., Hsu, M.-T., & Harianto, S. (2022). The journey of embracing life: Mothers' perspectives of living with their children with retinoblastoma. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, *66*, e46-e53.

Maurice-Stam, H., van Erp, L. M. E., Maas, A., van Oers, H. A., Kremer, L. C. M., van Dulmen-den Broeder, E., Tissing, W. J. E., Loonen, J. J., van der Pal, H. J. H., Beek, L. R., de Vries, A. C. H., van den Heuvel-Eibrink, M. M., Ronckers, C. M., Bresters, D., Louwerens, M., van der Heiden-van der Loo, M., Huizinga, G. A., Grootenhuis, M. A., & on behalf of the Dutch LATER study group. (2022). Psychosocial developmental milestones of young adult survivors of childhood cancer. *Supportive Care in Cancer*, *30*(8), 6839-6849.

McGrath, P. (2001), Identifying support issues of parents of children with leukemia. *Cancer Practice, 9*, 198-205.

McLoone, J., Wakefield, C. E., Sansom-Daly, U. M., Thornton-Benko, E., Govender, D., Gabriel, M., Walwyn, T., Signorelli, C., Johnston, K., & Cohn, R. J. (2021). The lived experience of children and adolescents with cancer. *Australian Journal of General Practice*, *50*(8), 545-549.

Mess, E., Misiąg, W., Klaszczyk, T., & Kryś, K. (2022). Depressive and anxiety disorders of parents of children with cancer. *Journal of Clinical Medicine*, *11*(19), 5670.

Michel, G., Brinkman, T. M., Wakefield, C. E., & Grootenhuis, M. (2020). Psychological outcomes, health-related quality of life, and neurocognitive functioning in survivors of childhood cancer and their parents. *Pediatric Clinics of North America*, *67*(6), 1103-1134.

Miedema, B., Hamilton, R., Fortin, P., Easley, J., & Matthews, M. (2010). "You can only take so much, and it took everything out of me": Coping strategies used by parents of children with cancer. *Palliative and Supportive Care*, *8*(2), 197-206.

Moğolkoç, H. (2014). *Kanser hastası çocuk ve ergenlerin ebeveynlerinde travma sonrası stres bozukluğunun ve travma sonrası gelişimin belirleyicileri: Sosyal destek, ruminasyon, yükleme biçimleri* (Unpublished Master's Thesis), Uludag University, Bursa, Türkiye

Moriconi, V., & Cantero-García, M. (2022). Bereaved families: A qualitative study of therapeutic intervention. *Frontiers in Psychology*, *13*, 841904.

Muscara, F., Burke, K., McCarthy, M. C., Anderson, V. A., Hearps, S. J., Hearps, S. J., Dimovski, A., & Nicholson, J. M. (2015). Parent distress reactions following a serious illness or injury in their child: A protocol paper for the take a breath cohort study. *BMC Psychiatry*, *15*(1), 153.

National Cancer Institute. *Cancer in Children and Adolescents*. Retrieved May 11, 2023, from https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-factsheet#:~:text=Overall%2C%20among%20children%20and%20adolescents,CNS)%20tumors%2C%20and%20lymphomas.

National Cancer Institute. *NCI dictionary of cancer terms.* Retrieved May 15, 2023, from https://www.cancer.gov/publications/dictionaries/cancer-terms.

Nicholas, D. B., Gearing, R. E., McNeill, T., Fung, K., Lucchetta, S., & Selkirk, E. K. (2009). Experiences and resistance strategies utilized by fathers of children with cancer. *Social Work in Health Care*, *48*(3), 260-275.

Noy, C. (2008). Sampling knowledge: The hermeneutics of snowball sampling in qualitative research. *International Journal of Social Research Methodology*, *11*(4), 327-344.

Otth, M., & Scheinemann, K. (2022). Back to school – The teachers' worries and needs having a childhood cancer patient or survivor in their class. *Frontiers in Oncology*, *12*, 992584.

Ovayolu, Ö., Ovayolu, N., Tuna, D., Serçe, S., Sevinç, A., & Pirbudak Çöçelli, L. (2014). Quality of life of caregivers: A cross-sectional study: Quality of life of caregivers. *International Journal of Nursing Practice*, *20*(4), 424-432.

Ozdemir Koyu, H., & Tas Arslan, F. (2021). The effect of physical and psychosocial symptoms on caregiver burden of parents of children with cancer. *European Journal of Cancer Care*, *30*(6), e13513.

Patterson, J. M. (1988). Families experiencing stress: I. The family adjustment and adaptation response Model: II. Applying the FAAR model to health-related issues for intervention and research. *Family Systems Medicine*, *6*(2), 202-237.

Patterson, J. M., Holm, K. E., & Gurney, J. G. (2004). The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology*, *13*(6), 390-407.

Picci, R. L., Oliva, F., Trivelli, F., Carezana, C., Zuffranieri, M., Ostacoli, L., Furlan, P. M., & Lala, R. (2015). Emotional burden and coping strategies of parents of children with rare diseases. *Journal of Child and Family Studies*, *24*(2), 514-522.

Pohlkamp, L., Kreicbergs, U., & Sveen, J. (2020). Factors during a child's illness are associated with levels of prolonged grief symptoms in bereaved mothers and fathers. *Journal of Clinical Oncology*, *38*(2), 137-144.

Porter, L. S., Baucom, D. H., Bonner, M., Linardic, C., & Kazak, A. E. (2019). Parenting a child with cancer: A couple-based approach. *Translational Behavioral Medicine*, *9*(3), 504-513.

Power, T. J. (2003). Preparing psychologists to link systems of care in managing and preventing children's health problems. *Journal of Pediatric Psychology*, *28*(2), 147-155.

Quast, L. F., Williamson Lewis, R., Lee, J. L., Blount, R. L., & Gilleland Marchak, J. (2021). Psychosocial functioning among caregivers of childhood cancer survivors following treatment completion. *Journal of Pediatric Psychology*, *46*(10), 1238-1248.

Racine, N. M., Khu, M., Reynolds, K., Guilcher, G. M. T., & Schulte, F. S. M. (2018). Quality of life in pediatric cancer survivors: Contributions of parental distress and psychosocial family risk. *Current Oncology*, *25*(1), 41-48.

Reifsnider, E., Gallagher, M., & Forgione, B. (2005). Using ecological models in research on health disparities. *Journal of Professional Nursing*, *21*(4), 216-222.

Rini, C., Manne, S., DuHamel, K., Austin, J., Ostroff, J., Boulad, F., Parsons, S. K., Martini, R., Williams, S. E., Mee, L., Sexson, S., & Redd, W. H. (2008). Social support from family and friends as a buffer of low spousal support among mothers of critically ill children: A multilevel modeling approach. *Health Psychology*, *27*(5), 593-603.

Rosenberg, A. R., Wolfe, J., Bradford, M. C., Shaffer, M. L., Yi-Frazier, J. P., Curtis, J. R., Syrjala, K. L., & Baker, K. S. (2014). Resilience and psychosocial outcomes in parents of children with cancer: Resilience and psychosocial outcomes. *Pediatric Blood & Cancer*, *61*(3), 552-557.

Russell, K. B., Patton, M., Tromburg, C., Zwicker, H., Guilcher, G. M. T., Bultz, B. D., & Schulte, F. (2022). Psychosocial risk, symptom burden, and concerns in families affected by childhood cancer. *Supportive Care in Cancer*, *30*(3), 2283-2292.

Sakarya, N. (2003). *Rehber öğretmenlerinin ve sınıf öğretmenlerinin kronik hastalığı olan öğrencilerle ilgili yaklaşımları: Bilgi kaynakları, bilgi düzeyleri ve tutumları* (Unpublished master's thesis). Anadolu University, Eskişehir, Türkiye

Salloum, A., Stover, C.S., Swaidan, V.R., & Storch, E.A. (2015). Parent and child PTSD and parent depression in relation to parenting stress among trauma-exposed children. *Journal of Child and Family Studies, 24*, 1203-1212.

Santos, S., Crespo, C., Canavarro, M. C., & Kazak, A. E. (2018). Family rituals when children have cancer: A qualitative study. *Journal of Family Psychology, 32*(5), 643–653.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, *52*(4), 1893-1907.

Savage, P., Mahmoud, S., Patel, Y., & Kantarjian, H. (2017). Cancer Drugs: An international comparison of postlicensing price inflation. *Journal of Oncology Practice*, *13*(6), e538-e542.

Schirrmacher V. (2019). From chemotherapy to biological therapy: A review of novel concepts to reduce the side effects of systemic cancer treatment (Review). *International Journal of Oncology*, *54*(2), 407–419.

Schweitzer, R., Griffiths, M., & Yates, P. (2011). Parental experience of childhood cancer using Interpretative Phenomenological Analysis. *Psychology & Health*, 1-17.

Seth, L. (2022). *Lived experiences of support among parents of children with acute lymphoblastic leukemia during the COVID-19 pandemic* (PhD thesis). Retrieved May 15, 2023, from https://www.proquest.com/dissertations-theses/lived-experiences-support-among-parents-children/docview/2649229676/se-2.

Shava, G.N., Hleza, S., Tlou, F., Shonhiwa, S. & Mathonsi, E. (2021). Qualitative content analysis, utility, usability, and processes in educational research. *International Journal of Research and Innovation in Social Scie*nce, 7 (5), 553-558.

Sodi, T., & Kgopa, B. (2016). Coping strategies of mother carers of children living with chronic illness and disease in a rural South African community. *Journal of Psychology in Africa*, *26*(5), 432-435.

Somkome, T. (2020). *The lived experience of Thai parents of a child diagnosed with cancer* (PhD thesis). Retrieved May 15, 2023, from https://www.proquest.com/dissertations-theses/lived-experience-thai-parents-child-diagnosed/docview/2412183505/se-2

Steele, R. G., & Aylward, B. S. (2009). An overview of systems in pediatric psychology research and practice. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (pp. 649–655). New York: The Guilford Press.

Taleghani, F., Fathizadeh, N., & Naseri, N. (2012). The lived experiences of parents of children diagnosed with cancer in Iran: Lived experiences of parents. *European Journal of Cancer Care*, *21*(3), 340-348.

Tan, R., Koh, S., Wong, M. E., Rui, M., & Shorey, S. (2020). Caregiver stress, coping strategies, and support needs of mothers caring for their children who are undergoing active cancer treatments. *Clinical Nursing Research*, *29*(7), 460-468.

Thavakugathasalingam, M., & Schwind, J. K. (2022). Experience of childhood cancer: A narrative inquiry. *Journal for Specialists in Pediatric Nursing*, *27*(2), e12367.

Tokyay, S. (2022). *Turkish education system's understanding of risk: The case of children of divorced parents through the experiences of counselors and divorced mother* (Unpublished master's thesis). Middle East Technical University, Ankara, Türkiye.

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 : Journal of the International Society for Quality in Health Care*, *19*(6), 349–357.

Türkiye Ministry of Health (2011). *Türkiye onkoloji hizmetleri yeniden yapılanma programı 2011-2023.* Retrieved May 11, 2023, from https://www.kanser.org/saglik/userfiles/file/11Mayis2011/turkiye_onkoloji_hizmetleri_kitapcik.pdf.

Türkiye Ministry of Health (2023). *Türkiye'de özellikli planlama gerentiren sağlık hizmetleri.* Retrieved May 11, 2023, from https://khgmsaglikhizmetleridb.saglik.gov.tr/TR-42884/turkiyede-ozellikli-planlama-gerektiren-saglik-hizmetleri-2011-2023.html.

Türkiye Ministry of National Education (2023). *Milli Eğitim Bakanlığı: Evde ve hastanede eğitim hizmetleri yönergesi.* Retrieved June 14, 2023, from http://mevzuat.meb.gov.tr/dosyalar/871.pdf.

Tutelman, P. R., Chambers, C. T., Heathcote, L. C., Fernandez, C. V., Flanders, A., Patton, M., Schulte, F. S. M., Guilcher, G. M. T., Simard, S., MacLeod, J., & Stern, M. (2022). Measuring fear of cancer recurrence in survivors of childhood cancer: Development and preliminary validation of the fear of cancer recurrence inventory (FCRI)□child and parent versions. *Psycho-Oncology*, *31*(6), 911-919.

