THE EXPERIENCES OF PARENTS, WHOSE CHILDREN HAVE A DIAGNOSIS OF LEUKEMIA, IN THE TREATMENT PROCESS

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To my lovely family…

My mom, my wingless angel Nurten Güney. She was always by my side. Her prayers gave me power and hope.

My dad, my harbor Ercan Güney. the process would have been much more difficult without his calmness, understanding, and of course his marvelous tea services.

My brother, my hero Emre Güney. He took my thesis defense into account even when he was determining his wedding day.

ABSTRACT

This qualitative study was designed to describe the experiences of parents whose children have leukemia. The participants were recruited from the child hematology units of two private and one state hospitals located in Istanbul through purposive sampling. One parent from each family participated in an in-depth interview. Nine mothers and one father participated in the study. The age range of parents was 28 to 40 years. Seven main themes emerged at the end of the study: (1) Fragmentation of the family, (2) Siblings: “Forgotten children”, (3) Changes in the children, (4) Changes in parenting, (5) Parents’ coping, (6) We are not alone vs Resentment, (7) Outsider view “finding the situation bizarre”. Further studies should try to get the fathers’ experiences in the treatment process, longitudinal and mixed research designs should be formed. Moreover, the foundations should be established to support the siblings of leukemia patients. Lastly, the government should prepare a systemic leukemia treatment program to support the families who have children with leukemia physically, psychologically and socially.

ÖZET

Bu kalitatif çalışma, çocukları lösemi teşhisi almış ebeveynlerin deneyimlerini anlatmak adına tasarlanmıştır. Katılımcılar, amaçlı örnekleme yoluyla İstanbul'da bulunan iki özel ve bir devlet hastanesinin çocuk hematoloji birimlerinden çalışmaya dahil edildi. Her aileden bir ebeveyn ile görüşme gerçekleştirildi. Dokuz anne ve bir baba çalışmaya katıldı. Ebeveynlerin yaş aralığı 28 ile 40 arasındaydı. Çalışmanın sonunda yedi ana tema ortaya çıkmıştır: (1) Ailenin parçalanması, (2) Kardeşler: "Unutulan çocuklar", (3) Çocuklardaki değişiklikler, (4) Ebeveynlikteki değişiklikler, (5) Ebeveynlerin başa çıkması, (6) Yalnız değiliz (–e karşı) Gücenme, (7) Dışarının görüşü "durumu tuhaf bulma". İleri çalışmalar, babaların tedavi sürecindeki deneyimlerini edinmeye çalışmalı, boylamsal ve karma araştırma modelleri oluşturulmalıdır. Ayrıca, lösemi hastalarının kardeşlerini desteklemek için vakıflar kurulmalıdır. Son olarak, hükümet lösemili çocuğu olan aileleri fiziksel, psikolojik ve sosyal olarak desteklemek için sistemik bir lösemi tedavi programı hazırlamalıdır.

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This thesis is not just a project that I had to complete to graduate for me, that was my dream which came from my own illness process. I feel so proud to run after my dreams and made them real. Of course, it is not just my success, I own more than one families and lots of friends. Without their support, it would have been very hard to move on. I never went alone not only in my treatment but also in my thesis period. Thanks a lot to all my fellows who were by my side in my rough road. Thank God, you are in my life. Stay there ☺

First of all, thanks a lot to my family. They put up with my all troubles and my all whims in that process. They gave me the priority for two years and they have organized even very little things by taking my schedule into account. Just as we overcame the illness process, we have struggled with the thesis process together. That was not just my mission, my dad's, mom's, and brother's mission. They have waited for making it completed patiently for a long time. Love them so much, they are my treasure!

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CHAPTER 1

INTRODUCTION

Leukemia is a malignant childhood disorder that occurs in the bone marrow. Blood cells differentiate into leukemia cells and start to proliferate rapidly, leaving no place for the normal blood cells (American Cancer Society, 2016). Leukemia is the most common type of cancer among other childhood cancer (Turkiye Kanser Istatistikleri, 2017) and has two types, which are acute leukemia and chronic leukemia. Acute leukemia is divided into two categories; acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML). Acute leukemia has a sudden onset and rapid progress. Chronic leukemia also has two types, which are chronic myeloid leukemia (CML) and chronic lymphocytic leukemia (CLL). Chronic leukemia has slow progress (Yasam Gucu Motivasyon Kitabi 2, 2016). The common symptoms of leukemia are bone aches, fever, bleeding, bruising, vomiting, headache, enlarged lymph glands and lethargy. For diagnosis, doctors conduct blood tests, peripheral blood smear and bone marrow aspiration (Apak, 2006).

1.1 Prevalence

In the US, the rate of leukemia as a life-threatening childhood illness is 37% and this is the most common type among other childhood diseases (Kazak & Noll, 2015). According to the American Cancer Society’s estimated analysis in 2017, 60,300 children were diagnosed with leukemia of whom 24,370 lost their lives (American Cancer Society, 2018). In Turkey, 0.0015 % of children under the age of 15 are diagnosed with leukemia (Apak, 2006). In 2014, leukemia was the most common cancer diagnosis among children under the age of 14 (Turkiye Kanser Istatistikleri, 2017).

ALL is the most common diagnosis of leukemia. Seventy-five percent of cases receive this diagnosis (Savage, Riordan, & Hughes, 2009). However, the survival rate is high, with

90% of the cases reaching recovery (Wilkes et al., 2016). Apak (2006) states that ALL is especially common in children between the ages of 1 and 4, living in developed countries. AML is somewhat rarer than ALL while CML is the least common leukemia type occurring in childhood. Also, Yöntem and Bayram (2018) indicate that the remission rate of ALL diagnosis reaching 80-90% in Turkey.

Male children tend to receive ALL and AML diagnoses more than female children (Apak, 2006). Investigating gender differences in ALL diagnosis in Brazil, Sousa, Ferreira, Felix, and Lopez (2015) reported that 65.8% of newly diagnosed cases were male. Moreover, the prognosis of the ALL tends to be worse for the males than females due to malignant cells spreading to testicles, causing a relapse (Tekgunduz, Demir, & Akpinar, 2010).

Socioeconomic status is another important factor in leukemia survival. Kent, Sender, Largent, and Culver (2009), investigated leukemia cases between 1996 and 2005 in California and reported that among patients under the age of 14, children who are non-Hispanic white, insured and with higher SES are more likely to survive. Furthermore, based on a meta-analysis of 29 studies conducted in the US, children with low SES are two times more likely to die from ALL (Petridou et al., 2014).

In another study in Iran, researchers examined 100 incidents of ALL between the ages of 1 and 14 and compared them to a matched control group to understand the possible impact of SES in childhood leukemia. They found that the risk of ALL was related to paternal smoking and the father having a high-risk job, such as a painter or farmer. The researchers hypothesized that these occupations can cause chemical exposure and concluded that SES was not a risk factor for ALL diagnosis (Hashemizadeh, Boroumand, Noori, & Darabian, 2013). Syse, Larsen, and Tretli (2011) studied childhood leukemia cases in Norway between 1990 and 2002, looking specifically at the parents of children under the age of 20 at the time of the diagnosis. They reported no correlation between parents’ employment and the likelihood of children receiving a diagnosis, although the children’s diagnoses had a slight impact on parental earnings. Specifically, mothers’ earnings were affected more than fathers’. The authors speculated that mothers might be leaving the workforce to care for their children with leukemia.

1.2 Treatment

The key treatment for leukemia is chemotherapy (American Cancer Society, n.d.). Chemotherapy is a treatment applied to destroy and/or prevent the growth of malignant cells (Yaşam Gücü Motivasyon Kitabı 2, 2016). In addition to chemotherapy, stem cell transplant and radiation therapy can be applied (Keene, 2010).

There are three main phases in the treatment of leukemia, which are “induction of remission, consolidation, and maintenance” (Savage et al., 2009, p. 36). The first phase, in which the goal is to reach complete remission, usually lasts four weeks. Patients receive chemotherapy during this phase and may stay in or out of the hospital. If patients reach the remission stage within the first two weeks of treatment, their long-term survival rates tend to be higher than patients who do not reach that stage within 30 days and patients who respond to chemotherapy slowly. The second phase is consolidation, aimed at eliminating and preventing the growth of any remaining malignant cells. During this phase, patients continue to receive chemotherapy. In the maintenance phase, the intense treatment process ends and patients continue to receive drugs orally. This phase lasts two years for females but three years for males because of the possibility of testicular relapses (Keene, 2010).

For ALL, treatment protocols last a minimum of at least 2-3 years, during which time patients receive chemotherapy, intrathecal chemotherapy, and cranial radiation. Intrathecal chemotherapy requires the chemo to be sent directly to the brain through the spinal cord. This treatment is administrated regularly during the treatment process. Cranial radiation (CRT) is applied to treat malignant cells in the central nervous system (CNS) (About Kids Health, n.d.). In relapse cases, bone marrow transplantation is offered to the patients and their families (Savage et al., 2009).

Blood cells are normally produced in the bone marrow. However, the bone marrow of patients with leukemia cannot produce healthy blood cells so if the chemotherapy does not work or the relapses occur after chemotherapy treatment, bone marrow transplantation is offered. For transplantation, a person whose tissue type matches the patient's is found. The patient's bone marrow is then evacuated fully or partially. Finally, stem cells taken from the suitable donor are transplanted to the patient's bone marrow to proliferate as healthy blood cells (Yaşam Gücü Motivasyon Kitabı, 2016).

1.3 Systems Theory

Systems theory states that different parts of the system come together to make it work effectively (Von Bertalanffy, 1972). If one part of the system gets damaged, the other parts are affected because all are interrelated and interdependent. To illustrate, bone cells come together and form bone tissue, bone tissues come together and form bones that have different positions in the body, and these bones come together to form the skeletal system. Moreover, all the related parts share the same aim, which is keeping the body system intact and creating homeostasis. At times, systems may experience some problems, but they have a tendency to try to heal themselves and regain stability (Dallos & Draper, 2015). For stability, systems may create two types of feedback: negative and positive. Negative feedback prevents change whereas positive feedback promotes it (Rabkin, 1981).

Like the human body, the whole is also greater than the sum of its parts in families, with family members being interdependent. Therefore, if one of them changes, the other members are also affected by that change. While the family system is dynamic and open to changes, if changes occur in family members, the system tries to reestablish hemostasis through negative or positive feedback loops (Lehman, 2005).

For the management of the family system and its relationships, family members create family rules and family structures. Rules, which can be both overt and covert, define what is acceptable in the family. The family structure consists of boundaries, subsystems, and hierarchy. Boundaries define the line and rules of communication (Colapinto, 2016). These might be clear, diffuse or rigid. Clear boundaries allow people to build healthy relationships with each other. Diffuse boundaries result in relational enmeshment whereas rigid boundaries initiate relational disengagement (Gehart, 2016). There are different kinds of subsystems, such as the parental subsystem and sibling subsystem, which may have different boundaries. For example, there may be enmeshed boundaries between parents and children but rigid boundaries between husband and wife within the same family (Colapinto, 2016).

Hierarchy is also an important element of the family structure and defined as the decision-making power among family members (Colapinto, 2016). Parents are usually at the top of the family hierarchy. There are three types of parental hierarchy. In the effective hierarchy, parents establish various limits and boundaries while maintaining their emotional contacts with the children. In the insufficient hierarchy, parents cannot manage their children’s behaviors. In the excessive hierarchy, parents impose unrealistic limits and set rigid boundaries with their children (Gehart, 2014).

Eventually, all these components of the family structure impact on family dynamics, which derive from systems theory. Also, these dynamics can be examined through a biopsychosocial approach. That is, each family member’s behaviors influence the other family members so getting know to these effects is crucial in order to provide a deeper understanding of the issue (Basak, 1997).

1.4 Biopsychosocial Spiritual Approach

In light of systemic theory, George Engel (1977) proposed the biopsychosocial approach as an alternative to the biomedical approach, which he criticized for creating a mind-body dualism. Engel also proposed that understanding the illness experience cannot only be based on objectively-measured variables. For instance, chest pain may derive from a lack of caring by professionals besides any medical problem in the body. In addition, Engel argued that the observer himself/herself impacts on the observed phenomenon so purely objective observations are impossible. Finally, he claimed that dividing the system into small pieces was reductionist; instead, he suggested that a holistic understanding of the system would be more valuable despite being more complex (Borrell-Carrió, Suchman, & Epstein, 2004).

In the biopsychosocial approach, the underlying assumption is that mental and physical health are interconnected. The approach, therefore, conceptualizes illness in four dimensions: biomedical, psychological, social/environmental and spiritual. The biomedical dimension consists of the illness' symptoms, diagnosis, and treatment. The psychological dimension includes the emotions, perceptions, thoughts, and behaviors created by illness. The environmental/social dimension consists of the impact of illness on people's relationships with families and friends. The spiritual dimension includes how people make sense of the illness spiritually. For example, after going through an illness, a patient's relationship with God may change – becoming more religious due to fear or seeing the illness as a message from God (Bruner, Davey, & Waite, 2011). Based on systems theory and the biopsychosocial approach, when one member of the family has an illness, siblings, parents, family relationships, roles and dynamics are all inevitably impacted.

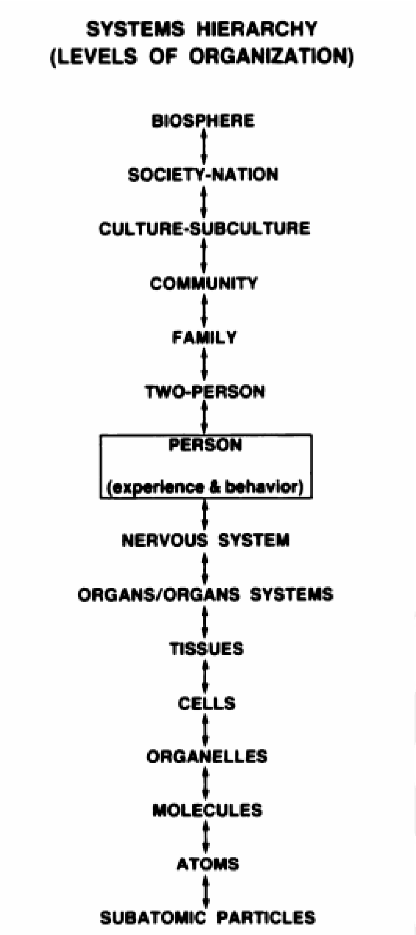

Figure 1.1. “Engel’s Systems Hierarchy" (Engel, 1980, p.537)

Figure 1.1 indicates how systems work interdependently so that one specific event at the subatomic level could influence even the biosphere because the stages are all interrelated and interdependent.

All in all, it is an undeniable fact that leukemia affects family dynamics due to both being the most common type of childhood cancer and the length of treatment. Therefore, it is very valuable to learn about the experiences of parents in the treatment process. In Turkey, as for other countries, few studies exist regarding the experience during the treatment process of parents whose children have leukemia so my study will address changed family functioning after the diagnosis period. Moreover, the parents’ relationships with professionals and the impact of this on the treatment process have also not been explored enough so my study will try to uncover deeper meaning about these issues. The results of the study will be planned to support an interdisciplinary process in cancer treatment. Through this research the needs of the families in the process will be better understood, the target points of mental health support will be developed.

In this study, the literature regarding the impacts of cancer on the family dynamics and the families' coping mechanisms will be discussed. Then, the study findings will be presented and discussed by taking the current literature and systems theory, and biopsychosocial spiritual approach into account. Lastly, clinical implication, limitations, and recommendations for further studies will take place.

CHAPTER 2

LITERATURE REVIEW

This chapter presents the literature discussing firstly, the impact of having a child with cancer especially leukemia on family dynamics. Under this topic, parents' roles and relationships and the impact of the process on the siblings are investigated. Secondly, the research studies regarding families' coping mechanisms take place and Turkish culture aspects are discussed accordingly.

2.1 Impact on family dynamics

Sickness has an impact on family dynamics. Rolland (2012) states that there is a mutual relationship between the sickness, the person who has a sickness and the family system. In this regard, leukemia as a serious illness matters the whole family members too and influences on family functioning. This part consists of the studies to explain how family dynamics are impacted by the cancer treatment process. Parental experiences, changes of family functioning and perception of the quality of life (QOL) are indicated in this section.

There are some studies that have been conducted with parents that investigate the impacts of cancer on families' quality of lives in the literature. In the UK, Eiser, Eiser, and Stride (2005) conducted a study to understand the impact of cancer on children's and their mothers' quality of life. Eighty-seven children (58 boys and 29 girls) and their mothers participated in the study. Fifty-seven children had ALL diagnosis. The mean age of the children was 7 years. The mothers filled out the QOL questionnaire on behalf of their children and themselves. There was a significant correlation between the children's and their mothers' QOL ratings. There was also a negative correlation between the level of mothers' worries and their children's physical, social and emotional functioning. Likewise, the relationships between QOL, family rituals, and adjustment were indicated in some studies (Santos, Crespo, Canavarro, Alderfer, & Kazak, 2015, 2016). The studies took place in Portuguese public hospitals. In the first study, 389 Portuguese children who were on treatment aged 8 and 20, of whom 141 had leukemia diagnoses, and their parents participated in the study. Both the children and their parents filled out the Family Rituals Questionnaire (FRQ), family cohesion subscale of the Family Environment Scale, the Adult Hope Scale (AHS), EUROHIS QOL and the Intensity of Treatment Rating Scale. In the second study, 244 Portuguese mothers whose children under the age of 21 had cancer diagnosis (100 cases with leukemia) and who were either in on- or off-treatment phases participated in the study. Mothers' adjustment, family rituals, and financial difficulties were measured using the Impact on Family Scale (IOS), the Family Rituals Questionnaire (FRQ) and the Hospital Anxiety and Depression scale (HADS). The researchers concluded that engaging in family rituals such as annual celebrations led to a better QOL, and lower anxiety and depressive symptoms.