Usluoğlu, F. (2018). *Kanser hastası çocuğu olan ailelerin dayanıklılık travma sonrası büyüme ve hastalık sürecine ilişkin deneyimleri* (Unpublished PhD thesis). Çukurova University, Adana, Türkiye.

Uzşen, H. (2021). *Kanserli çocuklara uygulanan terapötik oyunun yaşam kalitesi ve semptom kontrolüne etkisi* (Unpublished PhD thesis). Ege University, İzmir, Türkiye.

Uzun, P. (2016). *Çocuk hematoloji-onkoloji hastalarının ebeveynlerinin tükenmişlik düzeyleri ve baş etme biçimlerinin; Çocukların psikolojik belirtileri üzerine etkisi açısından incelenmesi* (Unpublished master's thesis). Haliç University, İstanbul, Türkiye.

Van Dongen-Melman, J. E., & Sanders-Woudstra, J. A. (1986). Psychosocial aspects of childhood cancer: A review of the literature. *Child Psychology & Psychiatry & Allied Disciplines, 27*(2), 145–180.

Vena, J. A., & Copel, L. C. (2021). Cancer survivorship and quality of life outcomes of adolescents and young adults with lymphoma: An integrative review. *European Journal of Oncology Nursing*, *52*, 101948.

Venkatapuram, S. (2019). Health disparities and the social determinants of health: Ethical and social justice issues. In A. C. Mastroianni, J. P. Kahn, & N. E. Kass (Ed.), *The Oxford Handbook of Public Health Ethics* (s. 0). Oxford University Press.

Wakefield, C. E., Sansom-Daly, U. M., McGill, B. C., Hetherington, K., Ellis, S. J., Robertson, E. G., Donoghoe, M. W., McCarthy, M., Kelada, L., Girgis, A., King, M., Grootenhuis, M., Anazodo, A., Patterson, P., Lowe, C., Dalla-Pozza, L., Miles, G., & Cohn, R. J. (2021). Providing psychological support to parents of childhood cancer survivors: 'cascade' intervention trial results and lessons for the future. *Cancers*, *13*(22), 5597.

Warman, K. D. (2021). *Latina mothers lived experience with caring for a child with cancer* (PhD Thesis). Retrieved May 11, 2023, from https://www.proquest.com/dissertations-theses/latina-mothers-lived-experience-with-caring-child/docview/2460108957/se-2

Wiener, L., Kazak, A. E., Noll, R. B., Patenaude, A. F., & Kupst, M. J. (2015). Standards for the psychosocial care of children with cancer and their families: An Introduction to the special issue: Pediatric Psychosocial Standards of Care. *Pediatric Blood & Cancer*, *62*(S5), 419-424.

Wiener, L., Kupst, M. J., Pelletier, W., Kazak, A. E., & Thompson, A. L. (2020). Tools to guide the identification and implementation of care consistent with the psychosocial Standards of care. *Pediatric Blood & Cancer*, *67*(9).

Williams, L. K., McCarthy, M. C., Eyles, D. J., & Drew, S. (2013). Parenting a child with cancer: Perceptions of adolescents and parents of adolescents and younger children following completion of childhood cancer treatment. *Journal of Family Studies*, *19*(1), 80-89.

Wood, A., Mott, A., & Gonzalez-Voller, J. (2022). Integrating psychosocial oncology into the counseling curriculum. *Journal of Counselor Preparation and Supervision, 15*(2).

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Retrieved June 7, 2023, from https://apps.who.int/iris/handle/10665/42407.

World Health Organization. (2007). *International classification of functioning, disability and health: children and youth version: ICF-CY*. Retrieved June 7, 2023, from https://apps.who.int/iris/handle/10665/43737.

World Health Organization. (2023). *Childhood cancer.* Retrieved May 11, 2023, from https://www.who.int/news-room/fact-sheets/detail/cancer-in-children.

Xiao, S., & Sang, H. (2020). *Parents experience of having a child with cancer: A descriptive review.* Retrieved May 18, 2023, from http://urn.kb.se/resolve?urn=urn:nbn:se:hig:diva-33134.

Yalug, I. (2011). Post-traumatic stress disorder and post-traumatic stress symptoms in parents of children with cancer: A review. *Neurology, Psychology and Brain Research, 17*(1), 27-31.

Yiğit, G. (2018). *Tedavisi tamamlanmış çocuk onkoloji hastalarının eğitim, çalışma, alışkanlıklar ve yaşam değişikliklerinin değerlendirilmesi* (Unpublished PhD thesis). Uludağ University, Bursa, Türkiye.

Yildirim Sari, H., Yilmaz, M., Ozsoy, S., Kantar, M., & Cetingul, N. (2013). Experiences of parents with the physical care needs at home of children with cancer: a qualitative study. *Cancer Nursing*, *36*(5), 385–393.

Young, K., Bowers, A., & Bradford, N. (2021). Families' experiences of child and adolescent brain tumor: A systematic review and synthesis of qualitative research. *Psycho-Oncology*, *30*(10), 1643-1662.

APPENDIX A

DEMOGRAPHIC INFORMATION FORM (ENGLISH)

Demographic Information Form

Mother/Father:

Total number of Children:

Ages of Children:

Current Age of the Diagnosed Child:

Date of Birth:

Sex:

Child's Diagnosis:

Stage of the Disease:

Date of Diagnosis:

Types of Treatment (Chemotherapy, Radiotherapy, etc.)

Start Date of the Treatment:

Did you receive psychosocial support during this process? Yes No

If yes, can you indicate what kind of psychosocial support you received?

APPENDIX B

DEMOGRAPHIC INFORMATION FORM (TURKISH)

Demografik Bilgi Formu

Anne/Baba:

Toplam Çocuk Sayısı:

Çocukların Yaşları:

Tanı Alan Çocuğun Bugünkü Yaşı:

Doğum Tarihi:

Cinsiyeti:

Tanı Alan Çocuğun Tanısı:

Hastalığın evresi:

Teşhis Tarihi:

Alınan Tedavi Çeşidi (Kemoterapi/Radyoterapi, Vb.)

Tedaviye başlama tarihi:

Bu süreçte psikososyal destek aldınız mı? Evet Hayır

Yanıtınız evet ise ne tür bir psikososyal destek aldığınızı belirtebilir misiniz?

APPENDIX C

INTERVIEW PROTOCOL (ENGLISH)

Before starting the interview questions, the above-mentioned demographic information will be gathered from the participants. Permission for video recording will be obtained by reminding the participants that their identity information will be kept confidential within the scope of the privacy policy. If s/he gives permission for recording, the following interview questions will be asked.

Interview Questions

I aim to understand the experiences of parents of children undergoing cancer treatment. Can you tell us a little about your story in this process?

Opening Questions:

What did you experience when you learned that your child was diagnosed with cancer?

Can you describe being a parent of a child receiving cancer treatment?

What changes in your life compared to before your child was diagnosed with cancer?

What challenges did you experience in the diagnosis and treatment process?

How has your family been affected by this process?

What do other family members experience in this period?

Opening Questions:

If you think about the physical, social, emotional aspects, what did other family members experience?

How were your experiences with the health care professionals?

How did you cope with this situation?

Opening Questions:

What thoughts and attitudes did you adopt as an effort to cope with the difficulties you experienced throughout this process so far?

Can you share what you have done as an effort to solve the problems you have encountered throughout this process so far?

Can you share what you have done to cope with the emotional difficulties that this process brings?

What is the helpful support for you in this period?

Opening Questions:

How did your family/friends support you?

If you think about social, emotional and financial support, what kind of resources have helped you?

Did your educational institution and school psychological counseling and guidance unit support you in this process?

What kind of support would make this process easier for you?

Opening Questions:

If you think about social, emotional and financial support, what other support from your family/friends/health professionals/school administration would make this process easier for you?

You talked about the changes you experienced during this process. When you think about where you started and where you are now, what has changed in your perspective, both positive and negative?

Opening Questions:

What positive and negative changes do you think have occurred in your perspective on yourself / others / your environment / the world?

APPENDIX D

INTERVIEW PROTOCOL (TURKISH)

Görüşme sorularına başlamadan önce, yukarıda belirtilen demografik bilgiler katılımcıdan alınacaktır. Katılımcıya gizlilik ilkesi kapsamında kimlik bilgilerinin saklı tutulacağı hatırlatılarak, kayıt için izin alınacaktır. İzin vermesi halinde aşağıdaki görüşme sorularına geçilecektir.

Görüşme Soruları

Kanser tedavisi gören çocukların ebeveynlerinin deneyimlerini derinlemesine, anlamaya çalışıyorum. Siz bu süreçteki hikayenizden biraz bahsedebilir misiniz?

Açıcı Sorular:

Çocuğunuzun kanser teşhisi aldığını öğrendiğinizde neler deneyimlediniz?

Kanser tedavisi gören bir çocuğun ebeveyni olmak nasıl bir deneyim?

Çocuğunuz teşhis almadan önceki yaşamınız ile kıyasladığımızda hayatınızda neler değişti?

Teşhis ve tedavi sürecinde hangi zorluklarla karşılaştınız?

Aileniz bu süreçten nasıl etkilendi?

Diğer aile üyeleri bu süreçte neler yaşadı?

Açıcı Sorular:

Fiziksel, sosyal, duygusal yönlerini düşünecek olursanız, diğer aile üyeleri neler deneyimledi?

Sağlık profesyonelleri ile deneyiminiz nasıldı?

Kullandığınız hangi yöntemler bu süreçte yaşadığınız zorluklarla başa çıkmanıza yardımcı oldu?

Açısı Sorular:

Bu süreçte yaşadığınız zorluklar ile başa çıkarken hangi düşünce, tutum, ve inançlardan faydalandınız?

Bu süreçte karşınıza çıkan problemleri çözmek adına yaptıklarınızı paylaşır mısınız?

Bu sürecin getirdiği duygusal zorluklarla başa çıkmak için yaptıklarınızı paylaşır mısınız?

Bu süreçte ne gibi kaynaklar size destek oldu?

Açıcı Sorular:

Aileniz/Arkadaşlarınız nasıl destek oldu?

Sosyal, duygusal, maddi destekleri düşünecek olursanız, ne gibi kaynaklar size yardımcı oldu?

Eğitim kurumunuzun ve okul psikolojik danışma ve rehberlik birimi bu süreçte size destek oldu mu?

Sizin için ne tür bir destek bu süreci daha kolaylaştırıcı kılardı?

Açıcı Sorular:

Sosyal, duygusal, maddi destekleri düşünecek olursanız, ailenizden/arkadaşlarınızdan/ sağlık profesyonellerinden/okul yönetiminden ne gibi başka destekler olması sizin için süreci daha kolay kılardı?

Bu süreçte yaşadığınız değişikliklerden bahsettiniz. Nereden başlayıp, nereye geldiğinizi düşündüğünüzde bakış açınızda olumlu ve olumsuz olarak neler değişti?

Açıcı Sorular:

Kendinize / başkalarına / çevrenize / dünyaya bakış açınızda olumlu ve olumsuz ne değişiklikler olduğunu düşünüyorsunuz?

APPENDIX E

INFORMED CONSENT FORM (ENGLISH)

Supporter Institution: Boğaziçi University

Research Name: Lived Experiences Parents of Children and Adolescents With

Cancer in Türkiye

Project Advisor: Assist. Prof. Gizem Toska

E-mail:

Phone Number:

Name of the Researcher: Sümeyye Özdemir

E-mail:

Phone Number:

Dear Parents,

This research aims to investigate the lived experiences of parents of children receiving cancer treatment in Türkiye. The study is conducted by Sümeyye Özdemir, a master's student in the Guidance and Psychological Counseling Program at Boğaziçi University under the supervision of Assist. Prof. Gizem Toska.

If you agree to participate in the study, an appointment will be scheduled for the interview. Our face-to-face interview will include approximately 15 questions and is planned to last 40-45 minutes.