Only one qualitative study from the US indicated the impact of leukemia on children's physical, psychological, social and spiritual well-being (Hicks, Bartholomew, Ward-Smith, & Hutto, 2003). Thirteen children (10 boys and 3 girls) with a mean age of 8.2 who had received an ALL diagnosis participated in the study. The time since diagnosis ranged from 8 months to 4 years. According to the children, leukemia and its treatment procedures made them exhausted, the medical procedures were very tough, and their activities and relationships were affected. Some children indicated that because of their 'port' (the medical equipment that delivered the intravenous drugs), their physical actions were limited. Having a child with leukemia impacted their family lives as well since extended family members took care of them so that their fathers and mothers could keep their jobs. They also reported that physical changes such as loss of hair impacted their relationships with their peers, and they were sometimes stared at.

Hearing the fathers' voices in this journey is very important because there is not enough study to examine the experience of fathers of the children with leukemia. Hill, Higgins, Dempster, and Mccarthy (2009) conducted a study with fathers of children who completed the treatment within the previous two and a half years and the children in the remission process. The study was a qualitative study and interview technique was used in order to learn the fathers' experience. Totally five fathers took part in that research and their ages were between 31-42. The researcher used interpretative phenomenological analysis to find out the main themes of the fathers' stories. The results showed that the process was hard for the fathers at the beginning because they tried to understand what did they face with and what would wait for them? Later on, they tried to take an active role in the process and considered what their reality was and what they could do. Many participants indicated that the mothers' role in the treatment process was more central. Because of this reality sometimes they felt resentful in that process. Moreover, the fathers reported that they would like to construct their proper life by leaving the illness behind and they preferred hiding their emotions because of their gender roles in the society. Two years later another qualitative study from the US found a different result regarding the cultural views of fathers' caregiving compared to a previous study (Wolff, Pak, Meeske, Worden, & Katz, 2011). In this research study, 15 fathers whose children had a terminal illness participated in the study and their ages between 32-56 (four of them the fathers of children with leukemia). In order to be a participant of that study the condition of getting the diagnose 6 months before starting the interview process was presented. According to one of the main theme of the study; because of the cultural norms or personal characteristics, the fathers became primary caregivers in their children' treatment process. Even the mothers realized that their children had more fun when they were together with their fathers. Being a caregiver meant being reputable for the fathers who came from minority groups, so it was an important reinforcement for the fathers.

According to Van Schoors, De Mol, Morren, Verhofstadt, Goubert, and Van Parys (2018), after the childhood diagnosis, there were some changes in the family functioning. The authors conducted a qualitative study in Belgium. Ten couples (six of them the parents of children with leukemia) participated in the study and the age range of parents was 37 to 56 years. Children have been diagnosed for 6-33 months. At the end of the study, the authors concluded the "Family Cohesion; Strengthened vs Fragmented" theme which meant that after the getting diagnosis, the families could be closer in order to cope with the disease, but they could also separate each other. The children with diagnosis became the main focus in the whole family. The primary caregiver started to spend more time with these children at the hospital setting, so parental roles started to come to first instead of marital roles. The family spent less time together and the siblings could be forgotten in this process and the grandparents took their responsibilities. In this regard, a quantitative study from Italy concluded that the mothers' ideal family functioning was enmeshment. The aim of this study was exploring the family functioning in pediatric oncology on the treatment process, thirty-four mothers whose children with acute lymphoblastic leukemia (ALL) participated in the study and their mean age was 35 years (Perricone, Polizzi, Morales, Marino, & Scacco, 2012).

Moreover, Van Schoors, Caes, Knoble, Goubert, Verhofstadt, and Alderfer (2017) conducted a meta-analysis which included 30 studies, most of them were cross-sectional studies and others were longitudinal (most frequent cancer diagnosis were leukemia, lymphoma, and brain tumors) showed that better family functioning, greater family support, cohesion, expressiveness, and less family conflict were found as signs of better child adjustment (for both diagnosed children and their healthy siblings).

Interestingly, only one qualitative research study investigated the difficulties of mothers in the treatment process (Elcigil & Conk, 2010). The study included qualitative interviews with 23 mothers of children diagnosed with cancer, fourteen of whom had leukemia diagnosis. The aim was to understand the burden of the mothers as they care for their children. The findings yielded four dominant themes: social, emotional, economic and physical burdens. Regarding the physical burden, mothers reported dealing with the negative impacts of the treatment while trying to handle their own physical problems, such as headaches and backaches. The family members' emotions and behaviors also changed, which created an emotional burden. Parents were nervous, sensitive and angry, both with each other and about the hardships of the illness. Furthermore, their children became more agitated after they received the diagnosis. Moreover, according to the mothers' responses, both their own and fathers' attitudes towards all of their children, both healthy and with cancer, changed drastically. They started to give in to the children's demands, saying "yes" to things that they had restricted before. Regarding the social burden, the mothers' social lives changed after the diagnosis in that they reported getting support from their neighbors, although they did not see their friends as often as before. Lastly, these mothers indicated that after the diagnosis, they started to face economic difficulties. For example, they started to spend more money on transportation or other essential needs.

As well as how the difficulties are experienced, how the information obtained is transferred to the children is also essential in this process. Clarke, Davies, Jenny, Glaser, and Eiser (2005) conducted qualitative interviews with 55 parents whose children had been diagnosed with leukemia to highlight the importance of the issue. The time since children had received the diagnosis approximately 4 months because the researchers thought that this was a suitable time period for the interviews since the parents' initial distress and shock may have ameliorated. The findings yielded multiple dominant themes. According to them, the parents used optimistic, realistic, pessimistic and factual information given to the children together with minimal information, ambiguous information, factual information or full information as communication styles. Furthermore, the parents had different perceptions of the illness. In particular, many parents lacked knowledge about the disease so they thought that most cases resulted in death. Consequently, they preferred not to share what they knew about the illness with their children.

With the aim of exploring the initial parental experience after diagnosis, Kars, Duijnstee, Pool, Van Delden, and Grypdonck (2008) interviewed 12 mothers and 11 fathers of 12 children in the Netherlands, aged from 2 to 12 years, using a grounded theory methodology. All the children had developed leukemia within the past year while the time since diagnosis ranged from 10 days to 12 months. The main theme identified from the interviews was “being there”, which meant that the parents were there for their children whatever they faced and went through. This fulfilled the parents’ needs as well since they could care for their children and feel like parents themselves. There were two purposes of “being there”: protection and preservation. During protection, parents behaved like guards to protect their children from negative impacts. During preservation, parents influenced the perceptions of their children’s lives so that they could handle difficulties in a good way. On the other hand, “being there” included some negative components as well. It was very demanding, and energy and time-consuming. It was also risky for parents not to separate themselves from their child’s experience and needs later on. The similar trend was seen in the research study in Russia by Afanasyev and Fedorenko (2016). Twenty-five mothers whose children were preschoolers (5-6 ages) participated in the study. The study used “the analysis of family relationships” questionnaire, PARI (parental attitude research instrument) and a projective technique to indicate the personal and emotional relationships of the child with other people. According to results, the main parenting style found was hyper protection: the mothers tried to build optimal emotional contact with their children. However, due to the child’s special health conditions, the mothers could sometimes exaggerate their reactions and behaviors towards their child. Moreover, the study revealed the need for both the mother and father as a couple, which could be due to seeing them separately, according to the researchers. The children spent most of the time with their mother while their fathers were at work, and they mostly stayed with their mothers during the hospitalization period.

After getting the perspectives of the parents, Erker, Yan, Zhang, Bingen, Flynn, and Panepinto (2018) explored the family relationships in the lenses of children with cancer and their healthy siblings. The researchers conducted a cross-sectional quantitative study in the US. Two-hundred and sixty-five children participated in the study and the age range of the children with cancer and their siblings were between 8-17 years. There were four cohorts; the children with cancer who were receiving treatment (cohort 1), the children with cancer who completed the treatment process (cohort 2), cohort 3 and cohort 4 involved siblings of children with cancer in cohort 1 and cohort 2. The children filled out PROMIS Pediatric Family Relationships short form, the Depressive Symptoms, Anxiety, and Peer Relationships short forms. In addition to these forms, the Mann-Whitney test, the Wilcoxon signed-rank test, and the actor-partner interdependence model (APIM) were used in this study. The results showed that the family relationships of the healthy siblings were worse than their diagnosed siblings on the treatment process. However, there was no difference between them off the treatment process.

Siblings are also a part of the family system so it is inevitable that they are affected by the process. Van Dongen-Melman, De Groot, Hählen, and Verhulst (1995) call the siblings of children with childhood cancer as “forgotten children”. They may feel isolated from the family system or not receive enough support from their already overburdened parents. Their study was conducted in the Netherlands with a sample including 60 siblings of children with cancer. Fifty out of 60 participants had siblings with leukemia. The participants’ ages ranged between 4 and 16. The control group had 300 children with healthy siblings. Participants were interviewed in their homes and shared their experiences about their sibling’s illnesses. At the same time, their mothers completed the following questionnaires: The Child Behavior Checklist (CBCL), the Self-perception Profile for Children (SPPC), the Amsterdam Biographic Questionnaire for Children (ABV-K) and the Children's Depression Scale (CDS). The interviews with the siblings revealed that siblings pay attention to their relationships with their parents and their positions in the family if there is a persistent concern in their lives. There were no significant differences between the psychological functioning of the two study groups based on the mothers' reports. The questionnaire responses indicated that, during the treatment phase, the siblings had more adjustment problems than the other family members, although these negative impacts were reversed once the treatment process ended, enabling the adjustment problems in the siblings' lives to decrease.

Buchbinder et al. (2011) found consistent results with the previous research study. The authors concluded that there was a positive correlation between survivor global psychological distress and sibling global psychological distress. In addition, sibling depression was associated with the survivor sibling's health impairment and depression. This study was conducted to identify the factors that make siblings psychologically more vulnerable by assessing the psychological symptoms of 3,083 adult siblings of cancer survivors (for at least five years) in North America, of whom 980 were leukemia survivors. The participants' ages ranged between 18 and 56. Psychological distress was the dependent variable while sociodemographic, health and cancer-related variables were the independent variables. Both the siblings and their matched cancer survivors filled out the Brief Symptom Inventory.

Researchers also examined the impact of children's leukemia on parents' roles and relationships. In the US, Kelly and Ganong (2011) conducted qualitative interviews with 13 parents whose children had cancer, including seven with ALL. The common issue for the parents was being separated from their child's biological mothers or fathers. The authors identified four main themes. First, after the child’s diagnosis, co-parental contact increased. The biological parents of the child involved themselves in the treatment process and decisions were made together. They refreshed their roles so that they were together for their child’s caring rather than romantically. Secondly, alongside the process, the biological family boundary was reinforced so the stepfamily boundary started to change. The biological parents spent a lot of time together for their child’s caring, which meant they could approach emotionally, although that could be irritating for the stepparents because of jealousy. The stepparents even started to feel excluded from the family as they also wanted to care for the child. However, when the biological parents showed up, they questioned their own roles. Thirdly, as a result of reinforced biological family boundaries, the biological parents who were re-partnered felt like they were pulled from both sides, and exhausted because of trying to meet the needs of both their ill child and their new partner. The stepparents were also exhausted as they tried to maintain support for both the ill child and their partner as well as maintaining contact with their own biological children. Fourthly, after the crisis of the diagnosis passed, both the biological and stepfamily boundaries began to normalize. Moreover, some biological and stepparent relationships were strengthened by the experience of this tough process.

Even if there is no stepparent relationship in the family, the marriage is impacted on this tough process inevitably. Researchers in Brazil interviewed nine married couples who had children undergoing cancer treatment for at least six months. One of the children was a leukemia patient. The partners reported that they had gone through many changes in their lives since the diagnosis and that they needed to focus on the present so they could not make any long-term plans. They felt together as a family but distant as a couple. After the mothers informed the fathers that they were overwhelmed due to long hospitalization period, the fathers started to share responsibilities and take care of the children. The couples also demonstrated that they were continuously adopting the parental role so that the ill child even started to sleep in the parents' bedroom after the disease so that they could monitor the child easily. As a result, they had difficulties with their sex lives. Likewise, the result of previous study, parents reported that they felt close and supported each other in order to deal with the negative effects of the illness despite these negative impacts of the illness and all partners hoped that as the treatment worked and their children got better, their marital relationships would improve (Silva-Rodrigues, Pan, Sposito, de Andrade Alvarenga, & Nascimento, 2016).

Besides the qualitative studies, Burns et al. (2017) conducted a quantitative study in Canada to investigate the marital adjustment of the parents who cared for their children with cancer. Forty-seven couples whose children with acute lymphoblastic leukemia (ALL) took part in the study. The mean age of the mothers' age at diagnosis was 34.23, and the mean age of the fathers' age at diagnosis was 36.95. The study was a longitudinal study so that the participants completed the assessments right after the diagnosis and 2 years after the diagnosis. The Locke –Wallace Marital Adjustment Test, The Family Well-Being Assessment, and Profile of Mood States-Bipolar Form were used as the measurement tools. At the end of the study, the authors reached out these results; greater marital adjustment was associated with the involved in less role conflict with their husbands and less role overload feeling in the process and more family support perception for the mothers. On the other hand, less marital conflict perception and the wives' perceptions of less role conflict were associated with the greater marital adjustment for the fathers. Interestingly, the researchers found that greater role ambiguity and feeling more tired were related to the greater marital adjustment too because these were the signs of fathers' efforts to taking responsibilities in this tough process.

In conclusion, as the systems theory asserted when one part of the system is damaged, the other parts also influence inevitably (Dallos & Draper, 2015). Many research studies showed that the children's cancer diagnosis impact on the whole family systems. Marital relationships, sibling relationships, roles, and responsibilities change accordingly. To illustrate, the parental relationships rather than marital relationships start to come first, the main focus becomes the children with cancer, so the healthy siblings start to be forgotten. Also, the fathers and the extended family members start to take the responsibilities of the healthy siblings.

2.2 Coping Mechanisms and Turkish Culture Aspects

While the leukemia is a long and tough process and impacts on the family dynamics, how the families cope with the difficulties of the treatment process? Investigating the coping is important at that point because together with these coping mechanism the parents can proceed with the treatment process. Also, Turkish culture consists of both autonomy and relatedness elements (Kağıtçıbaşı, 2005), so these aspects of the Turkish culture might impact on the families' coping and support mechanisms as well. This part consists of the studies to explain how parents and children cope with the struggles of the treatment process. In addition to coping mechanisms, spirituality, support mechanisms, the impacts of the Turkish culture on the illness, and causal attributions to the illness are also explored.

Many studies have investigated the factors affecting parental coping as they raise their children with cancer. When the look at quantitative research study trends, Goldbeck (2001) conducted a quantitative study in Germany comparing the parental coping strategies of parents whose children have cancer with those whose children have diabetes or epilepsy. The cancer group had 25 families, the mean ages of the mothers and fathers were 34 and 35.5 years respectively. The comparison group had 29 families. The Coping Health Inventory for Parents (CHIP), the Trier Coping Scales (TCS), and the Ulm Quality of Life Inventory for Parents of a Chronically Ill Child (ULQIE) were used. The researchers conducted the assessments first at 1-2 weeks after diagnosis and then 10-12 weeks after diagnosis. The researchers reported that families whose child had a cancer diagnosis adopted more defense (optimism or minimization) and rumination coping strategies (musing, backward-directed, withdrawing) than the control group. These families also used more information-seeking strategies than the control group. Moreover, there were gender differences in the coping strategies used: compared to the fathers, the mothers used more support, information-seeking and religious coping strategies, maintaining optimism and family integrity, protecting their own personal stability and understanding medical issues. Interestingly, in Sweden, the quantitative study of Norberg, Lindblad, and Boman (2005) which included 395 parents, 224 mothers and 171 fathers (174 of the parents had children with leukemia) found that in terms of coping strategies, there were no significant differences between the parents had children with leukemia and parents of children without any chronic or serious illness. In this study, coping strategies were assessed with the Utrecht Coping List Based on the parents' reports, the children's QOL scores were lower in the cancer group than the control group. According to another quantitative study from Greece reported that based on the assessment of 41 mothers and 30 fathers whose children had leukemia, family integration as a coping strategy was more helpful than healthcare communication and social support, stability, and self-esteem (Patistea, 2005).

In the perspectives of qualitative research studies regarding parental coping, Johns et al. (2009) carried out a qualitative study in the US to explore the role of culture in terms of the coping strategies of Latina and European mothers who have children with cancer. Three Latina and 3 European American mothers of children who got the cancer diagnosis recently participated in the study. The mothers' mean age was 39.8 years. These mothers took the problem-solving intervention by the mental health providers for 6 to 8 sessions in 4 to 5 months and their first, third, fifth, and final session were used. The aim of the study to compare and contrast the coping themes of Latina and European American mothers. In terms of coping behaviors, both Latina and European American mothers preferred getting information about their children' diagnosis and treatment process. Latina mothers also relied on the experience of other families of children with cancer compared to European American mothers. Also, European American mothers reported that they got information from the Web pages. Both mothers stated that they attempted to seek professional help regarding the hospital and school-based related things of both the diagnosed children and their siblings. Lastly, both mothers indicated that they applied lots of coping activities in this process such as taking walks, watching TV, crying, eating snacks, etc. In terms of cognitive coping strategies, both mothers used some problem-solving strategies (e.g. brainstorming, evaluating the results, etc.). Again both groups talked about the role of optimism and tried to live here and now in this process. Also, the mothers reported that they tried to notice the positive sides of the process to deal with the struggles. Both mothers preferred not thinking about their children' diagnosis and they wanted to run away from the difficulties in this process. Moreover, mothers in both groups indicated to get support from their spiritual beliefs. European American mothers reported that they preferred compromising with health professionals. Latina mothers, not the European American mothers stated that they tried to take medical staff' perspectives in this tough process. Again the just Latina mothers discussed the normalization as a coping mechanism.