In order to analyze data, an audio recorder will be used if you give your consent. If the use of an audio recording is not suitable for you, the interview will be recorded through taking notes by hand. Your personal information will be kept confidential in this research. The obtained information will be saved in an encrypted USB belonging to the researcher. Your full name will not be mentioned in the data collected during the interviews, and the data will be analyzed under the pseudonym assigned to you. The collected data will be open only to the above-mentioned researchers. This research will be conducted for scientific purposes, and the data will be utilized only in a scientific setting (journal, conference, etc.).

Participation in this study is completely voluntary. No prize or fee will be offered as compensation. You have a right to withdraw your consent without any reason at any stage of the study. In this case, the audio records and/or notes will be destroyed. It is not expected that this research puts you at risk.

Before signing this form, you can ask questions about the study. If you want to get additional information later, you can contact Assist. Prof Gizem Toska (Phone: 0 212 359 46 61) or Sümeyye Özdemir. Additionally, about your rights, you may contact the Boğaziçi University Ethics Committee for Master and PhD Theses in Social Sciences and Humanities (SOBETIK) (sbe-ethics@boun.edu.tr).

I, (name of the participant)..... read the above text, I understand the scope, the purposes, and requirements of this study as a volunteer participant. I had the opportunity to ask questions about the study. I understand that I can leave this study whenever I want and without having to give any reason, and that I will not face any negative consequences if I quit.

I agree to participate in this research voluntarily, without any pressure or coercion.

I have / do not want to receive a sample of this form (In this case, the researcher keeps that copy).

Name of the Participant: .....

Sign: .....

E-mail*: .....

Date (day/month/year): ……/……./.....

☐ I accept the audio recording.

*If you want to know the result of this study, please share your email address with us.

APPENDIX F

INFORMED CONSENT FORM (TURKISH)

KATILIMCI BİLGİ ve ONAM FORMU

Araştırmayı destekleyen kurum: Boğaziçi Üniversitesi

Araştırmanın adı: Türkiye'deki Kanserli Çocuk ve Ergen Ebeveynlerinin Yaşanmış Deneyimleri

Proje Yürütücüsü: Dr. Öğretim Üyesi Gizem Toska

E-mail adresi:

Telefonu:

Araştırmacının adı: Sümeyye Özdemir

E-mail adresi:

Telefonu:

Sevgili Ebeveynler,

Bu araştırma, kanser tedavisi gören çocukların ebeveynlerinin yaşadığı deneyimleri belirlemeyi amaçlamaktadır. Araştırma, yüksek lisans tezi kapsamında Boğaziçi Üniversitesi Rehberlik ve Psikolojik Danışmanlık programı yüksek lisans öğrencisi Sümeyye Özdemir tarafından, Dr. Öğretim Üyesi Gizem Toska danışmanlığında yürütülmektedir.

Bu çalışmaya katılmayı kabul ettiğiniz takdirde görüşmeniz için randevu planlanacaktır. Yüzyüze olarak gerçekleşecek görüşmemiz yaklaşık 15 soru içermekte olup 40-45 dakika sürmesi planlanmaktadır.

Onay verdiğiniz takdirde, verilerin analizini yapabilmek adına ses kaydı alınacaktır. Ses kaydına onay vermek istemezseniz görüşmeler not tutularak kaydedilecektir. Bu araştırmada kişisel bilgileriniz gizli tutulacaktır. Sizden alınan bilgiler sadece araştırmacıya ait, şifreli bir harici bellekte tutulacaktır. Görüşmelerde toplanan veriler içinde adınız geçmeyecek, veriler size atanmış kod isim altında analiz edilecektir. Verilere erişim sadece yukarıda adı geçen araştırmacılara açık olacaktır. Bu araştırma bilimsel bir amaçla yapılacaktır ve veriler yalnızca bilimsel bir ortamda (makale, konferans vs.) kullanılacaktır.

Bu çalışmaya katılmak tamamen gönüllülük esaslıdır. Çalışmaya katılmanız durumunda size herhangi bir ücret ödenmeyecektir. Katıldığınız takdirde çalışmanın herhangi bir aşamasında herhangi bir sebep göstermeden onayınızı çekme hakkına da sahipsiniz. Bu durumda sizden alınan ses kaydı ve notlar imha edilecektir. Yapmak istediğimiz araştırmanın size risk getirmesi beklenmemektedir.

Bu formu imzalamadan önce, çalışmayla ilgili sorularınızı sorabilirsiniz. Daha sonra ek bilgi almak istediğiniz takdirde Dr. Öğretim Üyesi Gizem Toska (Telefon: 0 (212) 359 46 61) veya Sümeyye Özdemir ile temasa geçebilirsiniz. Ayrıca araştırmayla ilgili haklarınız konusunda Boğaziçi Üniversitesi Sosyal ve Beşeri Bilimler Yüksek Lisans ve Doktora Tezleri Etik İnceleme Komisyonu'na (SOBETİK) (sbe-ethics@boun.edu.tr) danışabilirsiniz.

Ben, (katılımcının adı) ....., yukarıdaki metni okudum ve katılmam istenen çalışmanın kapsamını ve amacını, gönüllü olarak üzerime düşen sorumlulukları tamamen anladım. Çalışma hakkında soru sorma imkânı buldum. Bu çalışmayı istediğim zaman ve herhangi bir neden belirtmek zorunda kalmadan bırakabileceğimi ve bıraktığım takdirde herhangi bir olumsuzluk ile karşılaşmayacağımı anladım.

Bu koşullarda söz konusu araştırmaya kendi isteğimle, hiçbir baskı ve zorlama olmaksızın katılmayı kabul ediyorum.

Formun bir örneğini aldım / almak istemiyorum (bu durumda araştırmacı bu kopyayı saklar).

Katılımcının Adı-Soyadı: .....

İmzası: .....

E-posta*: .....

Tarih (gün/ay/yıl): ……/……./.....

☐ Ses kaydı alınmasını kabul ediyorum.

*Eğer araştırma sonucunu öğrenmek istiyorsanız lütfen mail adresinizi bizimle paylaşınız.

APPENDIX G

ETHICS COMMITTEE APPROVAL

Evrak Tarih ve Sayısı: 10.11.2022-97035

T.C.
BOĞAZİÇİ ÜNİVERSİTESİ
SOSYAL VE BEŞERİ BİLİMLER YÜKSEK LİSANS VE DOKTORA TEZLERİ ETİK İNCELEME KOMİSYONU
TOPLANTI KARAR TUTANAĞI

Toplantı Sayısı	:	36
Toplantı Tarihi	:	09.11.2022
Toplantı Saati	:	16:00
Toplantı Yeri	:	Zoom Sanal Toplantı
Bulunanlar	:	Doç. Dr. Arhan S. Ertan, Doç. Dr. Senem Yıldız, Dr. Öğr. Üyesi Yasemin Sohtorik İlkmen, Dr. Öğr. Üyesi Ayşegül Metindoğan
Bulunmayanlar	:	Prof. Dr. Feyza Çorapçı, Dr. Öğr. Üyesi Harun Muratoğulları

Sümeyye Özdemir
Eğitim Bilimleri

Sayın Araştırmacı,

"Lived Experiences of Parents of Children and Adolescents with Cancer in Türkiye" başlıklı projeniz ile ilgili olarak yaptığınız SBB-EAK 2022/77 sayılı başvuru komisyonumuz tarafından 9 Kasım 2022 tarihli toplantıda incelenmiş ve uygun bulunmuştur.

Bu karar üyelerin toplantıya çevrimiçi olarak katılımı ve oy birliği ile alınmıştır. Onay mektubu üye ve raportör olarak Yasemin Sohtorik İlkmen tarafından toplantıya katılan bütün üyeler adına e-imzalanmıştır.

Saygılarımızla, bilgilerinizi rica ederiz.

Dr. Öğr. Üyesi Yasemin
SOHTORİK İLKMEN
ÜYE

e-imzalıdır
Dr. Öğr. ÜyesiYasemin Sohtorik
İlkmen
Öğretim Üyesi
Raportör

SOBETİK 36 09.11.2022

Bu belge, güvenli elektronik imza ile imzalanmıştır.

APPENDIX H

QUOTATIONS (TURKISH)

1. Buna ne söylenir ki? Ben zaten duyduğum gün başka bir dünyaya geçiş yaptım gerçekten. Bugüne kadar benim çektiğim sıkıntı az boz değildi ama bir şey çekmemişim ben demek ki, hiçbir derdim yokmuş benim. Yani bunları ben gözetince, çok ağır bir şey, sonunu göremiyorsun. Bir tünelde karanlığın içerisindesin ama hiçbir ışık göremiyorsun, sonucunu bilmiyorsun. (P5)

2. Dünyadan koptum, kanatlarım koptu yani, her şeyden koptum. (P10)

3. Ya çok zor anne olabilmek gerçekten. Deneyim olarak sürekli onun karşısında güçlü durmak zorundasın. Yani ağlasan bile belli etmemek zorundasın çünkü fark ediyor her şeyi, üzgün olduğunda fark ediyor. Yani güçlü olmalıyız, alıştık artık sürece zaten çünkü 2. yılımız oldu tedavi sürecinde. Şu anda işte bilemiyorum, çünkü hem evde şey oluyorum hem burada çok yoruluyorum ama mecbur ayakta durmalıyız. (P6)

4. Zor, zor yani. Hakikaten lösemi olduğunu öğrenip, evladını kaybetme çizgisinde gidip gelmek gerçekten hem anne için hem baba için de zor. Hayat devam ediyor, mücadele etmen lazım, dik durman lazım. (P1)

5. Çok zordu. Yani çocuk ağlıyor, bağırıyor, yemek yiyemiyor çünkü ağrıları atak şeklinde geldiği için. çünkü götürüyoruz hiçbir şey yok, anlatıyoruz ağrılarının nerede olduğunu anlatıyoruz, aciller hiçbir şey yapmıyor. Çaresizlik çok kötü bir şeydi. Belki de hani ne olduğunu bilip de tedaviye başlamak da bizi biraz rahatlattı. (P4)

6. [Doktor] Al üniversite hastanesine götür dedi. Ben de çocuğumu aldım, üniversite hastanesine götürdüm. Üniversite hastanesinde de işte 1,5-2 ay oyalandık orada. Hani şüpheleniyorlardı ama tam teşhis konulamıyordu. Biraz geç işliyordu süreç. (P6)

7. Çok zor bir süreçti hocam. Zaten bizim şöyle oldu, önce size şöyle anlatayım: İlk bacağı ağrıdığında, alıp biz onu doktora götürdüğümüzde eğer tanısını bilseydik erken davranırdık ama biraz doktorların yanılmasına denk geldik biz. 2 ay, 2,5 ay boşu boşuna gidip geldik. O süreçte de tabii kitle büyümeye başladı, 2,5 ayımız öyle geçti. (P7)

8. İlk öğrendiğimde zaten ne yatabiliyorsun ne hiç şeyin yok yani, dünya başına yıkılmış sanki böyle. (P6)

9. Hastane başıma yıkıldı. Hiç beklemediğim bir şey yani. (P10)

10. Çok kötüydü çünkü bizde hiç öyle bir şey yok. Ailemizde, sülalemizde hiç öyle bir şey yok , yani hiç öyle bir hastalık yok. Kabul etmek edemedim zaten, hani yoktur dedim, değildir dedim. Ama hayat işte, çok zor oldu. (P9)

11. Mesela ben söyleyemedim, kendime bile söyleyemedim. "O hastalık" diyorum ya da "kötü hastalık" diyorum. O hastalığın ismi ne? Bilmiyorum. Çocuğumla ismini yan yana yakıştıramadım, konduramadım. (P2)

12. Yani ilk duyduğum anda yıkıldım, ailece yani hepimiz. Ben olayım, eşimin ailesi olsun, kendi ailem, çocuklarım… Çok zor bir sürece girdik duyduğumuzda. Kabullenemiyorsun daha doğrusu. Ama bilmiyorum, zordu. (P7)

13. Çok yıpratıcıydı. Ben kendimi çok zorladım. Nasıl bu kadar kör oldum, nasıl göremedim, nasıl hissetmedim? Yani kendime çok kızdım. (P2)