In connection with this previous research study result regarding the normalization, Earle, Clarke, Eiser, and Sheppard (2006) conducted a qualitative longitudinal study in the UK to explore how the mothers who have children with acute lymphoblastic leukemia (ALL) built their normality in this tough process. These mothers (n = 32) were interviewed at 3 time periods (3-4 months, 15 months, and 27 months). Based on the results of the study, the authors concluded that in the first phase of the study, the mothers were more optimistic by getting advice from the health professionals about continuing their normal lives. However, they knew that their daily lives would impact on this process. Also, the mothers were questioned about their children' behaviors and personalities during the treatment. The mothers reported that they started to behave differently to their children and they tried to adapt their new normality by accepting the illness' struggles. At the second phase, these mothers were a little bit disappointed because the normal life did not continue automatically as the health professionals said. However, they reported that without their treatment process at hospitals, they started to live their normal lives. At this period, the children strived for their normality, basically, they wanted to play with their friends. However, their mothers tried to protect their children from possible infections and injuries. At the last phase, the mothers started to behave their children like before the diagnosis process, the barriers in their lives started to remove, the children started to continue their school lives and the families started to go on a holiday together with their children with ALL. The mothers reported that they continued to use their normal discipline style. Moreover, the mothers considered that the tough process made their children mature and stronger.

Besides parental coping mechanism in general, the parents prefer using support mechanisms, and causal attributions to the illness as coping strategies as well. Two research studies come from two different continents to explore this topic. The first study which was mixed design was conducted in Ankara, Turkey by Esenay, Sezer, and Turan (2018) to investigate causal perceptions of the parents whose children with cancer. Two hundred twenty-nine parents participated in the study (one hundred and three of them the parents of the children with leukemia). The parents completed Introductory Information Form and Causal Representations Subscale of the Illness Perception Questionnaire. After that, they were asked some 3 most important causes regarding their children' illness. The result showed that 43.9% of the participants thought that the disease was associated with the faith, the evil eye, and the will of God. 20% of them considered that stress, worry, and sorrow played a role in that process. 12.6% of the parents reported that nutrition could impact on their children' disease. The second study was conducted by McGrath (2001) in Australia. The study was a longitudinal, qualitative together with a phenomenological methodology. The researcher investigated the support matters of the parents whose children with leukemia. Twelve parents of children with acute lymphoblastic leukemia (ALL) participated in the study (12 mothers and 4 fathers) and their age range was 28 to 44 years. The participants reported that the support was essential, but it started to weaken over time. It could result in the parent's choice because they started to feel unfair towards their acquaintance. Moreover, the parents stated some sort of support that you had in the process. These were partner support, family support, friend support, support from the parents in the same situation, hospital staff support, the support of children' friends, and community support. Generally, the parents got the emotional (e.g. empathic responding, being there for them, etc.) and practical supports (e.g. vacuuming, taking the healthy siblings' responsibilities, etc.) from their partners, families, friends, etc. On the other hand, the results showed that parents felt the lack of community support even they were not aware of this type of support that you have a right to get.

After talking about the support mechanism of the families and causal attributions to the illness, getting knowledge regarding Turkish culture is important to understand its influences on the illness. According to Ataca, Kağıtçıbaşı, and Diri (2005), Turkish families were close to the relatives and responsible for each other. In this regard, they felt relatedness. Basically, there was a hierarchy in the Turkish family, so the adults made the decisions rather than the children. Also, males were the authority figure, women's status in the family was lower than the males. Moreover, they showed the changed reasons for having children throughout the generations. Based on the findings, the parents wanted to have children for their psychological needs like to love and to be loved rather than to get economic contributions from their children. In another study, the authors indicated the traditional gender roles for the women in Turkish families such as childrearing, being responsible for household tasks, etc. Also, the importance of motherhood and breastfeeding for the Turkish culture were underlined (Özkan, Özkan, & Armay, 2011). Later on, another research study in Turkey discussed the concept of motherhood. Kulakac, Buldukoglu, Yılmaz, and Alkan (2006) conducted a phenomenological study with 10 midwives and 10 teachers. The researchers concluded that the mothers underlined both satisfactory and difficult sides of the motherhood. According to the mothers, the motherhood was “beautiful and hard to explain”, “full of rewards”, “the most difficult job”, and they stressed the “strain in the motherhood role”. In addition to parental coping strategies, children also use some coping mechanisms to deal with the struggles of the illness. Han, Liu, and Xiao (2017) carried out a qualitative study to investigate the coping mechanisms of children with leukemia in China. Twenty-nine Chinese children participated in the study and their age range was 7 to 14 years. The semi-structured interview was conducted. The results showed that during the hospitalization process, the children started to use both problem-focused (e.g. seeking information and problem solving) and emotion-focused (e.g. seeking emotional support, self-control, and venting emotions) strategies to cope with the difficulties of the disease. Moreover, the children provided their preferred coping strategies by themselves, professionals, and their parents. On the other hand, the meta-analysis by Aldridge and Roesch (2006) stated that there was a negative association between problem-focused coping and adjustments. This study included totally 26 studies together with 1230 children and their mean age was 10 years. Moreover, the researchers concluded that time was an important variable to measure the children’ adjustment, so if the children preferred using problem-focused strategies and they are at the beginning of the treatment process, these strategies work well, but if the time of the diagnosis increases, the children who use problem-focused coping mechanisms have poor adjustment. For emotion-focused coping mechanisms, the opposite impact was found compared to problem-focused strategies. Children could prefer using avoidant coping strategies because these reduce ongoing tension because using problem-focused strategies during the treatment phase makes the children’s adjustment decline.

Many research studies highlight the importance of spirituality as a preferable coping method. When the look at the qualitative studies in the US, Albaugh (2003) designed a study to explore the role of spirituality for the people who have a life-threatening illness. Seven people (2 men and 5 women) participated in the study and their age range was 44 to 74 years. These people had the diagnosis of breast cancer (2), colorectal cancer (1), prostate cancer (1), pulmonary fibrosis (1), and myocardial infarction (3). At the end of the study, the researchers indicated that the spiritual beliefs gave the participants comfort and they started to think of not being alone. According to these people, there should have been a meaning around the disease, so they were more willing to accept the results of the situations. Also, the participants considered that spiritual beliefs made you strong to cope with the illness. For these people the illness was a sign of being blessed by God, so they talked about their lives positively in general. Lastly, the participants indicated that the illness facilitated them to make your own meanings of life even it could be a wake-up call. Hexem, Mollen, Carroll, Lanctot, and Feudtner (2011) explored the beliefs of parents who have children getting palliative care about religion, spirituality, and life philosophy (RSLP). Seventy-three parents of 50 children participated in the study. Twenty-two parents’ age range was 21 to 34, 17 parents’ age range was 35 to 38, and 23 parents’ age range was 39 to 66. The researchers also found consistent results with the previous study’s. Based on the research outcomes, some participants reported general statements about the situations (e.g. that’s just life), some of them stated that they tried to find good things from their current situation, some participants talked about the human capacity to suffer, some others believed that “everything happens for a reason”. Moreover, the parents considered that spirituality, religion, and life philosophy facilitate the parents to stress their children's specialness and the role of their existence in this world. Also, the parents' spiritual beliefs helped the parents to think about the afterlife as a peaceful place. Some parents stated that religion and spirituality gave them positive outcomes to that they felt being supported (e.g. praying for their children), they have a sense of peace to trust God. Besides the positive outcomes of RSLP, some parents reported that during this experience, they were questioned about their faith, they felt anger so that God gave the disease to their children, even some of them preferred rejecting their faith after their children had the diagnosis. This result supported by other research studies (Schneider and Mannell, 2006 & Nicholas et al., 2017). These studies indicated that parents started not to get benefit from the spiritual beliefs or practices and they were questioned about their faith and they were far away from their spiritual practices.

There are also some qualitative studies in Canada regarding spirituality. Schneider and Mannell (2006) designed a phenomenological study to explore the place of spirituality for the parents of children with cancer. Twelve parents participated in the study (4 fathers and 8 mothers). The women' age range was 28 to 46 and the men' age range was 42 to 47. According to the results, almost all parents considered that having faith gave them support in this tough process and they started to have a sense of comfort via the help of these spiritual beliefs. For some parents, prayer was important to cope with the difficulties would arise in this process. Also, they believed the power of the prayer which made a valuable contribution in term of healing the children. Nicholas et al. (2017) designed a longitudinal study to search the parents' spirituality in the process of their children' life-threatening cancer. Twenty-five parents participated in the study (10 of the parents of children with leukemia). There were three time periods in this study. The first one was within 3 months, the second was at 6 months, and the last one was at 9 months. According to some parents, their spiritual beliefs gave them hope to cope with the suffering. Also, it facilitated the parents' acceptance of the course of the disease so that the parents could not have control over it. For some parents speaking to God made them the sense of not being alone. Besides, feeling the sense of spirituality throughout the practices of the parents' friends or families (e.g. praying for their children) was also valuable for these parents.

After the qualitative studies from the US and Canada, Khanjari, Damghanifar, and Haqqani (2018) carried out a cross-sectional quantitative study in Iran to investigate the experience of the mothers who have children with recurrence leukemia in terms of the quality of life and religious coping. There were 120 mothers participated in the study. Forty-four mothers were under 30, 124 mothers' ages were between 30-39, and 32 mothers' ages were between 40 and over. Demographic Information, Persian version of the Caregiver Quality of Life Index-Cancer, and Role of Religious Coping (RCOPE) were used to reach out to the aim of the study. At the end of the study, the researchers found a correlation between the quality of life and positive RECOPE, so when the people use positive RECOPE (e.g. "Looked for a stronger connection with God, "Sought God's love and care") the level of quality of life was increasing. Also, when the parents use negative RECOPE (e.g. "Wondered whether God had abandoned me", "Felt punished by God for my lack of devotion") their quality of life levels were decreasing for a while.

As a result, both the parents and children prefer using some coping methods in the treatment process. For instance, they seek information regarding the illness, consider positive sides of the process, receive support from the other people, pray, and so on. These strategies are essential to deal with the struggles of the illness. Also, Kağıtçıbaşı (2002, 2005) stated that Turkish culture included both the individualist and collectivistic aspects. Thus, the individuals needed to be both autonomous and related. At that point, the people's support needs especially in the crisis periods are very sensible.

To sum up, research studies indicated that getting the cancer diagnosis impact on family relationships and family functioning. During the treatment process, many changes occur in the family system, so the families prefer using some coping mechanisms to adapt to the new situation, and these methods are affected by the culture. In this process, it is important to consider all family members together because this is not just one's problem, all family members are influenced by this circumstance more or less.

CHAPTER 3

METHODS

The primary method of this study was to be transcendental phenomenology (Moustakas, 1994), which aims to capture the meanings and essences individuals attach to their experience. However, the study also drew on systems theory and the biopsychosocial-spiritual (BPSS) approach to make sense of the findings. We used this method because we had many interview questions which aimed to investigate the parents' experiences in the treatment process and how the family system was impacted by that process. This method helped us to understand what the participants really wanted to say.

In the biopsychosocial approach, Engel (1980) defined patients and their families as important agents who form their own narratives about their illness throughout the treatment process while trying to make sense of their experience. That is, both the patients who receive the diagnosis and their families are authors of the story, making it bigger than the sum of its episodes. All family members contribute to the treatment so this hard process becomes meaningful through everyone's participation. In short, although receiving the diagnosis is an important element, the changed lives of the family, together with the process, are more comprehensive than the single individual's disease.

3.1 Sample

A purposive sample of parents whose children have leukemia in the treatment phase were recruited from pediatric hematology units of state and private hospitals in Istanbul. In private hospitals, 3 out of 4 participants were in the high-middle class. Whereas, in the state hospital, 5 out of 6 participants were in the middle and low-middle class. Also, the participants from private hospitals had a higher educational level compared to participants from the state hospital. When I took SES and education level of the participants and the course of the treatment (generally, the children with leukemia in the state hospital were newly diagnosed compared to children in private hospitals) into account, participants in state hospitals talked about the process longer than the participants in private hospitals. The reasons behind might be difficulties of accessing to the therapy and fresh experiences. One parent of each child participated in an in-depth interview . Nine mothers and one father participated in the study. I tried to recruit more fathers from the state hospital because I made four interviews with the mothers in the private hospitals. So, my first preference was contacting with the fathers in the state hospital, but only one father was available to participate in the study. The age range of parents was 28 to 40 years. The selection criteria for the parents were, the mother tongue to be Turkish, being able to read and write in Turkish while the family had at least one more child apart from the child with leukemia because I wanted to learn how the healthy siblings' wellbeing and their relationships with their parents and children with leukemia were impacted by the treatment process. The parents of the child with leukemia should have been married and living together. The reason behind that criterion was investigating the impacts of the separation (because of the long hospitalization) on marital and parental relationships. Data collection ended up when I reached data saturation.

3.2 Procedure

First of all, the interview questions were formed by taking the biopsychosocial-spiritual (BPSS) approach into account (Figure 1.4). The questions were lined up general to specific. Thus, I tried to understand the participants' experiences in the treatment process by considering the impacts of all layers in the system (e.g. community, culture, family, etc.). After the proposal defense and approval, I applied to Özyeğin University's review board to get approval for my study. Once I received the ethics board's approval, I administered a pilot interview in a hospital setting with a parent who fits the study's inclusion criteria. After the interview, I revised the interview questions to create the final version of the interview guide. I added some probes, change the wording of the questions and added new questions based on my experience and feedback from the interviewee.

Next, I started my data collection process in private and state hospitals by getting the hospital staff's help in order to introduce myself and explain the study to the possible participants. In order to collect data from the state hospital, Özyeğin University and İstanbul Provincial Directorate of Health signed a protocol. After the required signatures received, data collection process in the state hospital started. For both the state and private hospitals, I made a contact with those parents who volunteer to participate in the study, arranging the date, time and place of the interviews based on the parents' convenience via phone calls. I first asked them to read the consent form and add their e-mails to be able to make contact to provide credibility for the study (member checking), and then sign the consent form. The participants filled out the demographic survey, which includes questions about the participant's gender, age and marital status, number of children, and the gender and age of the child with leukemia, and his/her birth order, the parents' educational levels and occupations, family socioeconomic status, time since leukemia diagnosis, and whether the participant has sought psychological and social support. They then participated in an in-depth, semi-structured, audiotaped interview about their experiences. The participants chose a code name for anonymity while their demographic forms and interview documents and equipment were stored with these code names in password-protected files on password-protected computers. After each interview, I wrote field notes to monitor my progress during data collection.

3.3 Data Analysis

I used *MAXQDA* (2016) software for analysis. The records were transcribed verbatim and stored on the password-protected computer. Once transcribed, I interpreted each interview by coding common themes. The data analysis took place in the following steps: epoche, phenomenological reduction, imaginative variation, synthesis, and trustworthiness.

3.3.1 Epoche

According to Moustakas (1994), epoche is a process of having a new eye in order to look at the phenomena that the researcher wants to study without taking previous knowledge, assumptions or judgments into account. For this, awareness is necessary. It is a fresh start to gain a new perspective for looking at a phenomenon. This also requires the researcher to be transparent to himself/herself. For this purpose, I first documented my own experience, judgments, beliefs, and feelings based on my self-location as a researcher. I also kept field notes throughout the process to develop more awareness around my own biases and judgments (as cited in Zeytinoglu, 2014, p. 113).

3.3.2 Phenomenological Reduction

Moustakas (1994) demonstrated the steps of the phenomenological reduction process. The first step is bracketing, in which the researcher "brackets" his/her own experiences through field notes to look at the data with a fresh eye. I also bracketed my previous knowledge and experiences before starting to the coding procedure because I should have looked at the data as if I have learned a new thing. The second step is horizontalizing, in which every statement is considered equal by the researcher while removing irrelevant or repetitive statements.In this part, I tried to give equal importance to each statement that the participants reported and formed a context for all of those statements one by one. After the horizons have been created and grouped, themes are formed, which enable us to describe each phenomenon and uncover its essence, which in this study concerns the experiences of parents of children with leukemia. At this point, I grouped the participants' single statements and tried to form a theme by finding a common point among those statements. In the reduction process, every single perception is considered important to contribute to the meaning of the experience.

3.3.3 Imaginative Variation

After the phenomenological reduction phase, imaginative variation starts. Imagination enables the researcher to seek possible meanings. The purpose of this phase is revealing the structural descriptions of the experience. “How” and “What” questions go hand in hand (Moustakas, 1994). For the purposes of this study, I explored how systems theory and the biopsychosocial-spiritual approach contribute to making sense of the experience of parents of children with leukemia. This exploration helped me to make sense what the participants wanted to tell exactly because their textural statements had many possible meanings in fact, so it was important to try to understand what they really wanted to say.

3.3.4 Synthesis

It is an integration process whereby the researcher puts the textural and structural descriptions into a unified statement of the meanings and essences of the phenomenon (Moustakas, 1994). That was the part I and my thesis advisor Senem Zeytinoğlu tried to understand what we heard the most from the participants, what they underlined the most. Through this way, we have determined the main themes at the end.

3.3.5 Trustworthiness

According to Lincoln and Guba (1985), the issue depends on the researchers’ effort in order to persuade the audience regarding the study’s worth. The researchers should determine the trustworthiness of the study by examining four areas which are credibility, transferability, dependability, and confirmability.

3.3.5.1 Credibility

Some methods are presented for researchers in order to increase the credibility of the research findings. I used member checking technique (Lincoln & Guba, 1985). For the member checking technique, I shared various themes or descriptions with the participants to determine their accuracy. At the end of the study, I sent the themes identified in the study to the participants using the e-mail addresses shared by the participants at the beginning. The participants evaluated whether these themes or descriptions reflect their experiences. I then got feedback from the participants to ensure their accuracy (Creswell, 2009).

3.3.5.2 Transferability

Lincoln and Guba (1985) state that the researchers can provide a thick description by applying the study to another context, or to the same context, but at a different time. Thus, he/she can assess the similarities between the earlier and later conditions. Through this way, the possibility of transferability can be evaluated.