14. Ama ilk 2 ay falan çok zor oldu benim için. Sürekli kavga ettim kendimle. (P9)

15. İlk 6 aylık serüven bizim için çok zor geçti. Yani gerçekten zor geçti. Ama hani kızımı ben yanılmıyorsam 4-5 sefer kaybetme riskiyle karşı karşıya kaldım diyeyim. (P1)

16. Hani kaybetme korkusu var ya! Düşüncesi bile çıldırtıcı. O fikir bile! Kaybetme korkusu o kadar kötüyse, gerçekten kaybettiğinde ne olacak? Hani bir anne için delirmek herhalde lüks, delirsem kurtulacağım. (P2)

17. O daha çok küçük yani, o acılara, o şeylere dayanamaz diye ben çok üzüldüm ilk duyduğumda. Ondan birden öleceği aklıma geldi. Bilmiyorum nedense. Zaten duyduğumda hastaneden çıktım, bir 10-15 dk dışarıda bekledim. Çok kötü olmuştum. (P5)

18. Ben şunu düşündüm Allah peygamber efendimize [Hz. Muhammed] yedi tane evlat vermiş, bu yedi tanesinin altısını kendi eliyle toprağa gömmüş. … Yani bunu, çocuğu Allah verdiği zaman bize sormadı. Bizden aldığı zaman da sormayacak. Şükürler olsun ama. Her zaman şükrediyorum ama kolay bir süreç değil yani. (P3)

19. Ben kendimden geçtim. "Allah'ım sen bu canı al, çocuğa ver, ben sadece çocuğa bakayım." diyordum. Bazen yanına oturuyorum, elini tutuyorum. Babası diyor ki sanki kaçacak, bir yere gidecek. (P10)

20. Kötü huylu olduğu ortaya çıktı. Kötüydü o süreç! Çocuğa nasıl söyleyeceğim, ben söyleyemem dedim doktora. Ya da söylemek de istemedim aslında, dedim ki söylemeyelim, tedavi olsun. Bilmeden olsun. O da şey dedi, olmaz dedi, bilmesi lazım, sonuçta küçük çocuk değil, yapılan işlemleri görecek, kemoterapiyi görecek, kendi araştırıp illaki öğrenecek dedi. Söylemeniz gerekiyor dedi (P2)

21. "Ben tedavi olmak istemiyorum, saçlarım da dökülsün istemiyorum. Eve gidelim." dedi. İşte orada zaten bir koptuk. O ağlamaya başladı, ben ağlıyorum. İkna olmaktan başka şansı yoktu ki! Sürecimiz öyle başladı. (P2)

22. Tabii biz bu süreçte Sena'ya nasıl anlatacağız, nasıl söyleyeceğiz, hani korkacak mı? diye Feride [annenin onkoloji hemşiresi bir arkadaşı] ile bunu bayağı bir konuştuk, biraz Sena'yı hazırladık. İlk önce ben kendimi hazırladım tabii. Aile olarak bu süreci nasıl atlatacağız, Sena'ya hiçbir şey olmamış gibi, normal bir hastalıkmış gibi, hani destekleyerek Sena'yı bir şekilde bunu anlatacağız. Sena tabii çok irdeleyen, çok meraklı bir çocuk ve her şeyi öğrenmek isteyen bir çocuk, ne olduğunu bilmek isteyen bir çocuk. Biz dedik ki senin belindeki kötü huylu bir iltihapmış, bu iltihap için sana bir tedavi uygulanacak ama bu tedavi senin kaşlarını, kirpiklerini dökecek, kalacağız bazen yatacağız hastanede diyerek biz Sena'ya ilk başta böyle anlattık. Yani kanser olduğunu söylemedik Sena'ya. Sonra baktık Sena bizden de metanetli, tedaviye başlayacağımızdan bir gün önce biz Sena'ya söyledik. … Dedi ki "Kanser neymiş ki, ben onu yenerim, korkmuyorum kanserden!". "Tek sıkıntım" dedi "niye saçlarım dökülüyor, niye kirpiklerim dökülüyor, ben dökülmesini istemiyorum." dedi. Bir tek biz Sena'da inanın onda zorlandık yani. (P4)

23. Yani çocuğu ben buraya getirirken bu hastalığın sende olduğunu, öyle bir şey olduğunu söylemedim. Sadece ayağında bir tümör olduğunu, o tümörün küçülmesi gerektiğini, onun için de kemoterapi görmesi lazım olduğunu, yerin geldiğinde saçları dökülecek, midesi bulanacak, halsiz olacak, kanları düşecek, bunların hepsini ona söyledim yani. Böyle böyle başından geçecek bunlar ama biz inşallah onlar bittikten sonra iyileşeceğiz. Buraya geldiği zaman buradaki annelere soruyor "Çocuğunuzun tanısı ne?" diye. Lösemi dediklerinde "Aa kanserli hastalar da burada kemoterapi görüyor." diyor. … Bazen çok düşünüyor, çok derin düşünüyor. Sanki öğrenmiş gibi geliyor ama sonra bazı şeyler söyleyince şaşırıyorum, "Aa gene bilmiyormuş" falan diyorum. Artık bir biliyor mu bilmiyor mu bilmiyorum. Keşke biriyle [ruh sağlığı uzmanı] görüşseydi en azından bunu bilip bilmediğini öğrenecektim. Kendisine soramıyorum, sen bu hastalığı biliyor musun diyemiyorum. Söylesem belki araştırmaya başlar, daha kötü olur. O yüzden irdelemeye korkuyorum, o yüzden de çok zor geçiyor. (P5)

24. Biz bir şey söylemedik, o internete girdi kendi öğrendi. Anne hayır bak, bu böyle diyor, gülerek söylüyor, yanağımı sıkıyor. O bizden daha güçlü, çok güçlü. Belki o bize daha çok moral oldu. O öyle olmasaydı, kafasına bir şey taksaydı ben herhalde kafayı yerdim. Bir şeyi kafasına takmıyor. (P10)

25. Saçlarının dökülmeye başlaması da çok kötüydü bizim için. O da bir travmaydı hem onun için hem benim için. Şimdi kemoterapiyi aldı, saçları eline gelmeye başladı. Ondan saklayıp yastıktan gizlice topluyorum görmesin, üzülmesin diye. 2 gün öyle sürdü, artık 3. gün öbek öbek gelmeye başladı. "Dilan artık izin ver keselim." dedim. Önce yok dedi. Baktı ki olacak gibi değil çünkü eline geldikçe o da çok kötü olmaya başladı. (P2)

26. Mesela o saçlarını falan… Ben ona bandana aldım renkli şeyli… Mesela gece bile, evde bile hep bandanalı. O çıplak kafasını görmek istemedim. Hani hep örtelim kızım başını. Gece yatarken mesela sıcak hava ama örtelim çünkü onu öyle çok acı görmek. Yani o çok dayanılmaz bir şey gibi geliyor insana. (P9)

27. Çok hareketliydi, şimdi de işte yerinden kalkamıyor, yürüyemiyor. Ayakları ile lambaları açardı, şimdi bir ayakkabıyı giyemiyor. Birkaç videosu var mesela öyle ayağını kaldırıp lambayı açıyor, şu kadar yükseklikte! O yükseklikte [Eliyle yaklaşık 1,5 metre yüksekliği işaret ediyor] lambayı açıyor. Biz 2 yıldır bir ayakkabıyı giyemiyoruz şu an. (P7)

28. Geceleri ağrı tuttuğu zaman uyuyamıyorsun, saatlerce onu bekliyorsun. O ağladığı zaman ailece ağlıyoruz, alt üst oluyoruz. Sabaha kadar oturuyoruz ya, düzenimiz bozuluyor. Hepimiz kalkıyoruz, ne yapacağını bilemiyorsun. Bir tedirginlik sarıyor, ne yapayım, nasıl ağrısı durur. O şekilde. Ya ağrı da öyle normal sıradan, baş ağrısı gibi değil. Öyle bir şey değil. Bir ağrın olsa ağrı kesici alıyorsun geçiyor ama bu geçmiyor. Dakikada bir tetikliyor, sanki kemiklerini bir şey oyuyormuş gibi çocuğun bağırtıları. (P7)

29. Daha çocuğun yaşadığı acıları, onları da saysam ben burada bayılır, ölürüm. (P8)

30. Doktor aradı ve Ahmet'in il dışına gitmesi lazım, burada tedavisi yok dedi. İlk önce kemoterapi sonra radyoterapi alması gerekiyor, ben radyoterapi veririm ancak burada o tedavimiz yok, çocuk onkoloji birimimiz yok dedi. Sadece 3 ilde olduğunu söyledi. Aldım çocuğumu kalktım geldim [İstanbul'a] … Büyük çocuğum ben kardeşlerimi istiyorum, ev ortamı istiyorum dedi. Mutlu olsun diye her şeyi yaptık. Sıfırdan başladık … Onu toparlayabilmek çok zor, bir evi ev etmek. (P6)

31. Bambaşka bir yere taşınıyorsun, her şeyin değişiyor. Orası gibi olmasa da her şeyin, bütün hayatım değişti. Çocukların oynadığı yerler... Şu an hapisler mesela. Bizim orada mesela her bir apartmanın oyun şeyi var, parkları var. Çocuklar çıkarlardı, oynarlardı. Ama burada öyle değil, burada doğru düzgün bir park bile yok yani çocukların çıkıp oynayacağı. Çocuklar hiç dışarı çıkamıyor daha doğrusu, öyle söyleyeyim, eve hapsolmuşlar. Orada mesela hep tanıdıklar oluyor. Ama burada işte hiç kimse yok. (P6)

32. Oradaki [memleketteki] doktor da büyük şehirlerden birine gitmeniz lazım burada çocuk onkoloji yok dedi. İşte öyle başladık geldik. Sadece bavul aldık geldik, terlikle çıkmışız yola. Sonra geldi eşyalarımız. Buradan eşyalı ev tuttuk, öyle gidiyoruz … 5 kişilik aileden 3 yere taşındık şu an. Ben buradayım (hastane), onlar evde, küçüğüm eltimde. Bölündük yani, parçalandık. (P8)

33. Ben çalışmadığım için, işten çıkarıldım çünkü çocuktan dolayı. o hasta olunca gidemeyince, işten çıkardılar beni. Zaten gidemezdim, bu süreçte hastanedeydim. [Büyük] Kızım işe başladı. (P2)

34. Eşim çalışıyordu [memlekette]. Şimdi de çalışamıyor, evde … Haftada iki gün geliyoruz ya yoksa benim eşim çalışkan, çalışamıyor. Ta Tuzla'dan geliyoruz, çocuk da yürüyemiyor, ben de getiremiyorum. Oradan getiriyoruz, o yüzden sıkıntı. (P8)

35. Yeri geliyor bir ay boyunca her Allah'ın günü hastaneye gidiyordum. Ondan sonra kemoterapi başladığı zaman bir gece hastanede kalıyorduk … Maddi olarak çalışamadığım için biraz sıkıntılar yaşıyorum. (P3)

36. Zaten eve gelme olayını kısıtladık biz, yani dışarıda karşılaştığımızda görüştük, telefonda görüştük [aile üyeleri ve arkadaşlar ile]. (P4)

37. Dışarı çıkarsam çıkardım. Küçük kız evde olduğu zaman onunla daha çok vakit geçiriyordum ben. Beraber gezerdik, kafeye giderdik. Pek arkadaş ortamım yok ama çocuklarla daha çok zaman geçiriyordum. Şimdi onların hepsi kısıtlandı. Hiçbiri yok artık. O bile diyor, anne önceden çıkardık gezerdik. Şu an yok! Hastane-ev yani. Hiç kimse ile görüşmüyorum bile ben. Bir telefonla. Sosyal yaşantımız yok zaten, bitti … Kimseyi evine de alamıyorsun, yasak yani. Çocuğun bağışıklığı düşüyor diye korkuyorsun. O gelir, bu gelir mikrop kapar. (P7)

38. Günlük tabii ki değişiklikler oldu. Gezmeye falan çıkamadım, topluma, kalabalığa ben girsem de Ece girmedi. Gerçi bu pandemi [COVID-19] çok etkiledi. 2 sene pandemi, biz de herkes gibi çekildik, çok çok kalabalıklardan. Ha gene işimize gidiyoruz, işimize gitmek zorundayız. Ama çok fazla sosyal ortamlara girmedik. (P9)

39. Zaten çok fazla kalabalığın da anlamı yok. Var bir sürü insanım var benim, akrabam, tanıdığım var. Çevrem geniş ama çevre genişliğinin hiç kimseye faydası yok. Başın dara düştü mü, cebinde para olmadı mı, hasta oldun mu istersen milyarlarca arkadaşın olsun. Kimse seni kabul bile etmez. Yani bu hayat felsefesi, biz onu öğrendik. Kimseye güvenmem, 1-2 vardır güvendiğim insanlar. Öyle herkese "Ay oraya gideyim, buraya gideyim" demem, gitmem. Çünkü gitmenin de bir mantığı yok, abuk sabuk şeyler

konuşuyorlar, boş boş şeyler anlatıyor. Ne yapayım? Boşu boşuna, hiç gerek yok … Ya bir sevdiğini kaybetmeyen, hastalığını görmeyen biri beni çok iyi anlayamaz zaten … Yaşamamış insan bilmiyor. Bilip de beni anlamayınca ben de onlara daha çok sinir oluyorum. En iyisi beni anlayan bir kişi var, bir arkadaşım. 1-2 arkadaşım. Hani onunla dertleşiriz. Genelde kendim yaşarım. (P9)

40. Mesela önceden yazın tatile giderdik ailece, denize giderdik hafta sonları. Onların hiçbiri yok artık. Mesela çocuğu götürsen çocuk bile gitmek istemiyor, yürüyemiyor. Yürüyemeyince ne oluyor? Büyük bir engel oluyor sana. Götürmek istiyorsun ama o istemeyince sen de gitmek istemiyorsun. Yani şöyle, eve bağlandık daha doğrusu. (P7)

41. Köyümüze yakındık, gidiyorduk geliyorduk. Çok şükür iyiydi. (P8)

42. Normal hayatta şartlar da çok kolay değil, o yüzden ben maddi açıdan çok zorlandım. Burada mesela bir iğne, mesela biz alerji iğneleri kullanıyoruz. Onlarda mesela ben çok zorlandım. Sadece şu 15 günde ödediğim para 1500, 2000 lirayı geçti, sadece ilaç parası. Onlar zorluyor yeri gelince işte. (P5)

43. Bizim için mesela [hastaneye] gidip gelmek masrafı olmasaydı daha kolay olurdu. Ulaşım. Öyle zaten kiradaydık, yine kiracıyım. Burada da olsun, orada [memleket] da olsun. Yani öyle, gidip gelmede çok sıkıntılar çekiyoruz. İlaçları oluyor ekstradan. [Hasta olan çocuğun kişisel] İstekleri oluyor yani oluyor, oluyor. (P6)

44. Şimdi de içine girdikçe girdik işte. XXX'e [özel bir hastane] geldik 70 milyarla çıktık. Burada ameliyat ettirdik YYY hocaya [uzman bir doktor], ona da 90 milyar verdik … Şimdi de çalışamıyor, evde işte. Ona bir yandan üzülüyorum, Ali'ye bir yandan. Borçları düşünüyorum. (P8)

45. Bir muayene ücreti 700 lira, şimdi bilmiyorum. Biz oraya 400-300 liraya başladık, şimdi 1000 lira vardır kesin. Yatak ücreti olsun, hastane masraflarında olsun büyük bir artış oldu. Sadece orada değil, her şeyde artış oldu. (P3)

46. 150 ile başladık yatışlara. İnanır mısınız 500'dü en son biz çıktığımızda. Nisanda biz 150 ile başladık günlük yatak ücreti ve bir anda 500 oldu. (P4)

47. En küçük kardeşi zaten 8 yaşında şu anda, o zaman daha küçüktü hiçbir şeyi algılayamıyordu. O biraz anneden uzak kaldığı için, anne hep burada [hastanede] olduğu için biraz psikolojikman yıkıldı. Ben de zaten o 3 aylık hastalık periyotlarını ona bağlıyorum, üzüntüye bağlıyorum abisiyle ikisini. (P1)

48. Şimdi 4 tane de çocuk olunca diğerlerini tabii ki ihmal ettim. Evdekiler ne olmuş, ne bitmiş çok da şeyimde değildi. Diğerleri de kendine kaçış noktası buldu. Mesela en büyük ablası olaya yaklaşmadı bile. Belki o kendini koruma içgüdüsüydü. Kabullenmedi, yanımda da durmadı, duramadı. Ben istiyordum mesela. O arkadaşları ile daha çok görüştü. Hele böyle yaptığımızda, Yelda yanımda durmanı isterdim, benim de acıma şey ol falan, o konuşmamayı tercih etti. Mesela bu süreçte hiç konuşmadık çünkü kaçtı. Diğer ablası şu an 18, o da 17 yaşındaydı o zaman, o daha çok yanımda olmaya çalıştı. Sonradan kendisi de söyledi, anne dedi, sürekli arkadaşımla buluşmaya çalışıyordum, eve gelmiyordum, ben de aslında kaçmaya çalışıyordum dedi. Küçüğüne, 12 yaşındakine söylemedim, anlayabilecek bir dönemde değil. Çok üzülür, gerek yok dedim. Ama zaten anlamış sonra anladığım kadarıyla. (P2)

49. Tabii ki de etkilendiler [diğer çocuklar]. Öğretmenleri etkilendiklerini, sürekli bizi konuştuklarını söylüyorlardı … Davranışları tabii değişti biraz bu süreçte. (P4)

50. Yeri geliyor ilgilenemiyorum [diğer çocuklarla] ama allah razı olsun bakıyorlar [annenin kız kardeşleri]. Küçüğü biraz zorlanıyor ama, özlem çekiyor. O da artık alıştı … Ağlıyor mesela, gideceğim zaman kapıyı tutuyor. Yani gitme diyor. Mesela ben buradan, mesela eşya almaya gittiğimde anne gitme diyor, bu gece beraber yatalım diyor. Yani çocuk çok şey oluyor. Ama gittikten sonra alışıyor. (P6)

51. Çocuklarımın mesela hepsinin psikolojisi bozuk … Mesela öbür çocuklarımla ilgilenemiyorum, onlar da diyor anne biz de varız ama ne bileyim ya onlara şey edemiyorum, onlara vakit ayıramıyorum. Mesela Arda'nın bir büyüğü dersleri falan çok iyiydi, geçen sene Arda'nın bu rahatsızlığından sonra hem derslerinde gerileme oldu, saçları falan hep döküldü. O da çok, çok etkileniyor çocuklar. Abisi desen gene aynı. (P7)

52. Eşimle özel şey [cinsel olarak] yapmak istemiyorum. O diyor o ayrı bu ayrı. Benim de haklarım var diyor. (P8)

53. Manevi yönden evladını kaybetme korkusu yani o her aldığı kemoterapide, her girdiği bel iğnesinde, her girdiği biyopside… Acaba narkozdan uyanacak mı ya da acaba içerde bir şey olacak mı? Hani onların korkusu, hala yaşıyoruz. (P1)

54. Evladımız arada arıza verse de, arada bir buraya gelsek de çok şükür genel durumu iyi görünüyor. Ama lösemi bu, göreceli bir kavram. Yarın bize ne yaşatacağını bilmiyoruz. Hasar bıraktı mı bırakmadı mı, onu da bilmiyoruz. (P1)

55. Kafamız hiç rahat değil, yani benim kafam hiç rahat değil. Hani şimdi böyle bir hastalık olmasa rahat rahat işini de yaparsın kafan rahat olur. Gezmeye gideceksen gidersin, rahatça bir iş yaparsın. … Acaba ateşlenir mi, acaba hastalanır mı, ne yaparız, ne ederiz? Yani kafam pek rahat değil. (P9)

56. Aslında hastane ortamı öyle kötü ki. Hani evde birazcık rahatlıyorsun. Hastaneye geldiğinde aynı dertten mustarip olanları gördüğün için, onlar da yeni nüksler falan olduğu için, onlarda çıktıysa bende de çıkar diyorsun mesela. Patoloji sonuçları %100 [temiz] gelen insanların şu an çektiklerini görüyorum; çok acı çekiyorlar mesela. Başka başka yerlerde nüksleri oluyor. (P5)

57. Biraz buradan [hastane] uzaklaştığın zaman kimseyi görmüyorsun. İster istemez buradaki insanları görünce moralin daha çok bozuluyor. Moralim bozuluyor yani. Onları görünce daha çok üzülüyorum. (P7)

58. Ya ben aslında çok şükür halime şükrediyorum, çok şükür iyi olacak ama bu hastaları, onları [hastanedeki hastalar] görünce çok kötü oluyorum. Çok şükür bizimki iyi. Ama bizimkinin şurasında şu çıktı, burasında bu çıktı diyor anneler, ben ona çok üzülüyorum. Korkuyorum da. (P8)

59. Hep ölüm korkusu. Hep o korku zaten. Çünkü bir sürü kişi vefat etti ya ondan diyorsun acaba biz de mi? Mesela çocuk soruyor "Anne falanca kişi nerede, niye o gelmiyor?". Yani vefat etmiş, diyorum ki "Memleketlerinde tedavileri çıkmış, oraya gitmişler.". Ama gerçeğini bilmiyor. Yani bir sürü kişi vefat etti. Hep de böyle şey de kaldığımız, dernekte kaldığımız, aile evinde kaldığımız kişiler. Yani çocuklar vefat ederdi ama aileler hani birdenbire çıkarlardı, sessiz sedasız giderlerdi. Görmezdik bile. (P6)

60. İnsanlardan koptum. Atıyorum şeyi fark ettim, artık gülümsemiyorum. Elimde değil, farkında değilim. Kalabalık yerde, 3-4 kişi oturduğumuz yerde normalde sohbet başlatan ben olurdum. Oradaki en neşeli insan bendim. Şimdi ortama girdiğim zaman donup kaldığımı fark ettim. Olaya adapte olamıyorum. Biri gelse de orada değilmişim gibi, sanki boşluktaymışım gibi. O şeye bir daha giremiyorum. Eskisi gibi değil yani olmuyor. Biraz düzelmeye başladı ama kimseyle hala iletişim de kurmak istemiyorum. Kimseyle görüşmeyi istemiyorum. İnsanla konuşayım, sohbet edeyim, paylaşayım, hiçbir istek yok içimde. Boşlukta hissediyorum. Hiçbir şeye tam olarak adapte olamıyorum. Eskiden yemek yapmak, çok severek yapardım, bayılarak. Şu an yapmak istemiyorum. Sadece geçiştirmek istiyorum ya da şey gibi karnımız doysun zaten yeterli. Hiçbir şeyden zevk almıyorum. Tahammülsüzleştim. Ve çok alıngan olduğumu fark ettim. (P2)

61. Kopuk yaşıyorum, sanki her şeyden kopmuşum. Artık yani bir yere bir şey koyuyorum aklıma gelmiyor, ben bunu nereye koydum. Bazen düşünüyorum nereye koydum bunu ya? Gelmiyor aklıma! O şekil olmuşum. Zaten uyku düzenim hiç yok normal insanlar gibi. Mesela önceden başımızı yastığa

koyduğumuz zaman koyup yatıyorsun çünkü sorun yok. Şimdi en büyük sorun, yatamıyorum böyle. Kafamı koyduğum zaman uyuyamıyorum, sanki o hastalık geliyor beynimi kemiriyor. Öyle olmuşum. Düşünmeden bir dakika, onu düşünmeden zamanım geçmiyor. Hani nasıl olacak, bitecek mi, gidecek mi bu hastalık, benim çocuğumu bırakacak mı? Hep çelişki var sende. (P7)

62. Ya hiçbir şey yapmak istemiyorum. Eskiden yurtdışında falan çöp ev yaparlardı, televizyonda izlerdim. Bunlar nasıl insanlar ya derdim. Şimdi bizim evin çöp ev olmasına ramak kaldı. Hiçbir şey yapmak istemiyorum. Oturduğum yer burası benim evim ya! Bura çöp yığını olsa affedersiniz hiç temizlik yapasım gelmiyor içimden. Dışarı çıkasım gelmiyor, kimseyle görüşesim gelmiyor. (P8)