3.3.5.3 Dependability

Lincoln and Guba (1985) indicate that the credibility of the research depends on the dependability. There are some techniques to increase the dependability of the research findings. Inquiry audit method was to be used for this research. My thesis advisor Dr. Senem Zeytinoğlu checked the codes that were formed in the research process.

3.3.5.4 Confirmability

Inquiry audit needs audit trails which is a method to reach out the confirmability. Audit trail includes raw data, data reduction, and analysis products, data reconstruction and synthesis products, process notes, materials relating to intentions and dispositions, instrument development information (Lincoln & Guba, 1985, p. 319-320). My thesis advisor Dr. Senem Zeytinoğlu used an audit trail technique to check the records of all steps in data collection and analysis.

After each interview I took some notes, these notes helped me to reach out the themes at the and of the study. Also, I realized some important points after each interview. For instance, the importance of getting support was underlined by the participants throughout the study. As I came to the last interview, I noticed that the responses of the participants got similar. Thus, I decided that the data was saturated.

CHAPTER 4

LEUKEMIA “FROM THE RESEARCHER’S PERSPECTIVE”

Cancer taught me so many things. Now I know the importance of every single breath I take. Sometimes we think that it is the end of the road but actually it is not; it is just the beginning. My story also started like this. And now I can’t think myself without my story.

I am a 26-year-old heterosexual woman who was born Üsküdar/Istanbul and raised in Darıca/Kocaeli. I am the youngest child in my family and I think I will never become an adult for my family. I can describe myself as an optimistic and happy person most of the time. Maybe because of this, nobody wanted to believe it when I was diagnosed with leukemia diagnosis.

Yes, I was the lucky one: cancer chose me because I learned many things from it, and still continue to learn. Even though leukemia is known as a childhood cancer, I was diagnosed in my adolescence when I was 16. Interestingly, I don’t remember how I learned my diagnosis because, at the beginning of my treatment period, my family and my doctors said that there was a type of microbe in my blood so I had to stay in hospital for a while. I didn’t need to question it because I trusted them and assumed they thought the best for me. Maybe I even selected this way of thinking to cope.

My family was my biggest support in that period. We were showing our love to each other more than ever. We survived together. My brother was in his last semester at university. He couldn’t even attend his classes during that year. He was just taking the exams so that he could be with me all the time. My father had to keep going to work so my brother had to help my mom.

My brother is my hero. I remember seeing him studying for his exams in the hospital's corridors. My mom was always with me. She is my angel. I was getting all my power from her. She never behaved like I was sick. This was so important for me because I felt like I could still do many things, that I could meet my needs so I was not a dependent person. Being dependent is always a fearful thing for me, maybe because my family raised me like this. They always pray: “God, do not let me be helpless”. My mom was always trying to stay calm. When we were packing to go to hospital, she was preparing like we were going on holiday. This attitude helped me to normalize the situation as I felt like everything was the same in my life, and I continued my life without any restrictions. As for my father, he was far away s during those times because he was the breadwinner and had to continue to go to work. However, I know that my illness affected him the most. He was anxious about me, checked my state of health all the time and seemed to feel guilty for being away. Even though he didn't show his feelings much, I knew that he was feeling desperate because he could not bear my suffering as he could not do anything to decrease those pains. I remember everyone, my friends, my teachers, wishing for me to get well again. Since my immune system was weakened due to chemotherapy, I was not allowed to be physically close to other people so my friends came to the front of our apartment and talked to me through the window. I felt that people always supported me. And I won. I survived. In 2009 May, my treatment protocol ended and I started to go to hospital just for regular check-up appointments.

Although I was the one who received the diagnosis, all my family members were affected by it. My brother became like my father because I felt that he was always with me even though he had to wait outside the hospital room as I received my treatment. My father had to work so he might have been alone and desperate. As my mother did not get enough support from our relatives, that period made her a tougher person who preferred to cut herself off from most of our relatives. Indeed, my neighbors, friends and teachers were more of a support system for me than my relatives. Since my illness overlapped with my adolescence, I think that I was unable to live these years like a real adolescent, so my self-confidence could not develop enough. Maybe my current hesitations, fears and anxieties are due to leukemia. Many families with leukemia diagnosis face similar changes in their lives. Even though the treatment ends, the impact of the illness endures. For this reason, I decided to become a psychologist and work with families with cancer.

I have tried not to dwell on leukemia's negative impacts in my life. After my treatment ended, I found a new purpose in my life by taking a role as a volunteer in various cancer foundations. I have contributed to several projects about cancer awareness. Currently, as a couple and family therapy graduate student, I work with parents whose children have been diagnosed with leukemia so my dreams to help others with this disease will come true soon.

CHAPTER 5

RESULTS

5.1 Demographics of the Participants

Table 5.1 Participant Pseudonym, Participants' Age, Participants' Age, 1st Healthy Siblings' Gender & Age, and 2nd Healthy Siblings' Gender & Age

Participant Pseudonym	**Participants' Age**	**Participants' Job**	**1st Healthy Siblings' Gender**	**2nd Healthy Siblings' Gender**	**1st Healthy Siblings' Age**	**2nd Healthy Siblings' Age**
Mother: Yeşil	35	Sales manager	Male	-	2.5	-
Mother: Hande	39	Banker	Female	-	12	-
Mother: Özlem	40	House-wife	Female	-	11	-
Mother: Yaşam	38	Building audit	Female	Male	9	1
Father: Ali	34	Data update staff	Male	-	<1	-
Mother: Betül	40	House-wife	Female	-	10	-
Mother: Ayşe	28	House-wife	Female	-	4	-
Mother: Umut	32	House-wife	Male	-	8.5	-
Mother: Leyla	33	House-wife	Male	-	10	-
Mother: Gül	28	House-wife	Female	-	<1	-

5.1.1 Interview 1: Yeşil

Yeşil is the pseudonym of the first participant, a 35-year-old sales manager. She was the mother of a boy aged 6.5 years with leukemia. The boy was the first child of the family. The mother said he was diagnosed with ALL 3 years ago and was receiving treatment in a private hospital in İstanbul at the time of the interview. The child had a brother aged 2.5 years. During the interview, the mother was breathing deeply while talking about the treatment process. After the interview, I realized that these nonverbal cues could be important so I started to pay attention to such cues in subsequent interviews. The mother highlighted the importance of family support so I added a question about sibling relationships for subsequent interviews.

5.1.2 Interview 2: Hande

Hande is the pseudonym of the second participant, a 35-year-old banker. She was the mother of a 7-year-old boy with leukemia. He was the second child of the family. The mother said he was diagnosed with ALL 1.5 years ago and was receiving treatment in a private hospital in İstanbul at the time of the interview. The boy had an older sister aged 12. From this interview and others, I realized that the mothers wanted to receive therapy during the treatment process, but tended to delay it because their children and the treatment came first. This interview helped me gain a perspective regarding the mothers' coping ways, specifically a preference to hide their emotions to protect their children. After the mother stressed the supportive role of hospital staff in this process, I realized that this support could be valuable for the families in addition to family support.

5.1.3 Interview 3: Özlem

Özlem is the pseudonym of the third participant, a 40-year-old housewife. She was the mother of a 4-year-old boy with leukemia, who was the second child of the family, with an 11-year-old sister. The mother said that he was diagnosed with ALL in April, 2018, and was receiving treatment in a private hospital in İstanbul at the time of the interview. This interview was the most memorable. The interviewee regularly stated "I'm strong" and "We have overcome the treatment process". This was also the only interview where a participant turned their eyes away from me. This behavior indicated the mother's coping mechanism. Like Hande, she was hiding her feelings to continue the process because her child with leukemia needed his mother. This interview prompted me to think more about sibling positions. From the mother’s comments, I realized that while the mother, father, and sick child remained a family, the other sibling had to leave the family system. Following this interview, I revised a question related to how cancer is talked about in the family. From the first three interviews, I noticed that families preferred use the term “leukemia” instead of “cancer”.

5.1.4 Interview 4: Yaşam

Yaşam is the pseudonym of the fourth participant, a 38-year-old building auditor, whose 3-year-old daughter had leukemia. She was the second child of the family. The mother stated that the daughter was diagnosed with ALL 66 days before the interview, and was receiving treatment in a private hospital in İstanbul at the time of the interview. She had an older sister, who was 9 years old, and a younger brother, who was 1 year old. From the interview, I noticed how the mother had to use the word “choose” when talking about her children, and how hard it was for her to verbalize this. That is, she had to choose the child with leukemia and leave her healthy children behind. From a video that the mother showed me regarding her child’s reaction to losing her hair, I also noticed that not only the caregivers but also the children with leukemia use various coping methods to deal with their struggles. The interviews made me realize that the participants perceived “reaction” as a negative word, so I removed it from the questions.

These interviews prompted me to ask whether the experience of private hospitals was different to that in state hospitals. Finally, only Yaşam’s child had been recently diagnosed with ALL, which made me wonder if the initial treatment process could be more vivid in newly diagnosed patients.

5.1.5 Interview 5: Ali

Ali is the pseudonym of the fifth participant, a 34-year-old verbal data update worker, who was the father of a 3-year-old boy with leukemia. He was the family’s eldest child. The father stated that he was diagnosed with leukemia, specifically ALL, AML, and another leukemia type usually just seen in adults, on October 19, 2018. He was receiving treatment in a state hospital in İstanbul at the time of the interview. He had a baby brother who was just a 40 days old. This was the only interview to explore a father's experience. It was also the longest one because, as I later realized, the father wanted to process his experiences. He described himself as a "çınar ağacı" (sycamore tree), which might explain why preferred to hide his emotions during the interview because he had many responsibilities to fulfil after the interview. This interview helped me to understand the fathers' position in the process, so it was unfortunate that I could not meet another father.

5.1.6 Interview 6: Betül

Betül is the pseudonym of the sixth participant, a 40-year-old housewife, whose 8-year-old son had been diagnosed with leukemia on November 16, 2018. As the family's second child, he had a 10-year-old sister. This was the first interview in which I witnessed a mother's emotions regarding her child's loss of hair. The interview made me realize that this could be a traumatic experience for all the mothers.

5.1.7 Interview 7: Ayşe

Ayşe is the pseudonym of the seventh participant, a 28-year-old housewife, with a 9-year-old daughter with leukemia. She was the first child of the family, with a 4-year-old sister. The mother stated that the child was diagnosed with ALL diagnosis 6 months before, and was receiving treatment in a state hospital in İstanbul at the time of the interview. This interview was particularly valuable in relation to the importance of religion as a coping mechanism. I also realized that the mothers tended to search for reasons for why this had happened to them. Religion helped them to make sense of the process.

5.1.8 Interview 8: Umut

Umut is the pseudonym of the eighth participant, a 32-year-old housewife, whose 4-year-old son had leukemia. He had an older brother, who was 8.5 years old. The mother stated that he was diagnosed with ALL 95 days before, and was receiving treatment in a state hospital in İstanbul at the time of the interview. This interview helped me to see the resentments that these families experienced in the process. To illustrate, the mother indicated that while the child had been in hospital, everyone continued life normally and shared their happiness on social media. However, this mother also cried while talking about her son's loss of hair. This again confirmed that it was an important experience for the families.

5.1.9 Interview 9: Leyla

Leyla is the pseudonym of the ninth participant, a 33-year-old housewife, whose 4-year-old son had leukemia. As the second child of the family, he had a 10-year-old brother. The mother stated that he was diagnosed with ALL 5 months before, and was receiving treatment in a state hospital in İstanbul at the time of the interview. Many of the things that I witnessed in previous interviews were confirmed by Leyla, including the importance of praying as a coping method, hiding emotions to protect the child with leukemia, and the support role of family and hospital staff.

5.1.10 Interview 10: Gül

Gül is the pseudonym of the tenth participant, a 28-year-old housewife of a daughter with leukemia, aged 2 years and 10 months. She was the family's first child. The mother stated that she was diagnosed with ALL 3 months before, and was receiving treatment in a state hospital in İstanbul at the time of the interview. She also had a younger sister who was just 15 days old. (The mother did not indicate the gender of the baby during the interview, but she mentioned that the hospital staff had prepared the hospital room with pink balloons, so it is most likely that the baby was a girl.) As in previous interviews, I noticed again that the hair loss and haircut were very hard for the mother to deal with, while she also highlighted her resentments during the process. The interview also highlighted the necessity of support. This mother used various coping mechanisms (e.g. hiding emotions, showing optimism). Finally, the interview revealed how the process can change family dynamics during the tough process.

Table 5.2 Participant Pseudonym, Date of the Diagnosis, Date of the Interview, Length of the Interview, Child's Gender, Child's Age at Interview, and Child's Diagnosis

Participant Pseudonym	Date of the Diagnosis	Date of the Interview	Length of the Interview, minutes	Patient's Gender	Patient's Age at Interview	Patient's Diagnosis
Mother: Yeşil	07.09.2015	23.07.2018	77	Male	6.5	ALL
Mother: Hande	09.12.2016	03.08.2018	87	Male	7	ALL
Mother: Özlem	04.2017	07.07.2018	59	Male	4	ALL
Mother: Yaşam	21.07.2018	27.09.2018	125	Female	3	ALL
Father: Ali	19.10.2018	26.12.2018	151	Male	3	ALL, AML, & a leukemia type just seen in adults
Mother: Betül	16.11.2018	27.12.2018	100	Male	8	ALL
Mother: Ayşe	04.07.2018	28.12.2018	100	Female	9	ALL
Mother: Umut	19.09.2018	29.12.2018	67	Male	4	ALL
Mother: Leyla	16.08.2018	05.01.2019	70	Male	4	ALL
Mother: Gül	01.10.2018	19.01.2019	80	Female	2 years 10 months	ALL

5.2 Main Findings

Seven dominant themes and 17 subthemes emerged from the interviews with parents whose children had leukemia. A theme was defined as dominant if more than half of the participants (i.e. at least 6) all mentioned a particular point. I considered the treatment process along a timeline, although this did not have specific restrictions; rather it was structurally fluid to remain open to any changes in the parents' lives. Both the thesis title and interview questions helped me to shape the dominant themes. In light of the participants' lived experiences, the following 7 dominant themes emerged: (1) Fragmentation of the family; (2) Siblings – "forgotten children"; (3) Changes in the children; (4) Changes in parenting; (5) Parents' coping; (6) We are not alone versus Resentment; and (7) Outsider view – "finding the situation bizarre".

Table 5.3 Themes & Subthemes, How Many Participants' Mentioned, and In How Many Segments?

Themes & Subthemes	**How many participants mentioned?**	**In how many segments?**
1. Fragmentation of the Family	9	44
1.1 Parents' Heavy Responsibility: Having to Bear Immense Pain	10	117
1.2 Being Separated: "For the Sake of Children' Wellbeing"	6	28
2. Siblings: "Forgotten Children"	10	162
2.1 Longing for Siblings	7	38
2.2 Compulsory Choice	7	38
2.3 Parents' Solution: Make up for Lost Time	10	43
3. Changes in Parenting Practices	8	32
4. Changes in the Children	-	-
4.1 Physical Changes	10	87
4.2 Behavioral/Emotional Changes	10	66
4.3 Social Changes	10	70
5. Parents' Coping	-	-
5.1 Being Hopeful/Optimism	10	169

5.2 Being Spiritual	10	272
5.3 Not Putting into Words	10	89
5.4 Protection of Children with Limited Information	10	126
5.5 Silent Scream	10	75
6. We are not Alone Vs Resentment	10	436
6.1 Partner Support: "Coming Close to Each Other"	10	106
6.2 Being a Team-Mate	10	49
6.3 Sibling Support: "Being Shield"	8	23
7. Outsider View "Finding the Situation Bizarre"	9	25
7.1 Appearing Fragile & Having Pity	7	18

5.2.1 Dominant Theme: Fragmentation of the Family

The first dominant theme concerned the separation of family members during the treatment process, both physically and in terms of their roles, because of the child's long-term hospitalization, the parents as caretakers, and the hygienic conditions. Nine parents described such experiencess in 44 segments. Question 5 in my interview questions (Appendix B) asked parents how their lives were before the illness and what changes had happened in their lives after the diagnosis. The parents explained changes in their family systems via these questions. This dominant theme has two subthemes: (1) Parents' heavy responsibility: Being a caregiver in the hospital; (2) Being separated: "For the sake of children's wellbeing".

After the diagnosis, all family members experienced a crisis and were impacted by the difficulties of the treatment process. In particular, due to the long hospitalization, they had to be separated from each other. This can be explained in terms of the biopsychosocial-spiritual

(BPSS) approach, which assumes that all layers in the system are interconnected and interrelated (Engel, 1977). The dramatic change in the family structure affected the family's homeostatic status through a positive feedback loop in which the status quo was inevitably disrupted (Rabkin, 1981). The parents shared their experiences of how their lives changed and how they were all separated from each other just a day after the diagnosis. As Yaşam put it:

> "So, one gets used to that, you know, to live alone, to do things, but of course all our lives were upside down. Imagine that you leave the home after breakfast in the morning and everything is regular, but no one goes home in the evening. So, we could not recover (tearful) and as a family, we were falling apart. It's like everyone was going to their own separate ways." [Mother, daughter with leukemia, aged 3 - healthy daughter, aged 9 - healthy son, aged 1]

Umut, the mother of a 4 year old boy, shared a similar experience (U: Umut and R: Researcher):

> U: "Family… There is no such thing. My husband and my son are staying at my mother-in-law's home, we closed our home. So, if my husband goes to the house, he just takes a shower. I do not go to the house; I go to my mom's house when we leave the hospital because someone should clean the house before so we can take the child to a hygienic place. My mom is preparing a special place for him (the child with leukemia), she is cleaning, disinfecting that place and I am taking him there. I do not see our house. Our house does not make me feel good.
>
> A: What reminds you?
>
> U: My running kids (tearful)… When they are missing, I do not want to get home.
>
> A: You say if we get home, we get together.

U: Yes. Together (crying)."

[Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

In addition to the separation of the family members, the parents underlined their longing for their ordinary lives.

Ali, a father of a 3 year old boy, shared the following:

> "So, you can be sure now, if someone tells me that there is way that my son can survive this, I would do it without blinking my eyes. As long as I can take my child home, I can continue my normal life." [Father, son with leukemia, aged 3 - healthy son, aged <1]

5.2.1.1 Subtheme: Parents' Heavy Responsibility: Having to Bear Immense Pain

According to the participants, the mothers were the children's primary caretakers during the process. Based on the 10 participants' experiences in 117 segments, the mothers took on a heavy responsibility as the mother of both a child with leukemia and the other children, a wife, a witness of their children's struggles, a person who still must do chores like cleaning or cooking, and a worker who has to take employment leave. Even though the mothers had many more responsibilities than their husbands, which were hard to fulfil, they considered that they had to do them – that they had no way out. As Yaşam said, "It would be great if there was one more of me".

Together with the treatment process, mothers were with their children in the hospital which led them to begin to take more responsibility. Mothers had to take care of children with leukemia and follow the treatment process. They also tried to maintain their regular daily responsibilities. When we look at Engel's System Hierarchy (Engel, 1980), mothers were among the most affected ones by the treatment process of children. Again, the separation of mothers from family systems was not for a short period of time, so the homeostatic stability of the family was disrupted by the positive feedback loop (Rabkin, 1981). During the treatment process, one of the toughest things that the mothers had to do was to be next to their child, witnessing of their pain. In such cases, the mothers continued to be there for them desperately.

Özlem, a mother of a 4-year-old boy, shared a common feeling regarding this issue:

> "I get very sad, very sad, but I tell my husband to go and wait outside (during the blood testing). I say, 'I will handle it', I send him out. Of course, it impacts me too, but there is nothing to do. This is how the treatment is. So, there is nothing else to do, it has to be done." [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

The mothers are not only caretakers but also housewives who had plenty of tasks to do each day. Yaşam, who has a 3-year-old daughter explained this in the following way:

> "This time, I did everything. Taking care of the kids, everyday cleaning, laundry. So that she (the child with leukemia) was sitting in the living room, I was cleaning downstairs. And then I clean her room. I clean our room. We were cleaning just like that, every other day. The previous week was very exhausting for me." [Mother, daughter with leukemia, aged 3 - healthy daughter, aged 9 - healthy son, aged 1)

Being a caretaker in this situation was not easy, especially for the mothers, because they had to experience their child's pain, but could not do anything to protect their children from this.

Umut, whose son was 4, stated her experiences like this:

> "I… I mean because I do not want to see him (the child with leukemia); even right now I do not want to go beside him because they are opening up a vascular access. So, he is suffering." [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

5.2.1.2 Subtheme: Being Separated: “For the Sake of Children’s Wellbeing”

The parents’ relationships were also inevitably affected by the process as they were often physically separated and could spend less time together. Six participants highlighted this experience in 28 segments. Question 8 (Appendix B) asked participants how their relationship with their partners was affected by the process. Özlem said: “There is something happened like we forgot each other.” To her, the separation was actually a devotion.

Thus, the treatment process changed the marital subsystem as the parents had to be separated from each other for the sake of the sick child’s wellbeing. The BPSS approach (Engel, 1977) is relevant to this finding in that the illness affected the spousal relationship. As an unexpected and dramatic change, this upset the family system for a long time through a positive feedback loop (Rabkin, 1981). Özlem, whose son is 4, shared the following:

> “For (spending) time, we haven’t spent too much time together. Doesn’t everything require a compromise? Let us compromise for ourselves (as a couple). It doesn’t matter anyway; like I said, after this, I hope to God when we have time, we’ll spend it together, no problem. We compromised. We had to actually. We did not have a choice. He is our kid.” [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

During the process, the parents wanted to guard their children to protect them from harm. They did not want to be apart from their children, even when they were sleeping. As Leyla, a mother of a 4 year old son, put it:

> L: “I sleep together with (her son’s name) when I come back home. I don’t know if it’s right. I couldn’t leave him. When I tell my friends here, (they were asking) ‘are you OK?’, and ‘Why is (her son’s name) not sleeping in his room?’ I told them I couldn’t sleep (without him).

R: Are you checking on him?

L: Yes, he should be with me, by my side. I need to feel him. Like, I will be with him till he gets better. We had to send my husband to the other room (she laughs).” [Mother, son with leukemia, aged 4 - healthy son, aged 10]

5.2.2 Dominant Theme: Siblings: “Forgotten Children”

According to the parents’, the sick child’s healthy sibling(s) had to play second fiddle because the one diagnosed with leukemia became the family’s main focus. Especially initially, everything was determined according to the dıagnosed child’s needs and wishes, so the healthy siblings were in a sense forgotten. All the participants mentioned this issue in 162 segments. Questions 9 and 10 (Appendix B) concerned the impacts of the process on the siblings, particularly how sibling and parent-children relationships were affected. This dominant theme had three subthemes: (1) Longing for siblings; (2) Compulsory choice; (3) Parents’ solution: Make up for lost time.

The family fragmentation started to make healthy siblings invisible. According to systems theory, a positive feedback loop causes radical changes in the system (Rabkin, 1981). During the treatment process, the place of siblings in the family system changed. The BPSS approach asserts that mental and physical health are interrelated and interconnected (Engel, 1977). Accordingly, the children’s treatment affected their siblings’ psychological well-being as well. Yeşil and Gül, who were both pregnant during the treatment process, shared the following experiences.

According to Yeşil:

> “Living that 9 months, pregnancy focused, like at my first son’s pregnancy, that wasn’t the case. It was passed somehow. But it was like, my focus was on my first son

> (the child with leukemia), 80%.” [Mother, son with leukemia, aged 6.5 - healthy son, aged 2.5]

According to Gül:

> “As I said, things all happened one after the other. I was like, neglecting the baby (the healthy sibling), I couldn’t do many things. I did not do the prenatal tests, I didn’t do any.” [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

The healthy siblings were aware of the attention paid to the child with leukemia, so some considered that the illness was a way to connect with their family.

Hande mentioned her healthy daughter’s complaint regarding this issue:

> “She (her healthy daughter) wasn’t doing well psychologically. She was saying ‘You are taking care of him (the child with leukemia) all the time, you are not taking care of me. Should I be sick too?’” [Mother, son with leukemia, aged 7 - healthy daughter, aged 12]

The parents also had to remain apart from their healthy children because of the long hospitalization period. Some preferred to move them to the home of an extended family member because the healthy children were mostly school age, so they could be carrying infections. Thus, these healthy siblings longed for their parents.

Ayşe reported the intense feelings of her healthy daughter:

> “But before this, surely, when the child (her healthy daughter) sees me, she couldn’t take her eyes off me because we had stayed away for so long (at the hospital). There were pretty long hospitalizations. When she was looking at me, she was like captivated, she couldn’t take her eyes off of me.” [Mother, daughter with leukemia, age 9 - healthy daughter, aged 4]

During the treatment period, siblings who did not get enough attention from their parents started to be resentful and aggressive.

As Umut recalled:

> “Aggressive, very aggressive. He (her healthy son) gets angry, he starts to cry when (someone) tells him something. He thinks I favor (her son’s name). During the breaks from the hospitalizations, I took him, with permission from school, with me to my mom’s place. When I got that permission, it became obvious, so like, when someone tells him to stay away from his brother, like ‘Don’t get too close’ or ‘Don’t do that’, he starts crying immediately.” [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

The parents gave much more importance to the happiness and motivation of their child with leukemia. Consequently, they had to deprioritize both their own and their healthy child’s needs.

Betül noted the following effects:

> “Morale… his (her sick son) morale (motivation) has to be high. His morale has to be high. He has to be happy. When he is sick, sadness triggers him more. He will be more like. The morale of these patients has to be high.” [Mother, son with leukemia, aged 8 - healthy daughter, aged 10]

5.2.2.1 Subtheme: Longing for Siblings

This subtheme included children with leukemia and the parents’ longing for the siblings. Seven participants, whose children’s treatment phases were newer than the other three participants whose children were treated in a private hospital, mentioned this theme in 38 segments. Except one participant, the children of participants who highlighted this subtheme were treated in a private hospital.

The longing for healthy siblings is a sign of returning to homeostasis because, through negative and positive feedback loops, the system tries to maintain stability (Rabkin, 1981). The physical status of the children with leukemia affected the emotions of the other family members (Engel, 1977).

Yaşam shared her longing for her healthy children:

> “You miss your child and you cannot see him. You want to go and see but you can’t do it at that time.” [Mother, daughter with leukemia, aged 3 - healthy daughter, aged 9 & healthy son, aged 1]

Umut expressed her sick child’s longing for his sibling from her own perspective:

> “My little son (the child with leukemia) misses him a lot. He misses him a lot. He wants to see his brother all the time, wants him to come to the hospital. He always says this. He misses him a lot.” [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

To eliminate that longing, the parents tried to bring the children together as far as possible during treatment s.

Betül shared the following:

> “She (her healthy daughter) came twice. They played together. And also my son feels very connected to his sister, like he always wants his sister. When she comes, they play pretty well and his morale, my son’s, increases when she’s here. She came twice since then. They played pretty well. After that, as I said, I try to be very careful about him speaking to his sister every night.” [Mother, son with leukemia, aged 8 - healthy daughter, aged 10]

5.2.2.2 Subtheme: Compulsory Choice

Although it was hard to mention the word “choice”, the parents indicated that they had to make choices in the treatment process. Taking the situation into account, they had to prioritize the child with leukemia over the other healthy siblings. Seven participants mentioned this theme in 38 segments.

Choosing between siblings was also an important change to the status quo, so the family system implemented this choice through a positive feedback loop (Rabkin, 1981). Like other changes, this significant change also influences all layers in the family system (Engel, 1977). Some parents found a meaning in this choice as a way to reunite the family. As Yaşam put it:

> “So, my preference is definitely (her sick daughter’s name), She needs to be healthy, so that we can be together again.” [Mother, daughter with leukemia, aged 3- healthy daughter, aged 9 - healthy son, aged 1]

Following this forced choice, the parents consigned their healthy children to their own parents. Some mentioned their uneasiness because it was somehow unfair for their healthy children. Ali expressed his feelings about that issue like this:

> “So, I was saying (psychologically to myself) that the child will be saved. I feel inner contentment because he is being taken care of. But being taken care of by a mother is different than taking care of by a grandma. Even if he is taken good care of, a mother’s care is different.” [Father, son with leukemia, aged 3 - healthy son, aged <1]

Some parents experienced this choice as an abandonment of their healthy children. According to Gül:

> “My mother-in-law told my husband yesterday that they wanted to take the baby (the healthy child) for a couple of months. They told us that they can take care of the baby

> because I couldn’t do it at that time. (Laughing) I cannot handle this.” [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

5.2.2.3 Subtheme: Parents’ Solution: Make up for Lost Time

This theme was mentioned by all participants in 43 segments. As the treatment progressed, they started to spend more time with their healthy children to make up for the lost time.

Initially, the parents could not spend much time with their healthy siblings, so the family’s normality was somewhat lost, creating a positive feedback loop in the system. However, as the treatment progressed, less time was needed for the system to regain normality, so a negative feedback loop emerged in the system (Rabkin, 1981). Thus, since the parents started to return to their normal life, all layers of the family system were affected (Engel, 1977).

Özlem shared the following:

> “After that, he (the child with leukemia) got better and we felt better; we are paying more attention towards to her (the healthy child).” [Mother, son with leukemia, aged 4- healthy daughter, aged 11]

Sometimes the parents admitted being prone to spoiling their healthy children to make up for their absence.

Betül mentioned the following:

> “I told him (her husband) to keep up her morale. Whatever she (her daughter) wants like a notebook or something, buy it.” [Mother, son with leukemia, aged 8 - healthy daughter, aged 10]

Some parents mentioned how their healthy children wanted to spend much more time with them.

Umut shared the following:

> "I, recently, spent time with him (her healthy son). He was doing (anything) for me not to leave. Like 'Mom, don't carry that, let me carry it', or ' Let's hug and sleep together'. We even sent his father to the other room and slept together. I'm like trying to buy whatever he wants online [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

5.2.3 Dominant Theme: Changes in Parenting Practices

This theme was mentioned by 8 participants in 32 segments. Question 5 (Appendix B) asked the parents how their lives were before the illness process and what changed in their lives after the diagnosis. In answering these questions, the parents compared both in terms of parenting practices. As there were lots of changes in the families' lives, parenting practices also changed over time. The parents started privileging the child with leukemia to take him/her to hospital. They started to be more flexible in the rules existing before the treatment started. Their attitudes towards their children also changed. The parents sometimes sent both the sick and healthy child to their relatives, thereby changing their caretakers. Thus, by adding new members to the family system, the family dynamics started to change.

According to the BPSS approach, any fluctuations in the system influence other parts (Engel, 1977). During the treatment process, extended family members were included in the family system, which inevitably changed hierarchies, roles, and boundaries in the system. Rendered unable to defend itself, the status quo was radically altered (Rabkin, 1981).

Yeşil, Hande, and Özlem all mentioned the different privileges that they gave to their children.

Yeşil shared the following:

> "At that time, unfortunately, we had to play the bribe games. We're going to the hospital, and will see this place on the way back, and buy this and that. It became more and more often, but it still happens sometimes." [Mother, son with leukemia, aged 6.5 - healthy son, aged 2.5]

Hande mentioned the same issue:

> "Because of this illness and staying at home, he showed more interest in PlayStation and tablets. We struggled to keep him (her son's name) away from them (laughs). It was hard to that." [Mother, son with leukemia, aged 7 - healthy daughter, aged 12]

Özlem mentioned her experience in this way:

> "He used to be in bed at around 9:30 p.m. But we cannot do it now because of visits to the hospital. I had to show tolerance; like sleeping time became midnight rather than 11:00 p.m. because you have to show tolerance." [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

While some parents mentioned their efforts to keep boundaries intact, some acknowledged that boundaries were broken.

As Ali put it:

> "His mother, for example, does not yell or get angry, but I do yell and get angry. I tell him 'I am not your mother', and 'You can't do the things that you do to your mother' because I have to protect him." [Father, son with leukemia, aged 3 - healthy son, aged <1]

Gül noted how her sick child changed after taking medicine and mentioned that she started to let her behave badly:

> “She (her child with leukemia) should not hurt herself, so instead she can hurt me. Some children in the hospital hurt themselves, so I didn’t want her to do that. She can bite me, hurt me instead.” [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

Regarding the changed family dynamics, Leyla mentioned how the grandmother started caring for the healthy child after the diagnosis:

> “The grandma feeds her, takes her school and stuff. She takes on all of the responsibilities.” [Mother, son with leukemia, aged 4 - healthy son, aged 10]

5.2.4 Dominant Theme: Changes in the Children

The parents reported various physical, behavioral, emotional, and social changes in the lives of their children with leukemia. These inevitably affected other family members. As the BPSS approach and systems theory would predict, these changes in the children’s lives affected all family members. According to these theories, if one part of the system gets damaged, the other parts are also affected. However, all parts can work together to regain stability (Engel 1977; Rabkin, 1981).

5.2.4.1 Subtheme: Physical Changes

All 10 parents highlighted this theme in 87 segments. Throughout the treatment process, the children with leukemia experienced various physical changes, including hair loss, cortisone side effects, and complications from the treatment process. These changes were reflected in the lives of the children themselves and other family members. Hande recalled her child’s feelings of fatigue from the medicines:

> “But, sometimes, he was feeling very tired because of the medicine. He was telling me, and it is not the words of a 5-year-old, ‘I wish you never gave birth to me so that I

> did not have these' (tearing up)." [Mother, son with leukemia, aged 7 - healthy daughter, aged 12]

For a fortnight, Umut could not stay with her son with leukemia because she had flu. She shared her dramatic experience when she finally saw him again. This experience showed how the children changed physically during the process and how this affected the parents:

> "I got better and came back. I saw my child, he had shrunk. He was on the way to the bathroom. When I came he smiled at me. He did not walk so his muscles were weak. I took him and hugged him… I felt his bones. [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

Hair loss was described as a traumatic experience for both the children with leukemia and the parents. Most parents mentioned its difficulties.

Gül shared the following:

> "Or, when I see her hair, I feel really sad. When there's hair loss. For example, when it happened for the first time, she was like 'Mom, put it back on.'" [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

During treatment, the children sometimes lost their appetite, yet sometimes could not stop eating due to the side effect of the cortisone.

Leyla shared the following:

> "His appetite is gone. He wants to eat but does not, cannot." [Mother, son with leukemia, aged 4 - healthy son, aged 10]

Ali saw the humorous side:

> A: "There are so many differences between the old (his son's name) and the new (his son's name). Sometimes I feel like I don't know my child anymore.

> R: How’s it different?
>
> A: Like it’s different, for example, because of the medicine, my son right now (laughing) is round like a ball (laughing more), because he gained weight.”
>
> [Father, son with leukemia, aged 3- healthy son, aged <1]

Özlem believed that wearing a mask outside the hospital could affect her child both physically and emotionally:

> “We try to stay away from crowded places as protection. So, I also had to do that for him not to get infected. But other than that, I didn't do anything that would put him in the ‘sick’ mode.” [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

5.2.4.2 Subtheme: Behavioral/Emotional Changes

This theme was mentioned by all 10 participants in 66 segments. Following the diagnosis, the children with leukemia started to change both behaviorally and emotionally. Yaşam shared how the process made her daughter change:

> “I see these kids as being more mature than any grown up. Like, this is not about getting used to it. It is as if this kid somehow knows that she is tired or her body is sick so that these things are being done to them. As if she understands this is where I have to be. It’s an unexpected reaction. I mean, all children become silent. I could not even walk by the hospital with my child. Now she is in complete silence. She has gone through so many procedures and I wasn’t expecting that. And believe me, all of the children are like the same.” [Mother, daughter with leukemia, aged 3-healthy daughter, aged 9 - healthy son, aged 1]

Umut expressed it in the following way:

> "He locked himself out of the outside world, he didn't even turn the lights on (with a shaking voice). I couldn't turn the lights on because he was getting mad, so he did not want the lights. He was pulling the edges off his nails. I don't know, he was making his lips bleed. I found a different child." [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

Gül also shared the difficulties that she faced during her pregnancy while taking care of her sick child:

> "The hard parts are at the beginning, for example, she was taking some pills, so she was having nervous breakdowns. My child was, in general, a very calm child, she had never hurt me. After she took the medicine, she became more aggressive. She was always biting me, always hurting me. She was kicking me when I was pregnant, always kicking." [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

Leyla indicated that her son did not want to be separated from her:

> "He was like a little baby, he followed me wherever I go. Like, he was always with me." [Mother, son with leukemia, aged 4 - healthy son, aged 10]

5.2.4.3 Subtheme: Social Changes

This theme was also mentioned by all 10 parents in 70 segments. The treatment process isolated them from other family members, especially at the beginning. They only started to meet with other people later if their child's blood values had improved. Everything depended on the children's blood values.