63. 72 kiloydum ben duyduğumda. 67'ye mi 68'e mi ne düşmüşüm. (P8)

64. Maddi anlamda destek olsaydı şey olmazdım. Hani eve yetiştirmeye çalışıyorum, buradaki hastane masraflarını karşılamaya çalışıyorum, o anlamda. (P2)

65. Sabitlesinler en azından, 200 [TL] yapsınlar. Belli şeyde olsun. Hiçbir destekleri olmadı. En azından onkoloji bölümünü ayrı tutarak bize daha yakın olabilirlerdi. Biz eşe dosta tamamlattık eksikleri çünkü MR'ın da belli bir kısmını biz ödüyoruz, hepsini devlet karşılamıyor. Diğerlerini biliyorsunuz ücretli. (P4)

66. Bir hastaneye gitsen bir doktorun muayenesi 2 milyar, 3 milyar, yani bu şekil. Biraz o yönden de şeyim yani daha farklı olmalıydı yani. Çünkü bu hastalık ağır bir hastalık. Sağlıkçıların daha az seviyede para almalarını isterdim, çünkü yüksek meblağlar insanı zorluyor. Yetişemiyorsun bir yerde yani. (P7)

67. Ya şimdi hiçbir şey bilmiyorsunuz. Bir hastalık geldi, en pis hastalık, en kötü hastalık ve o hastalık hakkında hiçbir bilginiz yok çünkü hani yok yani etrafında yaşayan, gören. Hiçbir şekilde yok. Sıfır bir bilgi. (P9)

68. Keşke bana yardım edebilecek ailemden birileri olsaydı. Mesela ben burada 15 gün değil de, 15 günün 1 günü, ben dinlenebilseydim. Öyle birini isterdim ama maalesef öyle biri yok … Mesela bazen ayaklarım şişik, gün boyu ayağımın ağrısıyla gidip gelmeye çalışıyorum. İsterdim yani bakabilecek biri olsun, 24 saat bile olsa, hani günlük ihtiyaçlarımı, banyomu yapabileyim, üstümü değiştirebileyim, çamaşırlarımı falan yıkayayım. Bu şekilde birini isterdim ama yok. (P5)

69. Birileri götürsün [hastaneye] isterdim. Aslında hem istiyorum hem istemiyorum. Şeyden dolayı, onu bırakmak da istemiyorum ama çok da yoruldum sürekli hep hastaneye git gel. (P2)

70. Bir de psikolojik yardım almayı isterdim. O sağlanmadı. O zaten isteğe dayalı olmaktan ziyade, böyle anne ve çocukların zaten biliniyor olması lazım. Çocuğun teşhisi konulduğu andan itibaren, süreç başladıktan sonra, nasıl ki onkoloji-hematoloji doktoru hep yanındaysa o psikoloji, psikiyatri, o da aynı paralelde, hep yanında olması gerekiyor diye düşünüyorum. Bunu benim talep etmeme bile gerek yok. (P2)

71. Gerçekten sadece inanç. Yani hiçbir şey gerçekten yok çünkü çaresizsin, bir şey yok. İlaç zehir biliyorsun. Tamam çocuğuna faydası var ama öldürüyor da aynı zamanda. Bütün kan değerlerini öldürüyor. Düşünün yani çocuğunuza zehir vermelerini kabul ediyorsunuz yani. Dedim yani rabbim verilen ilaçlar, kemoterapi zehir ama senin şifan yani yapacak bir şey yok. (P4)

72. Elhamdülillah, Müslümanız. Daha bundan ötesi yok. Mevla'ya yalvardık. Açtık ellerimizi. Hocalarımıza güvendik, teslim ettik. Bundan daha büyük bir inanç yok zaten benim gördüğüm. Yani Mevla'm da inşallah bize karşılığını verdi diye düşünüyorum. (P1)

73. Dedim ya peygamber efendimizi kendime örnek edindim … Ona 7 tane evlat verilmiş 6 tanesini toprağa gömmüş. O bana çok büyük güç kaynağı oldu yani. Hep Peygamber Efendimizin hayatı. Başka yok, ben hiç kimseyi örnek almadım. Tek örneğimiz. (P3)

74. Bence Allah ile barışık olan psikoloji ile de barışık olur çünkü hayat böyle yapacak bir şey yok. Biz elimizden geleni yapalım, gerisi takdiri ilahi. (P9)

75. En çok komşularımız, Allah bin kere razı olsun. Çevre komşularımız, eşler dostlar sağolsunlar özellikle mahallem. Daha hala sağ olsunlar ararlar, sorarlar, her zaman bize destek verirler. Yani sadece maddi değil maneviyat yönünden de Allah bin kere razı olsun. Hiçbir zaman şey yapmazlar bizi. Komşular ön planda, komşular ön planda öyle diyeyim. (P1)

76. Ailem Allah'a şükürler olsun maddi ve manevi benim yanımda. Mesela ameliyat oldu, biz onun ayağına 150.000 liraya ameliyat ettirdik. Benim öyle meblağım yoktu yani, 100.000 lirasını ailem verdi. Diğerlerini borç de borçlandım. Onlar ödediler mesela. Allah razı olsun. (P5)

77. İyi şeyler de var tabii, her şey kötü değil. Eşimin ailesi ameliyat parasını verdiler sağ olsun. Kaynanalarım topladı. İşte benim tarafım, her yerden destek çıkıyor… "Siz hiç düşünmeyin." diyorlar. "Yine isteyin yine göndeririz." diyorlar, sağ olsunlar. Ya benim hem kendi ailem hem eşimin ailesi iyi o yönden. Hep arkamızdalar, destekçiler, Allah razı olsun. Her şey kötü değil yani çok şükür … Kuzenlerim var benim. Teyzemin kızları köyde, böyle ceviz, üzüm, gerçi o da maddiye giriyor. Ama yani burada tekrar burada ev kurulmuş oldu ya, ne olursa olsun hepsini gönderdiler Allah razı olsun. Kimisi öyle destek oldu, kimisi para verdi, dua ettiler. (P8)

78. Çocuklar zaten dediğim gibi teyze bakıyor, teyze geliyor bakıyor. Teyzeler bakıyor daha doğrusu. Bir tanesi burada işte, diğeri gittiğinde işe, bu bakıyor. Öyle birbirimizi idare ediyoruz. Yeri geliyor ilgilenemiyorum ama Allah razı olsun bakıyorlar. (P6)

79. Bir işte halası var, o geliyor işte. Ben hastaneye geldiğim zaman. Onun da çocuğu yok, hiç olmadı. O geliyor işte, bizde kalıyor. Bir de çocuk da halasını çok istiyor. Eve geldiğimiz zaman o gelsin illa, yani halasını görecek. Bir o; onun dışında da herhangi kimse yok zaten. Geliyor, kalıyor sağ olsun. Mesela bazen yemeğimizi yapıyor, ben yetişemiyorum. İç çamaşırımı, hepsine o bakıyor. (P8)

80. Hep konuşurlar. Telefon ediyorlar "Hiç korkmasınlar o hastalık geçecek, tamam zor bir hastalık, tedavisi var. Ama hemen olmaz, ama geçecek, üzülmesinler, kafalarına takmasınlar." diyorlar. Hep böyle destek verdiler bize. Yola çıkıyoruz, başlıyor telefonlar "İşte biz arkanızdan kuran okuyoruz, dua ediyoruz." diyorlar. Yani ne bileyim. Onları insan duyunca bir güç oluyor. (P10)

81. Yani Allah bin kere razı olsun. Yani nasıl söyleyeyim en küçüğünden en büyüğüne derler ya. Hani hademesinden tutun, bakıcısından tutun. En küçüğünden en büyüğüne kadar mükemmel. O derece. Bizi yalnızca bir hasta gibi değil kendilerinden bir aile gibi gördüler. Sadece bana özel değil, herkese aynı, eşit. Yani bu yönleri çok hoşuma gidiyor. (P1)

82. Ya şimdi çocuklarla ilgileniyorlar. Yani nasıl diyeyim çok azarlama falan olmadı, çocuklarla falan ilgileniyorlar. Ee bizim psikolojimiz de arada bozuluyor ama güzel davranıyorlar, terslemiyorlar. Onlar da bilincinde bunlar kanserli çocuklar, annelerin de psikolojisi önemli. Zaten burada bozuk oluyor. Birçok anne ters oluyor, sinirli olabiliyor ama onlar da bilinçli olduğu için ona göre davranıyorlar. Onların da desteği oldu. Onlar da bilinçli sonuçta. Güzel davranıyorlar. (P9)

83. Sinem Hanım [onkoloji doktoru] her anlamda gece-gündüz, hafta sonu bile bana şey diyor, telefon numarasını verdi sağ olsun. şey diyor gece-gündüz bile arayabilirsin, hafta sonu hiç fark etmez, bir sorun oldu mu ara diyebilecek bir kadın. O kadar işine aşık, o kadar bize saygı duyuyor, Allah ondan razı olsun. Kadın düşünsene, aslında psikolojinin, psikiyatrinin yapması gerekeni kadın hem onu yapıyor hem onu yapıyor. Yapmayabilirdi de. O yüzden doktor olarak bana fazla bile geldi, donanımlı. Bu kadarını beklemiyordum. İyi bir doktora denk gelmemiz bizim için çok büyük bir şans, iyi ki ona denk gelmişiz. (P2)

84. Sıla Hoca [onkoloji doktoru] gerçekten de iyi bir hoca. Ben gecenin yarısında, 2:00'de mesela telefon açabiliyorum ona, cevap veriyor. Böyle bir

doktorun da gerçekten şu an piyasada öyle bir doktor bence yoktur. Cevap veriyor, Allah razı olsun, vermeyebilir. Öyle bir görevi de yok. Gece saat 3:00'de bana cevap verecek bir görevi de yok. (P5)

85. Çok şükür ben o hastaneden çok memnun kaldım. Sinem hocadan da onun ekibinden de. Yani ilgileniyorlardı bizimle. Yani gerçekten Sinem Hoca, maddi hastane kurallarına göre uysaydı ben biraz zor altından kalkardım. Yani Allah var yukarıda. Gerek muayene ücreti olsun gerek tahlillerde olsun çok esnek davranıyorlardı bize. Acaba bize karşı mı öyleydi bütün hastalarına karşı mı öyleydi bilmiyorum ama yeri geliyordu 2 ayda bir, 3 ayda bir muayene parası almıyordu bizden. (P3)

86. Okul rehberliği sağ olsun ilgilerini, alakalarını üzerimizden hiç eksik etmiyorlar şu an bulunduğu okulda. Biz bu yıl dahi özel eğitim istemiş olsaydık, bu yıl dahi özel eğitim vereceklerdi. (P1)

87. Her zaman destekleri oldu öğretmenlerinin. Müdür olsun, müdür yardımcısı olsun hem maddi hem manevi biz Sena'ya "Elimizden gelen desteği vermeye hazırız." diye. Sena'yı uzaktan eğitime yönlendirdiler çünkü Sena çok istiyordu. Derslerinde başarılı bir öğrenciydi geri kalmasın diye … Sena'yı aradılar, sordular. İlkokul öğretmeni mesela. Yani diyorum ya hepsi destekçi oldular çok sağ olsunlar. Hepsi elbirliğiyle destek verdiler. Onlar Sena'ya çok iyi geldi. (P4)

88. Sadece belirli şeylere çalışsın, biz onu online olarak sınav yapabiliriz diyerek bize bir kolaylık sağladılar, sağ olsunlar. Allah razı olsun öğretmenlerden. Bir de grup oluşturdular. WhatsApp grubu. Kendisiyle yeri gelince konuşuyorlar, hâl hatır soruyorlar. Öyle yani. Hamdolsun, iyiler yani Allah razı olsun. Tabii ki büyük destek oldu, onun eğitimi de bir yerleri de aksamasın istiyoruz. (P5)

89. Çok şükür sürecim rahat geçti. Pek fazla bir şeye ihtiyacım olmadı. Sürecim rahat geçti yani. Beril de çok güçlü bir kız. Onun sayesinde çok güçlü geçirdik. (P3)

90. Tedavi sürecinde Sena bize hiçbir zorluk yaratmadı. Sadece saçları döküldüğü için, kirpikleri döküldüğü için, kaşları döküldüğü için çok üzüldü. O bana sarılıp ağladı, ben ona sarılıp ağladım. Birbirimize destek vererek kolay geçirdik diyelim hamdolsun. Elhamdülillah. Ama dediğim gibi Sena'nın güçlü olması bana da güç verdi. (P4)

91. Başımda böyle anlayışlı, büyük bir çocuk ki. 9 yaşında olmasına rağmen 15-16 yaşında gibi. Bazen ağlıyorum, kendine çaktırmamaya çalışıyorum, ağlama anne ben iyiyim diyor. O beni düşünüyor. (P8)

92. Dediğim gibi o süreçte ateşlenmeler, kan almalar, kan vermeler, kan ışınlandırmalar vs. Bunlara ben koştum … Baba her halükârda dışarıda olduğu için bütün yük annenin üstündeydi. (P1)

93. Eşim götür getir hastaneye, hastane masrafları sağ olsun. Ona o yükü verdik … Hep ben kaldım Sena'nın yanında. Yani eşim de sağ olsun maddi olarak her şey ondaydı. (P4)

94. ABC [bir sivil toplum kuruluşu]. ABC sağ olsun hiçbir zaman maddi manevi bizi yalnız bırakmadılar. (P1)

95. Ben aile evinden çıktım, hiçbir eşyam yoktu, hiçbir şeyim yoktu. Bir tane yorgan, bir de yastığım vardı hiçbir şeyim yoktu. Ondan sonra burada onkoloji derneğine söyledim, dernek yani her şeyimi verdiler. Rabbim binlerce kez razı olsun. Hem hastalık [tedavi] olsun, hem şey olarak yardım ettiler. (P6)

96. Eşim şimdi raporu olduğu için bakıcı parası alıyor, annesi. (P3)

97. Belediye ile görüştük, belediye yardım etti. Devam edeceklerini söylediler, hatta bugün Sena'ya bilgisayar gelecek belediyemizden. Ne ister bu süreçte dediler, dedim eğitim alacak ama bu süreçte bilgisayarı yok, olsa sevinir. Sağolsun onlar da bugün gönderiyorlar bilgisayarı, onların da isteği oldu. Hala da Sedat Bey var, belediye başkan yardımcısı, arayıp soruyor bir şeye ihtiyacınız var mı, ne yapabiliriz bu süreçte diye. Sağolsun onların da desteği var. (P4)

98. Tek samimiyetlerine inandığım, burada kendimi iyi hissettiğim, benim gibi aynı serviste yatan hastaların anneleriydi. Onlar beni anlıyordu, ben onları anlıyordum. Birbirimize destek oluyorduk. O gücü onlardan ben alıyordum. Ben eminim ki onlar da benden alıyordu. Çünkü aynı yerden yaralıyız, yaralarımız aynıydı. Damdan düşenin halinden damdan düşer hesabı. (P2)

99. Mesela buradaki [hastanede] bir tane arkadaş vardı. Mesela onun hikayesini dinliyorsun. Yani birbirinden insan şey yaptıkça bana o iyi geliyor. Diyorum ki tek ben değilim, başka anneler de var. Yani o bana biraz iyi geliyor. Tek ben değilim, benim gibi bir sürü kişi var. (P6)

100. Bizim bir komşumuz vardı, onun çocuğu daha çok hastaydı. Çocuğu iyileşti, şimdi iyi yani. Diğer çocuklara karışmış geziyor, tozuyor. Onu düşündüm, göz önüne aldım. O bana moral oldu. Başka hastaları görünce, anneleri görünce, onları duyunca bir moral geliyor. (P10)

101. İş yerimden destek oldu. Eşimin iş yerinden para gönderenler oldu. (P2)

102. Yani Allah'a sadece dua ettim. Ben ibadetlerimi yapan bir insanım. Duanın da gücüne inanıyorum. Bir tek bana iyi gelen de o. Ben bir tek Allah'tan yardım diliyorum. (P5)

103. Bir de ilk başta Allah'a teslimiyet, sonra doktorlara güven. Yani ikisini beraber götürdük, öyle söyleyeyim süreci. Zaten inanç olmasa dayanılmaz, gerçekten dayanılmaz. Ama şey dedik, veren de o [Allah], alan da Allah. Dedik ki yapacak bir şey yok, şifa da rabbimden, doktorlar vesile. Yani ikisinin şeyiyle, dualarımızla atlattık bu süreci. (P4)

104. Elimden gelen her şeyi yapıyorum. Doktorlar gel diyor geliyoruz git diyor gidiyoruz, öyle yapın diyor yapıyoruz, iğne vurun diyor vuruyoruz. Yani ben en iyi şekilde evladım için her şeyi yapıyorum zaten. Ama işler yine ters gider veya her yerini sarar veya Allah korusun ölürse de benim vicdanımın hiçbir rahatsızlığı yok yani o Allah'ın takdiri. Bunu kabul etmek bence daha rahatlatıyor insanı. (P9)

105. Diyorum ya artık alıştım bu sürece. Yani ağlasan da değişmeyecek ki, neyse o olacak. Rabbim ne dediyse o olacak. Eğer ki nasibi varsa olacak, bu hayatta nasibi varsa olacak, iyileşecek inanıyorum. İnşallah inanıyorum, iyileşecek, umudum var. (P6)

106. Bizim umudumuz var. Biz öyle iman etmiş insanlarız. Biz biliyoruz ki hasta olan ölmez, eceli gelen ölür. (P5)

107. Ne iyi geldi? Hani insan yeni bir güne kalkar ya, hani güzel olacak diye. Ben de diyorum yani umudum var. Güzel olacak inşallah. Onun da hayalleri var, zevkleri var … Umudumu hiçbir zaman kaybetmedim. Daha yeni yeni tanışıyorlar hayatla. (P6)

108. Ama iyi olacağız, iyi günler ilerde. Ona inancım sonsuz, hep hastalıkla uğraşmayacağız ya canım! Biraz da iyi olacağız, gezeceğiz, tozacağız. Kredi bile çekmeye razıyız yani! Gezeriz, tozarız. Her zaman iyi olunmaz yani, her zaman kötü de olunmaz. Ama ne oluyor mesela gidiyoruz geliyoruz tedavilere, bir yer buluyoruz hemen oturuyoruz. Eşime diyorum "Oturalım, biraz bakınalım. Tamam, cepte üzüntümüz var. Biraz bakınalım içimiz açılsın" … Denize gideceğiz, tatil yapacağız, havuzlu bir yere gideceğiz. Hayallerimiz var yani o hayallerle bu hastalığı daha iyi geçirmeye uğraşıyoruz. (P9)

109. Ben orada hastanedeyken neler neler gördüm O da bana çok büyük bir dayanak oldu. Bizim hastalığımız gene iyi, orada felç olanı var, aynı hastalıktan mustarip ama onun bir de artısı var felç olmuş, ayağını kullanamıyor, konuşamıyor. Bizden sonra tanışıp da vefat eden çocuklar oldu. Bizim durumumuz çok şükür, şu anda çok iyi. (P3)

110. İşte her zaman hayatta senden kötüsüne bakacaksın. Senden iyisine baktın mı psikolojin bozuluyor. (P9)

111. Bu süreçte benden daha kötü durumda olanları da gördüm. Sena'dan daha zor durumda olan çocukları da gördüm. Şimdi beterin beteri var yani, halinize şükrediyorsunuz. Yani diyorsunuz ki, sizin çocuğunuz da kanser ama diyorsunuz ki "Buna da şükür!", çünkü o kadar çok kötü olan çeşitleri ve metastaz yaşayanlar var ki! (P4)

112. Çocuğum yani en azından sağ salim. O beni teselli eden şey. Anı yaşamak yani, o anı yaşamak. (P6)

113. Mesela moralim bozuldu, yapıyorum bir kahve içiyorum, türk kahvesini severim. Çay içiyorum. Yani artık öyle yapıyorum. Ne yapayım bozuksa bozuk, ölecek miyiz? Ölünmüyor. Hani ne diyor "Hayat çatlak bardaktaki suya benzer, içsen de akacak bitecek, içmesen de akacak bitecek.". Yaşasan da yaşamasan da ölmüyorsan eğer nefes alabiliyorsan o zaman iyi bir şekilde yaşamaya çalışmamız lazım. Niye o hayat bize zehir olsun. (P9)

114. Hani bizim derdimiz, sıkıntımız var diye dünya durup "Ayyy bu kadının üzüntüsü de sıkıntısı var." demiyor yani. Kimsenin umuru bile değil, herkes kendi hayatını yaşıyor. O yüzden çok da takılmamak lazım bu kısa dünyada. Çok fazla da her şeye takılmamak lazım. (P9)

115. Bu hayatta gelip geçiyor her şey geçiyor. En büyük, dayanamadığım acılar bile ilk günkü gibi olmuyor, her şey geçici yani. İlk günkünün acısı, üzüntüsü şu an üzerimizde yok, alıştık. Zaten ilk gününkinin acısı üzüntüsü olsaydı ben kafayı üşütürdüm. (P9)

116. Konuşuyoruz bazen bana diyorlar "Aa Hacer ne kadar güçlüsün, maşallah ağlamıyorsun, tutuyorsun kendini.". Ben de dedim ki aslında güçlü değilim ama öyle olmak zorundayız, çünkü o çıta kırıldığı zaman biliyorum ki toparlaması çok zor. Dedim yani bir şekilde olmak zorunda yani, bir şekilde oluyoruz. O şekilde çocuğun yanında sürekli ağlayan bir anne düşünsenize, harap olmuş, beter olmuş. O çocuğu kötü yönde etkileyecek, mecbur güçlü olmak zorundasın. Dediğim gibi o çıta kırıldığı anda toplaması çok zor olur, ben onu kırmamaya çalışıyorum elimden geldiği kadar, hem Sena için hem de diğer çocuklar için çünkü bir tane yok, diğerleri de var. Dediğim gibi ağlayan, sızlayan. Eşim için de aynı şey geçerli, ona da sürekli ağlayıp sızlansaydım onun için de çok zor olacaktı yani bu süreci idare edebilmesi. Çocuklarım için de psikolojik olarak daha da kötüye gideceklerdi, yani ben bir tek kendimi düşünemiyorum bu durumda. Aman ben ağlayayım, heder olayım, kahrolayım yapamazdım ki! Böyle bir lüksüm yoktu, hala yok. (P4)

117. Bence evin direği anne. Anne çökerse bütün sistem çöker. Annelerin güçlü olması lazım. O çok önemli yani. Salarsın, hani hasta olduğum zamanlar da

oldu. Mesela bir iki kere hastalandım tansiyonum yükseldi, kendim hasta oldum. Baktım ben hasta oldum çocuk hasta oldu. "Ooo" dedim bu iş böyle olmaz, benim hiç hasta olmamam lazım ki o çocuğa bakayım ilgileneyim çünkü başka hiç kimse yok bakıp ilgilenecek … O çocuğun bakıma, ilgiye ihtiyacı var. (P9)

118. Bu süreçte anne-baba, özellikle hastane işlerini yürüten kişi kendini salıverse zaten baş edemez. Hani bildiğini bile unutur. İlk olman gereken şey güçlü olman lazım. Güçlü olamazsan zaten çocuğun tedavisini göremezsin. (P3)

119. Köşede ağladım ağladım sonra geldim çocuğun yanına yine güldüm güldüm eğlendim. Önce içimi döktüm, sonra çocuğun yanına oturdum hiçbir şey olmamış gibi. Çocuğum üzülmesin diye. (P10)

120. Hiçbir şey yapmıyorum, Allah'a dua ediyorum. Bir de ilk kez size anlattım, yabancı olarak. Kimsenin telefonunu açmıyorum. Ağla, dua et o kadar … Kendime ağlamak için sürekli bir bahane arıyorum. Bazen bir şarkı duyuyorum, o şarkıyı döndürüp döndürüp dinliyorum. Ondan sonra bir dini söz buluyorum, sırf ağlamak için kendime, onu tekrar tekrar açıp ağlıyorum. Sanki ağladıkça iyi geliyor gibi geliyor. (P8)