Yeşil regretted that they could not make any plans after the treatment process:

> “We spend so much time together in the hospital. While other families are scheduling other kinds of programs, we have to schedule for the hospital.” [Mother, son with leukemia, aged 6.5 - healthy son, aged 2.5]

Hande mentioned how she checked about infections before meeting with anyone else:

> “So, after a while, right after he got used to the social situations… and I always asked if there was any sick kid or if someone had a sickness before so that I would say ‘We’re not coming. We cannot meet you there.’ We were acting based on this.” [Mother, son with leukemia, aged 7- healthy daughter, aged 12]

Özlem noted how she protected her son from physical touching:

> “Like, for instance, some people who came to our house wanted to hug my boy or he wanted to something with his sister. I tell them, ‘No, you cannot kiss him directly, only from a distance.’ I am afraid that something will happen.” [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

Yaşam mentioned how the process isolates the mothers:

> “Like, I lost (my social life). During the hospital process, a mother, loses all contact with the outside world.” [Mother, daughter with leukemia, aged 3- healthy daughter, aged 9 - healthy son, aged 1]

Umut mentioned how her child’s freedom was restricted:

> “The thing that he hates the most at that moment, he thinks that his freedom is taken away. He doesn’t like walking around with the serum, but…” [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

Leyla recalled the puzzlement she and her son experienced when they first went out after long periods of hospitalization and staying at home:

> “The weather was pretty well last week so that we wanted to take (his son’s name) outside, and we did it. And we sat. Both (his son’s name) and I were staring everywhere. We were staring at the people who were passing by. I know that we were thinking nothing at all. But I think, (his son’s name) needed this too since he has been in indoor places for a long time. Everything caught his attention. The trees. (He was like) ‘Look, mom! The trees are so green’” [Mother, son with leukemia, aged 4 - healthy son, aged 10]

5.2.5 Dominant Theme: Parents’ Coping

The parents used several coping strategies to deal with their struggles during the process. These were like a tool to help the parents go on. Question 6 (Appendix B) asked participants what were the most difficult parts of the process for them and how they coped with these difficulties during this period. This dominant theme has five subthemes: (1) being hopeful/optimism, (2) being spiritual, (3) being afraid of facing the truth/not putting into words, (4) protection of children with limited information, and (5) silent scream.

According to systems theory, the reason for using these coping methods to overcome difficulties during treatment was regaining the family system’s stability (Rabkin, 1981). According to the BPSS approach (Engel, 1977), all elements of the system are interrelated and interconnected, so all family members coped with the process in their own ways. However, these coping methods also impact the lives of other family members.

5.2.5.1 Subtheme: Being Hopeful/Optimism

In this subtheme, the parents indicated that the progression during the treatment process made them stronger while knowing that the process would end eventually and being patient helped them to cope with the difficulties. The parents even started to think positively in negative circumstances. All 10 participants mentioned those coping strategies in 169 segments. They tried to be hopeful and optimistic regarding the treatment process, which is compatible with both system theory and the BPSS approach (Engel, 1977; Rabkin, 1981) because all family members worked together to maintain their homeostatic plateau through a negative feedback loop. Yeşil shared the following:

> “We were always reminding ourselves that of course, we’re struggling. That’s true, but it’s a temporary phase, it will pass. As we were showing patience and telling ourselves like ‘it’s almost done’, we are really close to the end.” [Mother, son with leukemia, aged 6.5 - healthy son, aged 2.5]

For Hande, one of the most important benefits of the process was spending much more time with her children:

> “Now, as a positive thing that this illness brought to us, we see it as a positive thing, is that me being at home and spending more time with my children. We think that this was better for them.” [Mother, son with leukemia, aged 7 - healthy daughter, aged 12]

Özlem explained how she looked at a negative situation that happened during a festive period in a positive way:

> “We spent Ramadan here (in the hospital). All the children got fevers. If we had been at home, we might not have had a good time because everything would have been restricted.” [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

Betül stressed the importance of hope for coping with her struggles:

> “I’m going to uh… to the families that heard about this illness, and say ‘Oh my, we will lose our child, he will not survive.’ I want to say this, that I never want them to lose hope. Never lose hope. The hope is always important. If I had lost my hope right after the diagnosis, I would still be crying now, helpless. I didn’t lose my hope.” [Mother, son with leukemia, aged 8 - healthy daughter, aged 10]

5.2.5.2 Subtheme: Being Spiritual

In discussing their experiences during this period, the parents repeatedly included 'Thank God!' and 'If God allows' in their sentences. They also mentioned the importance of spirituality and prayer, and attributed religious meaning to the illness, such as the evil eye, fate, or a test. All participants included this theme in 272 segments.

According to the BPSS approach (Engel, 1977), one of the most important dimensions of illness is spirituality. This approach tries to explore how families make sense of illness. The participants in this study mentioned that their spiritual beliefs were important during the treatment process. For example, they prayed for a return to their healthy lives. This desire related to regaining their normality (Rabkin, 1981). Özlem shared the following:

> "I hope God won't make that happen to me. I pray to God not to let this happen to anyone, even to my enemies. I wish God does not test anyone through his kid."
>
> [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

Yaşam mentioned unchangeable fate:

> "Then you say people do so many things if they have time for it, they survive. Or, you can give everything to her, but you can't give her life. I reached this conclusion in the end. If God gives us life, everything will be ok. But if he doesn't, we can't do anything about it." [Mother, daughter with leukemia, aged 3 - healthy daughter, aged 9 & healthy son, aged 1]

Leyla stated that praying relieved her:

> "What does soothe me? Again, praying soothes me very much. Like, wishing that Allah/God really makes me calm. I really do feel as if (Allah) is in my carotid artery. Allah makes me calm." [Mother, son with leukemia, aged 4 - healthy son, aged 10]

Ayşe tried to explain their situation as a test from God for her sick child:

> "I told her that Allah loves you very much and that's why Allah is testing you right now."
>
> [Mother, daughter with leukemia, aged 9 - healthy daughter, aged 4]

Ayşe also mentioned the view of her daughter's teacher regarding the cause of the illness:

> "She/He (teacher) also said that she (the child with leukemia) was affected by the evil eye. It happened suddenly; she did not have any health problem. But is there any sign of the illness for a moment?" [Mother, daughter with leukemia, aged 9-healthy daughter, aged 4]

5.2.5.3 Subtheme: Not Putting into Words

This theme was mentioned by all 10 participants in 89 segments. The parents reported that they did not want to think about the illness or the treatment process, either generally or in the family environment. They said that such sharing made them sad, so they tried to focus on positive things.

The illness was a crisis for all family members, so the family prefered using an avoidance coping method to try to avoid moving away from their normality (Rabkin, 1981). Such choices inevitably impacted all family members (Engel, 1977).

Gül shared the following:

> "I said that, within the family, I did not want this illness to be talked about because I am also affected by that. Like, I don't want to hear that all the time… my kid is sick, she got cancer. Like I said, even when I hear them telling the kid that you're sick, I cannot accept that. I feel sad about it." [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

Özlem reported that she did not share the diagnosis with those around her to protect her son's psychological wellbeing:

> "People around me, they don't know that my son has this kind of sickness. I mean, we went on like that. It was not a nice thing because I don't want his psychological well-being damaged in the future." [Mother, son with leukemia, aged 4-healthy daughter, aged 11]

5.2.5.4 Subtheme: Protection of Children with Limited Information

The parents reported that they either gave only limited information regarding the treatment process to both their sick and healthy children or sometimes hid some facts to protect them from the seriousness of the illness. That is, none of the children exactly understood the leukemia diagnosis because the parents did not use words like "leukemia" or "cancer" while talking about the process. This protected the children from learning the real reason for the many changes that had happened in their lives. Thus, the children were not properly aware of the process. All 10 participants reported this issue in 126 segments.

Both not putting into words and giving just limited information regarding the treatment process to the children were avoidance coping methods. Through a negative feedback loop, the families tried to return to their homeostatic level (Rabkin, 1981). This choice impacted all the family system's layers (Engel, 1977). For instance, extended family members were also not allowed to talk about the treatment process near the children. As Yeşil put it:

> "For example, about the hospital procedures at first, we go to the hospital and come back home but we did not say what will happen. Like, we're hiding it (because) it was becoming a big crisis." [Mother, son with leukemia, aged 6.5 - healthy son, aged 2.5]

Instead, the parents shared information about the illness or treatment methods in ways that the children could understand.

Hande shared the following:

> "He was so little. What should I be telling him now? I told that there was a big x-ray machine. They wanted to take a look at the germs in your stomach but that machine can't go upstairs. Because it was pretty big, you should go downstairs. But we cannot go there with our regular clothes. We need to wear that hospital outfit, and head bonnet so that our hair won't fall out or we won't get dirty. I explained to him like that (smiling)" [Mother, son with leukemia, aged 7 - healthy daughter, aged 12]

Betül recalled her experiences regarding the same issue:

> "We told them you got germs in your blood. We're here until that germs are cleaned from your blood." [Mother, son with leukemia, aged 8 - healthy daughter, aged 10]

Umut indicated that she created a game for wearing the mask:

> "We're fighting against the germs (laughing). Look, because those germs make us sick, I make his hands disinfected all the time, by saying 'Come on and fight the germs!" I made that as a game. Let's put on the masks and fight against them." [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

Ali reported that it was an advantage that his child was young because he was unaware of what was happening to him:

> "Of course you cannot say (that it's a hospital). The advantages of the illness are that our kid is 3 years old and he doesn't know what this illness is. We told him that he was coming to school. We need to pass this school. You get grades for your activities in here, from your teachers. With things like that, we give comfort to our kid."

> [Father, son with leukemia, aged 3-healthy son, aged <1]

The parents also tried to explain the hospitalization period to their healthy children. As Umut put it:

> “So, you have everyone in here. You have your grandma (from the father’s side), your uncle, your aunt, your grandma (from the mother’s side). But I need to be with (her son’s name), there can only be one person. He needs me. Your brother has this illness. Because he was not eating or drinking anything, the blood levels are always low. I said exactly like that. Like he has to be treated at the hospital. This treatment is long, it will last 2 years. I said this.” [Mother, son with leukemia, aged 4-healthy son, aged 8.5]

5.2.5.5 Subtheme: Silent Scream

This theme was mentioned by all 10 participants in 75 segments. During the illness process, the parents had to hide their emotions so that their children would not ask or worry about their parents’ moods. Moreover, they had to stay strong as the child with leukemia needed them. Ultimately, therefore, the parents could not express their intense emotions freely.

According to the BPSS approach, individuals’ mental and physical health are not distinct from each other (Engel, 1977). In this study, too, the children’s current physical situation also affected the families’ emotional status. However, the parents preferred to hid their intense emotions to maintain the family system’s stability (Rabkin, 1981).

Özlem and Umut shared the reasons behind hiding their emotions:

Özlem shared the following:

> “I did not cry afterwards because I said that we’re gonna make it. If I let myself cry, I will cry fiercely.” [Mother, son with leukemia, aged 4-healthy daughter, aged 11]

Umut mentioned her experience in this way:

> "We, as all of the mothers in here, are keeping everything inside ourselves. We have to be strong because we keep coming back to our children." [Mother, son with leukemia, aged 4-healthy son, aged 8.5]

Ali talked about his feelings using a storm metaphor:

> "I never show my sadness to the outside world. There was always a tornado inside me. I've always kept it to myself because, as I said, I know myself. I never show it to anyone, even to my wife." [Father, son with leukemia, aged 3-healthy son, aged <1]

5.2.6 Dominant Theme: We are not Alone versus Resentment

All 10 participants mentioned this theme in 436 segments. Question 7 (Appendix B) asked the participants about who was with them in this process and how these people supported them. The parents emphasized the intense support they received from their families, partners, their healthy children, the children's schools, hospital staff, and other families in the hospital. In contrast, the parents also indicated that sometimes they felt resentful when other people made negative or inappropriate comments regarding the process or when they behaved inappropriately. This dominant theme was divided into three subcategories: (1) Partner support: "coming close to each other"; (2) Being a team-mate; (3) Sibling support: "being a shield".

According to Engel's System Hierarchy (Engel, 1980), a system has many interacting components. The parents mentioned receiving a lot of support from other layers of the system, although they also received some negative comments. Overall, the participants tried to proceed with the treatment despite both positive and negative feedback received from their surroundings. Their common aim was protecting their own family's status quo (Rabkin, 1981).

Hande, for example, mentioned the school support that they received for her healthy daughter:

> “I wanted help from her teachers at school. Like, we’re going through this and they are aware of it. So, I did not want her to feel that I give less attention to her. I’m like, help me with that. I’m grateful that they did so.” [Mother, son with leukemia, aged 7 - healthy daughter, aged 12]

Yaşam shared the following regarding support she received from a friend:

> “Seeing a stranger cry or pray or feel sad about your child (is important/valuable) … It was a big deal. I saw them sharing my problems. I felt relieved somehow. I mean really, you can really understand spirituality in these times.” [Mother, daughter with leukemia, aged 3 - healthy daughter, aged 9 & healthy son, aged 1]

Yaşam underlined family support in this way:

> “Of course, family comes first. It’s very important. I am very grateful that I have my mom and dad, and elder sister. By the way, I (like) that I have many siblings. We are 5 people as siblings. I am grateful that I have 5 siblings, including me. If it wasn’t for my elder sisters, elder brother, and little brother, what would happen? Like, he (her healthy son) is a kid. One of them is taking care of him, the other is taking him to the hospital, my father never stops, like he was at the hospital all the time. It’s like you see their support every time. I even tell them not to come anymore.” [Mother, daughter with leukemia, aged 3 - healthy daughter, aged 9 & healthy son, aged 1]

Ali stressed the importance of feeling support from others:

> “‘I’m sorry for you, is there anything I can do for you?’ Even this was enough. I know that they can’t do anything, I mean the people who asked. Being asked this, and hear ‘ we’re here’ makes me happy. Believe me, I felt relieved because you feel them by your side. Like I told you before, I know that they can’t do anything but even being asked this is a nice thing.” [Father, son with leukemia, aged 3 - healthy son, aged <1]

Umut mentioned the support they received from others about finding the appropriate stem cells:

> "For example, we needed stem cells. We shared this through social media, asking them to donate to Kızılay. There were lots of messages. I feel like so many people gathered around so we can find them. We're from Gönen, Balıkesir. All of the young people from Gönen brought a Kızılay car to the city and all of them donated. This makes you feel different. Like, the silver lining is there, up again. Especially when you're feeling desperate, these things made you say 'it's gonna be alright.'" [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

Özlem explained how her family and the hospital staff became a team:

> "People (hospital staff in the hospital) were like perfect. They tried to help as much as possible. I am grateful for that. We got through this process because of them. We, mom, dad, and my son, and our doctor, the nurses, we were like a team." [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

Umut highlighted the support received from other families in the hospital:

> "Like, for instance, I was so bad a while ago. I went downstairs to get some support from my friends. I came back upstairs and now I'm fine. It's always like this. This made me rise again when I fall down. I see them as my friends, I mean people who are in here. We're like friends who have the same destiny. Sharing a common fate. That feels so good." [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

However, Umut also mentioned her resentment from some comments:

> "I mean, the phone calls saying 'Feel better!', 'Be strong!' impacted me. I told to myself this when I had a nervous breakdown. I was screaming like 'They're telling me be strong, but I can't. Let them be instead!' It was hard to hear in those phone calls

> like ‘(participant name), you have to be strong! You’re a mother.’ Since so many people were saying the same thing, I resented that. [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

Yaşam had a similar experience:

> “For example, some people said something like, ‘So and so got sick and got better.’ As if what we have is not that bad. Like (telling us), ‘Yours is nothing, your child will get better.’ Like, there is no such world. How come I was not important there? I know what kind of things that a child was going through. Only people who experience this know. These people only hear it when people got better.” [Mother, daughter with leukemia, aged 3 - healthy daughter, aged 9 & healthy son, aged 1]

Umut and Gül emphasized resentments due to their own families:

Umut shared the following:

> “During these times, the biggest morale breakdown was because of my father-in-law. Like, he visited me in the hospital and said, ‘You couldn’t take care of a child, that’s why this happened.’ I still, remember that. Even now, I can’t get it out of my head.”
>
> [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

Gül shared the following:

> “Because no one gets you, no matter how many times you tell them so. For example, when your kid is not doing well, she shouldn’t be seeing anyone (due to hygiene precautions). People get it wrong. I try to protect my kid.” [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

5.2.6.1 Subtheme: Partner Support: “Coming Close to Each Other”

This theme was mentioned by all 10 participants in 106 segments. Question 8 (Appendix B) asked the participants how their relationship with their partners was affected by this process. The parents mainly mentioned supporting and becoming closer to each other through this tough process. During the treatment, the parents started to get support from each other and this process made them closer. Thus, the current situation of the children with leukemia impacted the marital subsystem too (Engel, 1977). In addition, the support from the spouse helped the participants regain their previous family normality (Rabkin, 1981). Özlem discussed the support from her partner in this way:

> “We grew closer because we had only each other for support like that. Especially from me towards him. I supported him in so many times. Like, it’s gonna be alright.”
>
> [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

Ali considered himself as if he were a sycamore tree (çınar ağacı):

> “Of course this process started very early for me because you know why? Think about a sycamore tree (çınar ağacı). There’s shade from that tree. Under the shade, I need to be the shade for my partner and for my family.”
>
> [Father, son with leukemia, aged 3 - healthy son, aged <1]

Ayşe shared her experience after they received the diagnosis:

> “We were like holding hands together.When we got out, we told ourselves that we’re gonna get through this together. (He told me) nothing will happen (tearing up).”
>
> [Mother, daughter with leukemia, aged 9 - healthy daughter, aged 4]

5.2.6.2 Subtheme: Being a Team-Mate

All 10 parents highlighted this theme in 49 segments. Question 12 (Appendix B) asked participants what changed in their family relationship after the diagnosis. This gave the parents a chance to discuss how sharing responsibilities with their partners was affected. According to the BPSS approach and systems theory, all layers interact in the system's hierarchy (Engel, 1980, Rabkin 1981). The research findings showed that the parents tried to fill in the gaps in their family system during the treatment to maintain its normality. Yeşil shared the following:

> "Soon after (the treatment started), we realized that it was easier to go alone. Either he (her husband) took him (the child with leukemia) or I did. This still, happens, especially when there is no hospitalization. Either he takes him, or I do so." [Mother, son with leukemia, aged 6.5 - healthy son, aged 2.5]

Özlem had a similar experience:

> "There are times when I cannot keep up with my son. For example, I was studying with my daughter and was telling my husband to feed him, entertain him. Because, at first, my son did not eat much or he (her husband) was giving him a bath to entertain him. I was telling him to dress him up. While he was doing that, I was taking care of our daughter. Whenever he was at home, I was saying these kinds of things."
>
> [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

Umut indicated that her partner started to take care of the healthy child more during this process:

> "But right now, he is with (the healthy child). When he comes here, he even says (the healthy child) would wait up for him. He became very close to (the healthy child)."
>
> [Mother, son with leukemia, aged 4 - healthy son, aged 8.5]

5.2.6.3 Subtheme: Sibling Support: “Being a Shield”

This theme was mentioned by 8 participants in 23 segments. Their healthy children also tried to help their siblings with leukemia as much as possible. Thus, the siblings were also included in this process. Throughout the treatment, the healthy siblings also started to take on responsibilities to maintain the homeostatic plateau (Rabkin, 1981). Thus, leukemia was not just one child’s illness; rather, all family members were impacted (Engel, 1977). Hande shared the following example:

> “Her name is (her healthy daughter’s name). (Her daughter’s name) told like ‘Mom, I wish mine is a better fit (bone marrow), so that they could take mine.’”
>
> [Mother, son with leukemia, aged 7 - healthy daughter, aged 12]

Ali also mentioned how his baby son could help his elder brother by donating stem cells:

> “(His healthy son’s name), well, he was a surprise to us. So, (his other son’s name) was in that condition. We thought like was that a surprise from God/Allah to us? Like when they wanted a bone marrow transplantation ... you think these things.”
>
> [Father, son with leukemia, aged 3 - healthy son, aged <1]

Hande also mentioned her daughter’s support:

> “She (her healthy daughter) supports us in her own way. For example, she was successful at school. I never had a concern about that. Like giving her a tutor so that she will be successful at school. I did not deal with these things. She was very aware of everything, she always understands her school duties. She never made us unhappy about it. She supported us in that way.” [Mother, son with leukemia, aged 7 - healthy daughter, aged 12]

Ayşe shared how her healthy daughter protected the child with leukemia:

> "The last day when we go for blood tests I also brought (her healthy daughter's name). (Her daughter with leukemia) is nauseous because of chemo so she didn't want to take the chemo. (The healthy daughter) said 'Don't do that!' (mimicking), says to the nurse (laughing): 'Wait, sister. I'm going to tell the nurse not to give you chemo, okay?' (mimicking)." [Mother, daughter with leukemia, aged 9 - healthy daughter, aged 4]

5.2.7 Dominant Minor Theme: Outsider View "Finding the Situation Bizarre"

All participants except for the father mentioned this theme in 25 segments. Question 16 (Appendix B) asked the parents for their observations about how other people approached them, given that they had a child with leukemia. The parents reported that the people they met usually looked at them in a weird way because their sick child was bald and wearing a mask. Moreover, the parents also wore masks to protect themselves from infections that they might then pass onto their child. This theme had one subtheme: (1) Appearing fragile and having pity.

According to Engel's System Hierarchy (Engel, 1980), the community is an important component of the system that may itself be influenced by other components. However, based on the participants' reports, the community did not have very permanent impacts. Thus, through the negative feedback loop, the family system regained its stability as soon as possible (Rabkin, 1981). Yeşil shared the following example:

> "There was a boy, once, who was with his father. And my son wanted to play with him but that boy did not. That boy said 'He doesn't have hair. I won't play with him.' I was so sad." [Mother, son with leukemia, aged 6.5 - healthy son, aged 2.5]

Özlem expressed her thoughts regarding this issue in this way:

> "In the street, one time, he wore a mask because his blood levels were low. There were some people who looked at us strangely as if they were finding this odd. This was not nice." [Mother, son with leukemia, aged 4 - healthy daughter, aged 11]

Gül mentioned that they were exposed to tares when they (the parents) put on the mask:

> "We had a couple of things to do in the bank. We went there. And they were like asking why she was wearing a mask." [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

5.2.7.1 Subtheme: Appearing Fragile and Having Pity

Seven participants mentioned this theme in 18 segments. Question 15 (Appendix B) asked the parents how they evaluated people's attitudes and behaviors towards them after the diagnosis. The parents stated that other people saw them as fragile, so they tried to be more sensitive in their behavior and speech. However, the parents appeared to be dissatisfied with such responses.

The BPSS approach rejects mind-body dualism by asserting that mental and physical health are inseparable (Engel, 1977). In this regard, people from outside groups made comments regarding the appearance of the children with leukemia, which affected the family's psychological well-being. Nevertheless, the family system tried to preserve itself through the negative feedback loop (Rabkin, 1981).

Yeşil shared the following:

> "Other people are also sad for him, looking in a pitying manner. You can clearly see that." [Mother, son with leukemia, aged 6.5 - healthy son, aged 2.5]

Ayşe mentioned how her sick child's teacher approached her:

> "Yeah, exactly, they always see us as fragile. For example, our teacher said, when (her daughter's name) got diagnosed, that there were activities done about children with

> leukemia. She wanted to do it that year but she didn't want us to know about it. She thought we would be offended." [Mother, daughter with leukemia, aged 9 - healthy daughter, aged 4]

Gül stated her displeasure regarding the same issue in this way:

> "When they say to the child like 'you're sick' all the time, the child feels bad. And asks 'what's wrong with me? why am I sick?'" [Mother, daughter with leukemia, aged 2 years and 10 months - healthy daughter, aged <1]

5.3 Observations

From the interviews, I mainly observed that the parents found it hard to talk about the initial period following diagnosis. They were mostly not able to stop themselves from crying. However, they tended to recover their mood as soon as possible because they had to go back to be with their sick child after the interview and did not want to make the child worried. In addition to crying, they sometimes laughed while talking about a difficult situation regarding the treatment process, or they laughed and cried at the same time. I considered laughter or outbursts of mixed emotions could be coping mechanisms for the parents to deal with the struggles of the process.

5.4 Member Checking

Following the initial data analysis, I sent back each interviewee's draft results via e-mail or WhatsApp. Before that, I talked to the participants by phone to learn how they would like to reach out to the findings. I asked them about the following issues: (1) if the findings reflected their experiences accurately; (2) if they would like to make any comments regarding the findings or the interview process; (3) if there were points that I could not cover as a researcher. I also asked them to send their feedback via e-mail or WhatsApp by July 7, 2019. Three of the 10 participants responded. Ayşe stated that "You have already written everything. I hope you are very successful. God bless you." Gül noted that "You have expressed it well, thank you. Only the friends who are in the same situation can understand us. It gives us more pleasure to talk to them. Solely, we understand each other. Everyone listens, but not everyone can understand." Yaşam wrote "I read your letter, I hope this brings you plenty of successes. I could not see anything that is missing. However, as we experience something in the process, the sentences that can be added cannot end. Our responsibility is to wait patiently, but this waiting has taken many things away from the mothers as leading actors, unfortunately. Like the diseases that are haunting you because of fatigue (eczema, neck spasms), especially if you have young children. Of course, the relationship with your partner is included in this process. You are not enough for everyone and everything, and nobody else realizes this. So, a tired mother's/wife's profile emerges. I wanted to write those things to you again. Congratulations (Hayırlı olsun). You have taken a place that will not be forgotten." I sent reminder messages/e-mails to the parents who did not respond on July 10, 2019. Again, I requested them to send their feedback via e-mail or WhatsApp by July 12, 2019. Five more mothers responded after this reminder. Umut stated that "I have read your evaluation. You have reflected our experiences very well, so there is nothing I can add. Thank you." Leyla said "Thanks a lot for your attention. I do not have a comment to add." Özlem wrote "Hello Merve! I read your thesis project. First of all, congratulations! You discussed the issues that needed to be mentioned one by one very well, so I do not have anything to add. Great job! (Eline, emeğine sağlık). All the best (Her şey gönlünce olsun)." Yeşil said "I read your project. It is appropriate." Lastly, Hande wrote "Hello Merve! You've reflected what we are trying to tell you. I hope you complete your thesis successfully and will be a light to anyone who needs it. I hope you are successful."

CHAPTER 6

DISCUSSION

The aim of this phenomenological study was to investigate how family dynamics change after a child's leukemia diagnosis. This study is important because no previous phenomenological study has investigated the impacts of leukemia on the family system through comprehensive research questions in Turkey. This study focuses specifically on parents whose children are currently undergoing leukemia treatment. It therefore, contributes to the literature by providing a deeper understanding of the struggles of families during this process.

The following main themes emerged from the interviews with 9 mothers and 1 father of children diagnosed with leukemia: (1) fragmentation of the family; (2) siblings: "forgotten children"; (3) changes in parenting practices; (4) changes in the children; (5) parents' coping; (6) we are not alone versus resentment; (7) outsider view: "finding the situation bizarre".

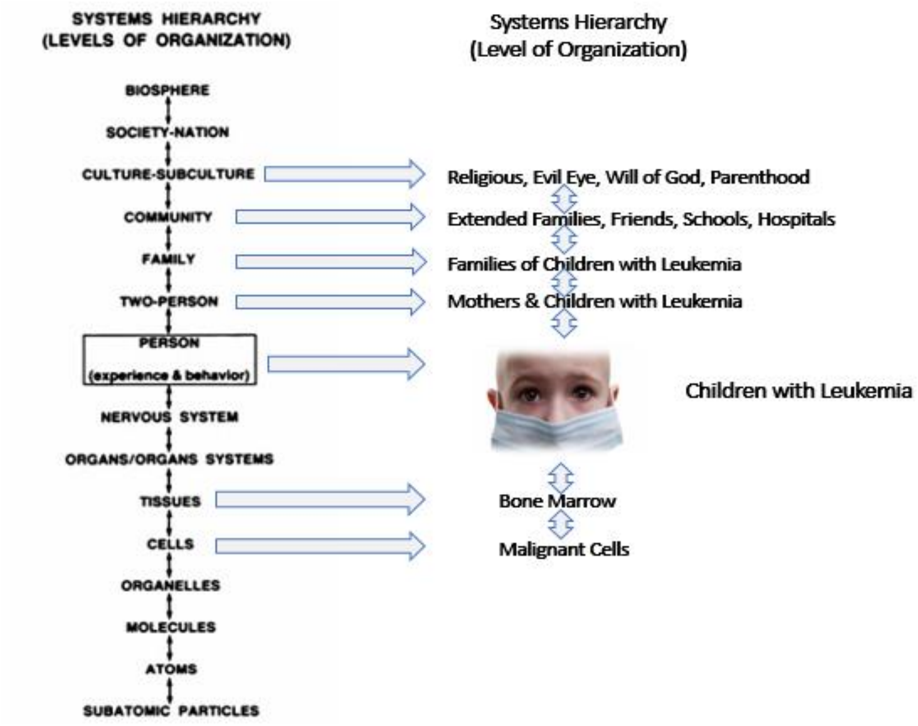

Figure 6.1 Engel’s System Hierarchy & Equivalent in This Research

6.1. Review of Main Findings

This part discusses the main themes that emerged from the research in relation to earlier studies and the perspectives of systems theory and the BPSS approach.

6.1.1 Fragmentation of the Family

The experiences of these families were generally in line with the BPSS approach and systems theory. They underlined how illness affected different layers of the family system around the sick child. Because leukemia treatment is very long and demanding, all family members are inevitably impacted by the process, not just the child with the illness. This is the main claim of systems theory: that because the simple parts of an entity are interconnected, they are all influenced by the movements of the other parts (Dallos & Draper, 2015). Due to the length of the process, the families have to spend a lot of time in the hospital. For females, the treatment lasts two years whereas for the males, it takes three years because of the risk of testicular relapse (Keene, 2010). Acute lymphoblastic leukemia (ALL) treatment lasts 2-3 years at least, during which the patient undergoes chemotherapy, intrathecal chemotherapy, and cranial radiation (About Kids Health, n.d.). In the present study, the parents mentioned that their children had chemotherapy and intrathecal chemotherapy. However, no parent stated that their child had undergone cranial radiation, which is probably because of the diagnosis and subsequent treatment protocol.

In this phenomenological research study, the participants stated that after the leukemia diagnosis, the family members had to be separated, which started a fragmentation period, unfortunately. During this period, the families had to leave their ordinary family lives behind in that they were alive but not together. They were even unable to sleep under the same roof. Consequently, they frequently talked about their longing for their normal lives because they wanted to be together again as a family and feel the emotion of being a family. These wishes of the parents can be explained by the homeostasis principle of systems theory. According to Lehman (2005), the family system is a dynamic unity and open to change, although it tends to protect its stability. When we think about the leukemia treatment process, the families found themselves in a new and unexpected reality. Despite trying to adapt to the treatment process, the parents eventually long for their normal lives. From their qualitative research in Belgium, Van Schoors et al. (2018) concluded that the cancer diagnosis causes many changes in family functioning. One of the most important concerns spending time as a family. They found that families whose children had had a cancer diagnosis perceived the times that they spent together as a gift. They also tended to pretend that their normal lives were continuing. This is also consistent with the homeostasis principle of systems theory and my research findings. In short, families of children diagnosed with cancer want to return to their ordinary routines.

In this study, mothers were the primary caretakers who stayed in the hospital. All mentioned the challenges of this process and the responsibilities forced on them. Elcigil and Conk (2010) also demonstrated in their qualitative study that mothers with children undergoing cancer treatment experienced physical (e.g. loss of appetite, headache, or backache), emotional (e.g. being more nervous or sensitive), social (e.g. not seeing their friends), and economic burden burdens (e.g. transportation problem). These results support the BPSS approach (Engel, 1977). According to BPSS, people’s physical challenges also affect their psychological and social states. That is, biological, psychological, and social states are all interconnected, so they need to be investigated holistically. The parents reported having to witness all the intense treatment protocols, as they had to be by the side of their child. Thus, the parents were affected by their child’s treatment and their physical, emotional, and social experiences.

According to Colapinto (2016), the family structure includes boundaries, subsystems, and hierarchies. The long hospitalization process affects the parent subsystem because the parents spend less time together as a couple. The research participants mentioned how the treatment process had changed their marital relationship. Especially at the beginning, the parents became distant from each other physically, although they indicated that that was not a problem for them, but something they had to do for the sake of their children. This result confirms earlier qualitative studies from Brazil and Belgium, which also found that the parents of sick children were unable to see themselves as a couple because they had to prioritize their parental responsibilities (Silva-Rodrigues, Pan, Sposito, de Andrade Alvarenga, & Nascimento, 2016; Van Schoors et al., 2018). The factor that makes parents behave in this way could be their intense fear of losing their children. Consequently, the first thing the parents give up might be their marital relationships. In contrast, Afanasyev and Fedorenko (2016) found from their quantitative study of Russian families that children with leukemia needed to see their parents together. The present study focused on the parents without contacting the children with leukemia. However, given the finding of Afanasyev & Fedorenko) (2016), I consider that learning about the needs of children with leukemia from conducting interviews with them would contribute to the cancer literature in Turkey. In addition, I realize that the treatment process involves very complicated issues. In particular, the parents have to separate from each other due to long periods of hospitalization, yet the children with leukemia want to see their parents together. This strongly supports the claims of systems theory (Dallos & Draper, 2015) and the BPSS approach (Engel, 1977) in that family members are parts of the same unity that are all impacted by any changes in the system.

6.1.2. Siblings: “Forgotten Children”

Besides the changes in the parental subsystem, changes in the sibling subsystem can also be seen. According to Engel’s BPSS approach (1980), which was derived from system theory, all layers are interconnected and interrelated, from the biosphere to the subatomic particles. Thus, being diagnosed with cancer is not just an issue for the sick children themselves; rather, it is a shared reality that all family members have to face. The research participants’ reports indicated that their child with leukemia was the family’s main concern, so everything started to be determined by the wishes and health condition of that child. Consequently, healthy siblings were pushed into the background, although they sometimes attempted to make themselves visible to their parents. These findings are supported by various other studies. Van Dongen-Melman, De Groot, Hählen, and Verhulst (1995) reported from their mixed design study in the Netherlands that healthy siblings showed some adjustment problems during their sibling’s leukemia treatment. However, these problems decreased as the treatment came close to ending. Buchbinder et al. (2011) used quantitative methods to explore distress and depression in healthy siblings in North America. They found positive correlations between survivor global psychological distress and sibling global psychological distress, and between sibling depression and survivor sibling’s health impairment and depression. From their cross-sectional study of US families, Erker et al. (2018) reported that healthy siblings’ family relationships were worse than those of their sibling with cancer during treatment whereas there was no difference between them in the non-treatment period. Overall, all three studies showed that the experiences of children with cancer and their healthy siblings are related, even after the treatment period. Since the data were collected at just one time point in the present study, I could not evaluate changes in family relationships, adjustment problems, or the psychological well-beings of siblings during or after the treatment process. As mentioned above, it is important to understand the needs of children with cancer during treatment. However, I also think that hearing the voices of the forgotten siblings is also crucial to understand their needs.