121. Mesela doktorlara bir şey sorduğum zaman korkuyorum kötü bir şey diyecekler mi diye. Sorma cesaretim bile yok artık. Hani duymak istemiyorum. (P7)

122. Babası kendini işe attı. O bir ay kimseyle görüşmedi, kendini eve kapattı. Arkadaşları ile, komşularla görüşmedi. (P10)

123. Benim kızımın okul arkadaşımın babası da doktordur, bölümü farklı. Onunla ben hep istişare yapardım, XY'de [özel bir hastane] görev yapıyor Enver Hocam. Enver Hocama her tahlil çıktığında atardım. Çok şükür çok şükür. Oda kendi onkolog arkadaşlarına gönderirdi vs., "Çok şükür iyi gidiyor Mehmet'im [kendini işaret ederek], iyi gidiyor." derdi. (P1)

124. Tamam bu benim başıma geldi, ama ben bunu nasıl iyi bir şekilde atlatabilirim. Yani ne yapabilirim, biraz daha hafifletebilirim (P9)

125. Bir yere gidiyorum, dışarı çıkıyorum, markete gidiyoruz. Yürü Ceyda [tanı alan çocuk] diyorum, takalım maskeleri, markete gidelim. Gidiyoruz bir dolanıp geliyoruz. Eve kapatmıyoruz kendimizi. Tamam hastaysan hasta olacak zaten, oluyor. Sakınan göze çöp batar hesabı, olacaksa oluyor zaten. Hani hava güzelse, müsaitse hadi gel diyorum bir dolanalım, dolaşalım. Kısa bir yürüyüş hani, o da yorulmasın diye çok uzun bir şey değil. (P9)

126. Hayat kötü, insanlar ilgilenmiyor birbirlerinin dertleriyle. Tamam, tamam diyorlar bu sefer sinir oluyorsun. En iyisi kimseye söylemeyeyim de nasıl olsa yaşıyorum ben onu. Beni anlayacak insan zaten o bana yaklaşıyor, diyor ki ben geldim ne yapayım, ne edeyim, senin için ne yapabilirim. Veya anlat dinliyorum diyor. Yani beni anlayacak insan zaten bana o şekilde yaklaşıyor. (P9)

127. Çok boş şeylere takılıyormuşum. Öyle yaptı, böyle dedi. (P2)

128. Yani insanları ben şöyle, insanların o kadar basit o kadar gereksiz şeyler için üzüldüğünü görüyorum ki! Onları gördüğümde ben, yani eskiden de böyle değildim ben aslında, ben böyle basit şeyler için hiçbir zaman üzülmüş bir insan değilim, hani çözebileceksem çözüyorum, çözülmüyorsa zaten öyle bırakmıyorum. Çok fazla üzülmüyorum öyle basit şeyler için … Ben onlara baktığım zaman dünyayı ne kadar önemsediklerini görüyorum. Aslında hiç önemsememek lazımmış. Sağlık olmadan hiçbir şey olmuyormuş, ben bunu öğrendim. (P5)

129. Çocuklarımla daha az zaman geçiriyordum. Sanki böyle bir hastalık hiç başımıza gelmeyecek, sanki ölmeyecekmişiz gibi. Daha çok "ben" derdim, bencildim. Ben demek bencillik aslında. Ama ben bunu itiraf edebiliyorum. Başka … Çocuklarımın kıymetini daha iyi anladım, onlarsız asla nefes alamayacağımı anladım. Şu an her şeyin üstünde onlar, zaten öyleydi ama farkında değildim. O anlamda iyi oldu, sanki beni biraz silkeledi. (P2)

130. Yani telafi ediyorum mesela, önceden yapmadıklarımı yapıyorum. Keşke önce, daha önce yapmadıklarımı önceden yapsaydım. Mesela çocuğum çok hareketli bir çocuktu, şey yapardı öperdi, sarılırdı, sıkı sıkı ama şu an ben onu yapıyorum ama kendimi biraz suçlu hissediyorum. Sevdiğimi söyleseydim. Sevdiğimi söylerdim ama böyle sık sık değil. Seviyorsun ama içinden seviyorsun çocuğunu düşün, onu dışarıya çıkartamıyorsun. Bizim oralarda bir de şey oluyor yani nasıl diyeyim ayıp, ayıp şeyine oluyor. Hani çocuğunu seviyorsun ama ayıptır bilmesinler, gülerler bana. Keşke öncesinde yapmış olsaydım. Yani çocuğum zaten sevdiğimi biliyor, sürekli onun yanındayım. Biliyor ama ne bileyim kendimi suçluyorum bazen. Keşke şunu yapsaymışım diye düşünüyorum. İnsan gerçekten o keşkeler yaşamasaymış, daha önceden yapmak istediklerini yapsaymış. Ben hani çok pişmanım, çocuğuma sevgimi gösteremedim. (P6)

131. Mesela bir şey olurdu, bir kavga olurdu. Benim çocuğum hareketli olduğu için hep onu suçlardım, kesin sen yapmışsındır derdim. Yani haklıysa da haksızsa da ben öyle derdim, o durmuyordur derdim. Bütün anneler çocuklarını böyle şey yaparlardı, mesela biliyor ki o çocuğu yanlış yapmıştı ama destekliyordu. Ben öyle değildim. Çocuğum hareketliydi mesela onu derdim. Mesela, o yapmıştır derdim. (P6)

132. Çocuklarımı mesela arada şey yapıyordum, büyük kızımı özellikle arada şey yapıyordum, [dayak] atıyordum. Ergenliğe girdi, biraz zorluyordu beni. Bundan sonra böyle bile vurmamayı [koluna yumuşakca dokunarak] şey yaptım, düşünüyorum. İnşallah uygularım. Dünyada en kıymetli, en değerli şey çocuk bir de. En acıtan evlatmış onu anladım. Hiçbir şey bu kadar acı değil. (P8)

133. Olumlu olarak şöyle değişti. Aile olarak biz zaten kopuk bir aile değiliz. Allah razı olsun eşimden, öyle karakterde bir insan değil, öyle bir yapıda bir insan değil. Beni ayakta tutar, her türlü kahrımı çekti, hala çekiyor. Kendi içimizde yani şu olmadı, asla kopma olmadı. Daha çok kenetlendik. Zaten çekirdek bir aile, 5 kişilik bir aile, daha çok kenetlendik. Daha çok üstüne düştük. Yani zaten ben çocuklara düşkün olan bir babayım. (P1)

134. Olumlu, olumsuz çok şey değişti. Hele bu hastalık sürecinde daha çok çok şey değişti … Kendim kendimi daha çok seviyorum ama aile de tabii çok önemli. Ailemi her şeyden çok severim. Ailem, eşim, çocuklarım çok önemli. Gerisi dış kapının dış mandalı, kapıyı kapatınca onlar dışarıda kalıyor. Eş dost, komşu, akraba... Onların hepsi dışarıda kalıyor. Aile çok önemli. Karı koca, çocukların çok önemli. O yüzden, ötekiler teferruat. (P9)

135. Ya benim hayatımda şunu biraz olumlulaştırdı. Mesela daha önce böyle hastalarda biz nasıl bir hastalık olduğunu bilmiyorduk, yani adını biliyorduk ama nasıl bir süreç, nelerden geçiliyor, o hastalar nelerden geçiyor, ne zorluklar çekiyor onu bilmiyorduk. Sadece diyorlardı kan kanseri, beyin kanseri veya akciğer kanseri… Bize sadece bu kadar basit geliyordu. Ama insan bunu birebir yaşayınca bu sefer farklı oluyor yani nasıl bir zorluk olduğunu görüyorsun. O hastanın neler çektiğini tahmin edebiliyorsun artık, biliyorsun. Bilmekle duymak arasında çok fark var. (P3)

136. Çok olumlu yönden değişti çünkü insanın başına gelmeyince hiçbir şeyi anlamıyor ya. Ee duyuyorduk tabii LÖSEV, kan kanseri vs. Bu süreçte Kızılay'a kan verilmesi gerektiğini daha daha farkına vardık. Kan gerekiyor, Kızılay'da kan yok. Bağış yapan yok. Hani bu yönde çevremdekilere biraz dedim ki "Hani başa gelmeyince anlaşılmıyormuş ama Allah aşkına Kızılay'a kan bağışı yapın, çünkü gerçekten çok zor.". Trombosit gerekiyor ama yok, donör gerekiyor, yok, verici yok! (P4)

137. Ya nasıl diyeyim … İnsan her böyle düştüğünde daha çok üstüne basmaya çalışanlar çok oluyor. O yüzden artık alıştım, şaşırmıyorum ben her şeye çünkü bu yediğim ilk kazık değil. İlk kazıklar değil yani, artık alıştım yani. Sen iyiysen hadi yemeğe gidelim, gezmeye gidelim, kafeye gidelim dersen herkes gelir. Bir sürü eşin dostun olur. Ama sen bir düşmeye gör, hiç kimse olmaz etrafında. (P9)

138. İnsan mesela dostunu anlıyor. İyiler kötü çıktı, diğerleri iyi çıktı. Hiç aramayan sormayan kişi aradı, öbürü, her zaman konuştuğumuz aramadı. Çevremizde de karışık şeyler var yani. (P10)

139. Delirsen ne yapacaksın ki? Hadi tamam çok moralin bozuldu, kafan bozuldu, delirdin, hap kullandın, bilmem ne yaptın? Ne yapacaksın? O hapların da çok yan etkisi var. O psikoloji haplarının çok yan etkisi var. Ha deyince bırakamıyorsunuz, bırakılmıyor. Ya benim çocuğuma faydalı olmam lazım, ben iyi olmam lazım! (P9)

140. Telefondan araştırıyorum hastalığı ile ilgili. Bunu karıştırdıkça başka şeyler çıkıyor, daha beynimi yoruyordu ve ben bıraktım. Hani görmeyeceğim, bakmayacağım çünkü hiç geceleri uyuyamıyordum ve çocuğuma bakamıyordum. Sürekli ağlamakla geçerdi günüm. (P6)

141. Öğretmenler eve geliyor. 3 gün geliyorlar eve, pazartesi, salı, cumartesi. 3 gün eve geliyor. Bu senelik dedim Ceyda'ya. Hani seneye gideceksin gene okula dedim. Bu sene enfeksiyon, mikrop kapmasın diye böyle oldu. Yani Ceyda'nıın psikolojisini en iyi ben düzeltirim. Öğretmen ne anlayacak. Ne anlayacak demeyeyim, tabii ki onlar da öğretmen ama hani "Biz de bir ilgilenelim. Var mı desteğe ihtiyacınız?" diye soran olmadı açıkçası. Diyorum ya kimse kimsenin umrunda bile değil, o yüzden ben düzeltirim herkesin psikolojisini. (P9)

142. Okulla ilgili destek sıfır! Bir kere ben okula gittim, müdürle görüşmeye, hani ne olacak eğitimi diye. Neyi var, hangi öğrenci bilmiyor bile. Ben şok oldum. Dedim çocuk 1,5 senedir okula gelmiyor beyefendi dedim müdüre. Hangi öğrenci, kimin velisisiniz, niye gelmiyordu, hastalığı ne bilmiyor. Öğretmenleri de arkadaşlarından duymuş ama hiçbiri de bir arayalım, geçmiş olsun ya da yapabileceğimiz bir şey var mı, hiçbirisi şey yapmadı. (P2)

143. Başka yerler [diğer birimler] böyle değil. Mesela benim çocuğumun geçenlerde kan kontrolü vardı. Ben oraya gittiğimde şey yapmadılar, nasıl diyeyim kendini dev aynasında görürler ya öyle görüyorlar. (P6)

144. Arkadaşlar [hastanedeki diğer ebeveynler] bazen sigara içiyor, yanlarına gidiyorum. Ben hiç hayatımda sigara içmedim, bazen diyorum kör şeytan başla! … Kayserili Mehtap var, bilmem hiç gördünüz mü, o diyor ki "Ben çocuğumun hastalığından sonra başladım." diyor. Sigaraya başlamamak için kendimi zor tutuyorum. (P8)