The results from this study demonstrate that parents make forced choices between their children. They tend to choose the child with leukemia because they were more vulnerable even though they do not want to, probably because they blame themselves for neglecting their other child(ren). These parents also tend to make up for this lost time later. This is consistent with previous research studies (Murray, 2002; Sloper, 2000), which suggest that maintaining daily family activities or trying to fullfil the healthy siblings' interests are important ways of supporting them during their sibling's treatment. To create this time and enable the healthy sibling's activities to continue, it is important to receive support from the surroundings (McGrath, 2001). In the present study, the participants expressed their longing for the healthy siblings. According to the participants, both they themselves and their sick child felt like this. To my knowledge, this is the first study to investigate directly the longing of both parents and children with leukemia towards their healthy siblings. It is also the first study to consider the issue of forced choice between siblings. These findings should therefore lead to other studies that can explore these points further.

6.1.3. Changed Parenting Practices

The finding of this study regarding changed parenting practices is compatible with both the BPSS approach and systems theory. The parents indicated how their parenting practices changed during the treatment process. According to Colapinto (2006), there are several elements underlying the family structure: subsystems, boundaries, and hierarchy. A leukemia diagnosis, initiates a crisis in the family system, which causes disequilibrium and upsets the family's homeostatic stability (Parad & Caplan, 1960). The crisis also affects the components of the family system (i.e. subsystems, boundaries, and hierarchy), which respond by trying recover their balance to maintain stability (Olson, 2000). Thus, the family system is flexible and tries to adapt to changes caused by a crisis. I discussed changes to the family subsystems throughout the process because leukemia is not just one person's issue; instead, all family members are affected. In this regard, family dynamics should be investigated holistically rather than in a reductionist way (Borrell-Carrió, Suchman, & Epstein, 2004). The parents reported some changes in terms of family boundaries and hierarchies. To illustrate, they started to let their child with leukemia use tablet computers a lot and allowed them to go to bed later. From their quantitative study in Turkey, Elcigil and Conk (2010) found that parents give more “Yes” responses to the demands of the child with leukemia. Moreover, extended family members start to take responsibility for the healthy children, so the grandparents enter the family system, which can change balances in the family hierarchy. Hicks, Bartholomew, Ward-Smith, and Hutto (2003) reported a similar trend in the US, particularly the involvement of extended families to care for healthy siblings. In the present study, the participants reported that grandparents and other relatives had also taken responsibility for caring for the healthy children. Thus, new members were added to the family system, which inevitably changed the family hierarchy.

The families’ approaches to their sick child also changed For example, the mothers reported that they had been sleeping with their sick child since the treatment process started while their husband slept in another room. Afanasyev and Fedorenko (2016) found that parents in Russia developed exaggerated reactions to protect their sick child during treatment. Thus, the changed behavior of the mothers in the present study could be related to her fear of losing her child. A quantitative study from Italy concluded that mothers’ ideal family functioning was enmeshment in the treatment process (Perricone, Polizzi, Morales, Marino, & Scacco, 2012). This family functioning may also apply to the families studied in Turkey because, especially at the beginning, the children with leukemia and their mothers as the primary caretaker started to spend much more time together, including sleeping.

6.1.4 Changes in the Children

The findings from this study indicated various physical, behavioral, emotional, and social changes during the treatment process. According to the BPSS approach (Engel, 1977), mental and physical health are interrelated rather than distinct domains. Thus, when we have a physical problem, our psychological, social, and spiritual states may also be affected by that physical issue. This relationship is not uni-directional; rather, all four domains reciprocally influence each other. This result is in line with systems theory in that different layers of the family system are affected by the treatment process (Rabkin, 1981). Moreover, instead of being limited to the children with leukemia, these changes also affect the child’s family members. In the BPSS, Engel (1980) indicates that both the patients and their patients constitute their own experiences through the process. In this regard, all family members are important and active agents.

According to the parents’ reports, the children with leukemia felt intense tiredness and bone pain due to the treatment protocols, which included chemotherapy and cortisone intake. This is consistent with a phenomenological study conducted by Wu et al. (2010) in China that reported how children with leukemia experienced physical fatigue in various parts. According to the research participants in my study, the cortisone also made the children eat too much so that they put on weight. A similar effect was reported by McGrath and Rawson-Huff (2010). In the present study, all family members were adversely affected by the sick child’s hair loss. Hicks, Bartholomew, Ward-Smith, and Hutto (2003) reported that such hair loss harmed the relationships of sick children in the US with their peers. Thus, physical changes also damage the social lives of children with leukemia.

From the interviews, I can conclude that the children’s hair loss affected the parents more than their sick child. According to the parents, the children were not much concerned about their hair loss. This may be because of their young age and limited knowledge regarding the process, or their coping method.

The parents also noted behavioral and emotional changes in their sick child. These included becoming introverted, being aggressive, and having difficulty with separation with their caretakers. From their qualitative study of children in leukemia in Australia, McGrath and Rawson-Huff (2010) identified cortisone intake as a main stressor during this period, which caused various behavioral changes (e.g. temper tantrums, anger, and physical violence). In the present study, one mother reported that her daughter had started biting her, which the mother attributed to the medicines taken. Unsurprisingly, the stress that the children experienced during treatment also adversely affected the mothers' emotional states, thereby creating an emotional burden for them too (Elcigil & Conk, 2010).

One mother reported that "during the hospital process, a mother, was like, lost all of the contacts with the outside world". This was such a striking and true statement because both the child with leukemia, who must be isolated, and the caretakers have to restrict their contacts during treatment. Thus, the factors that restricted children with leukemia also started to restrict other family members. For example, the sick children were not allowed to meet who they wanted to or to go wherever they wanted because of hygiene precautions. Consequently, other family members, especially the primary caretakers, were also socially isolated during the treatment for the sake of their child's wellbeing. Silva-Rodrigues, Pan, Sposito, de Andrade Alvarenga, and Nascimento (2016) found from their qualitative research in Brazil that families gave up making long-term plans, and tried to live in the present. I think parents prefer behaving like that because to avoid disappointment. They also do not know how the process will end, or what the parents are waiting for, so behaving like this may provide comfort to them. Moreover, various medical equipment also restricts the activity of child leukemia patients, such as the serum, catheter (Hicks, Bartholomew, Ward-Smith, &

Hutto, 2003). To illustrate, one mother in my study stated that it was hard to find a proper t-shirt that did not limit the catheter usage. If she found a suitable one, she told the other mothers where to buy it, so this situation enabled this mother to interact with other mothers, which helped her social status. This again demonstrates how the biological, psychological, and social changes in these families' lives are all interrelated (Engel, 1977).

6.1.5. Parents' Coping

The research findings demonstrated that the families attempted to use various coping methods to deal with the struggles of the treatment process. Both the BPSS approach and systems theory were evident in these results in that different components of the system worked together to regain their stability (Engel 1977; Rabkin, 1981) One of the main coping methods the parents used was maintaining hope and optimism. They tried to look at their current situation in these ways because they believed that it made them strong. Similarly, Santos, Crespo, Canavarro, Alderfer, and Kazak (2015) reported the positive impact of hope on the quality of life of parents whose children have cancer. They conduct their struggle by hoping that their lives will return to normal someday. Silva-Rodrigues, Pan, Sposito, de Andrade Alvarenga, and Nascimento, (2016) also supported this finding in that hope helped parents keep going despite the difficulties of the treatment process. Several other studies report that the parents whose children have cancer use optimism as a coping mechanism (Goldbeck, 2001; Johns et al., 2009).

Related to hope and optimism, the participants in the present study reported that spirituality helped them as well. According to the BPSS approach, spirituality is one of the most fundamental components of the illness process as it helps people find meaning in the illness (Engel, 1977). The parents I interviewed emphasized expressions like “god willing” (inshallah) and “gratitude” throughout the interviews. This is consistent with previous studies that report how spirituality is an important coping method that helps parents deal with the tough process of cancer treatment for their child (Albaugh, 2003; Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011; Johns et al., 2009). In my interviews, parents also sought meaning in the illness. They believed that the process could be a test given by God or that their child had developed leukemia because of the ‘evil eye’. According to Esenay, Sezer, and Turan (2018), most parents who have children with cancer thought that the illness resulted from faith, the evil eye, or the will of God. Some parents in my study also mentioned that they found other people’s prayers for their children very meaningful, which is supported by Schneider and Mannell (2006). They also found that receiving support from other people is very valuable for parents whose children have cancer. On the other hand, some parents report that their spiritual beliefs and practices weaken after their children are diagnosed with cancer (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011; Nicholas et al., 2017; Schneider & Mannell, 2006). However, in the present study, no participants reported such thoughts.

Participants in this study admitted that they preferred not to talk about the illness. They tended to avoid struggles like thinking about the hard process to come or talking about the current treatment process with someone else. For example, they stopped answering phone calls. This finding is supported by Johns et al. (2009), who reported that both Latina and European American mothers used avoidance as a coping mechanism. The present study demonstrates that Turkish mothers have the same tendency. My research participants also preferred to give only limited information to their child (both the one with leukemia and any healthy siblings) to protect them from possible emotional upset Clarke, Davies, Jenny, Glaser, and Eiser (2005) also found that UK parents whose children have leukemia do not want to share what they know about the treatment process with their children. In contrast, Wilkins and Woodgate (2015) revealed from their review study that healthy siblings want accurate information regarding the treatment process. This indicates the need to discuss how much information can be shared with both the children with cancer and their healthy siblings in an age-appropriate way. Participants in the present study also mentioned that they had to hide their emotions to continue the struggle. This strategy may be due to their heavy responsibilities as caretakers during treatment. Finally, Hill, Higgins, Dempster, and Mccarthy (2009) found that fathers preferred to hid their emotions because of their gender roles. I think that this also explains why the one father interviewed in my research could not express his emotions. He described himself as a “çınar ağacı” (sycamore tree) to avoid feeling depressed.

6.1.6. We are not Alone versus Resentment

The experiences that families highlighted regarding the treatment process were in line with the BPSS approach and systems theory. In particular, the participants emphasized how healthy family members and the people surrounding them were included in the treatment process, and provided vital support. They also referred to people in the broader environment who give them great support. For example, support could come from their families, spouses, healthy children, friends, schools, hospital staff, and other families with the same experiences in the hospital. On the other hand, the parents also recalled some unfavorable comments from close relatives, and mentioned how they felt resentment.

McGrath (2001) underlined the necessity of others’ support during cancer treatment. Johns et al., (2009) reported that Latina mothers received support from other families sharing the same experiences to deal with the difficulties. During this tough process, both the children with cancer and their healthy siblings need to be supported. According to Van Schoors, Caes, Knoble, Goubert, Verhofstadt, and Alderfer (2017), greater family support is associated with better adjustment in the children with cancer and their healthy siblings.

Although the parents in this study had to remain physically apart most of the time, they claimed that the treatment process brought them closer together. These parents also mentioned that they supported each other and shared responsibilities, especially to care for healthy siblings. Kelly and Ganong (2011) conducted a qualitative study in the US with the parents whose children had cancer. However, these parents had divorced and remarried. They found that these parents started to come together again to fulfill their parental responsibilities, but this involvement started to change the family boundaries. Consequently, both the step-parents and biological parents experienced role confusion. However, once the crisis ended, there was renormalization phase whereby the parents returned to their normal lives. Silva-Rodrigues, Pan, Sposito, de Andrade Alvarenga, and Nascimento (2016) found that the long hospitalization period meant that the fathers of the sick children started caring for their healthy children. Although it seems unlikely in Turkey, several studies have shown that fathers can become a primary caretaker during the treatment period. They even find this situation respectable because being a caretaker during this process makes them “better men” (Wolff, Pak, Meeske, Worden, & Katz, 2011). In short, the treatment process forces changes in roles within the families (Lehman, 2005).

In the present study, the mothers reported that the healthy siblings also supported their parents in lots of ways. These included being a potential bone marrow donor, helping their sick sibling regarding hygiene issues, spending time with the sibling by playing together, and fulfilling responsibilities (e.g. doing homework). To my knowledge, there are no previous studies in the literature regarding sibling support. Thus, this study contributes a novel finding in terms of thinking about how siblings support their brother or sister with leukemia during the treatment process. In contrast, previous studies have noted benefits from the process for the healthy siblings, such as increased maturity, empathy, and compassion (Alderfer et. al., 2010; Long et al., 2018). However, whether this maturity is something that the child wished to or had to develop needs deeper examination.

While families can be perceived as a source of support for parents while their child is being treated for cancer, they can also be perceived as a source of resentment and anger. From their qualitative study in Australia, Kelada et. al. (2019) reported similar findings to the present study. They found that parents started to feel resentment, anger, and frustration due to the lack of support from their extended families. Moreover, the extended families seemed insufficiently aware of the seriousness of the illness, so they behaved as if the families with a sick child had experienced something normal. Based on the parents' reports in my study, people in their surroundings, such as extended family members, friends, or acquaintances, sometimes made improper comments regarding the seriousness of the illness or the reason for the diagnosis. There are very few reports in the literature about parents' negative feelings (e.g. anger, frustration, or resentment) regarding the other people's comments in the treatment process. Thus, this study contributes to the literature regarding the question of how parents whose children have leukemia feel about other people's inappropriate comments (especially from extended family members).

6.1.7. Outsider View "Finding the Situation Bizarre"

System theory asserts that all parts of a unity are interrelated and interconnected (Dallos & Draper, 2015). Accordingly, the impacts of other people on families whose children have leukemia are undeniable. The BPSS approach is also compatible with this finding in that the components of the system interact with each other and are impacted by each other (Engel, 1977).

More specifically, the present study showed that when these parents went out with their children or encountered someone who did not know them in a hospital environment, they were sometimes exposed to strange looks. Thus, they experienced a sense of pity. Similarly, Gunawan et al. (2016) explored parental experiences of chemotherapy-induced baldness in Indonesia. They reported that these parents perceived baldness as a pity before their children were diagnosed with cancer. Highly-educated families received more pity from teachers and pupils than less-educated ones.

Hicks, Bartholomew, Ward-Smith, and Hutto (2003) found that sick children who had lost their hair reported that their peers stared at them. Moreover, even after the treatment ended, these children still faced some difficulties. Rivero-Vergne, Berrios, and Romero (2010) found that when children with cancer returned to their schools, they were exposed to negative comments from some peers because of their appearance. Thus, parents' concerns about their child's life after treatment seem very sensible and consistent with the BPSS approach (Engel, 1977). That is, while children with cancer face challenges outside the home, other family members also worry about these situations.

Although these studies are useful, I would argue that research into the social stigma that children with leukemia and their families are exposed to is insufficient. In particular, social stigma throughout the treatment process needs to be further investigated while research regarding the sense of pity that these parents experience would also enrich the literature. Moreover, I think that feeling a sense of pity during the treatment process may be a specific cultural characteristic of Turkish people due to the relatedness component of Turkish society (Kağıtçıbaşı, 2005). That is, Turkish families have a sense of emotional relatedness to their surroundings, especially to their close relatives. Thus, the participants in this study might have certain expectations of support from other people during the treatment process; when their expectations are not met they may feel a sense of pity.

Finally, there were only small differences in the demographic characteristics of the participants. One distinction was that the participants whose children had been most recently diagnosed with leukemia mentioned their longing feelings for their healthy children. I would infer from this that the participants might be in the middle of adapting to this recent dramatic change in their lives, so their longing feelings might be more vivid. Another distinction was that only the father failed to highlight the effects of being exposed to strange looks by outsiders. Given that, as mentioned earlier, he described himself as a sycamore tree, he may not have noticed these looks due to his heavy responsibilities during the treatment process.

6.2 Clinical Implications

My own participation in this study made me somewhat anxious at the beginning because the topic is directly related to myself. It was indeed hard remembering the treatment process 10 years later; yet I also felt lucky because I could look at the process as both a patient and a researcher. I also always reminded myself that such studies of the experience of cancer can help us understand the experiences of the families; this thought strengthened me. Moreover, at the end of each interview, almost all parents gave me constructive feedback regarding the process. Many participants said that they were relieved to share their experiences. To ensure trustworthiness, I used the member checking technique by contacting the families again. The feedback that I received was very positive as they stated that the findings reflected their experiences during the treatment process. They also thanked me for conducting this type of study. I can just say that I was so proud; it is hard to describe my feelings adequately.

To my knowledge, this is the first study using in-depth interview questions to understand how families are affected by childhood leukemia treatment in Turkey. The questions were designed to investigate the biopsychosocial spiritual dimensions of the disease, based on system theory. The research is thus important for both psychologists and social policy makers in terms of realizing the needs of families who have children with leukemia.

The findings of this study should encourage interdisciplinary leukemia treatment because the child's body, psychological well-being, and social and family environment are all affected by the disease and its treatment. Because family members have to engage in a difficult process, they may need resources as a family to cope with the resulting adversity. One important implication is that health professionals should involve family members in the treatment process. When a child is diagnosed with leukemia, doctors, nurses, psychologists, psychiatrists, physiotherapists, dietitians, teachers, and other hospital staff should work together for the welfare of the family. Thus, from the beginning of the process, families should proceed with all these professions to complete the treatment successfully. At this point, we can mention the necessity of Medical Family Therapy (MedFT). In this approach, medical family therapists give importance to collaborative working with those responsible for the patient's care. That is, the family, physician, pharmacologist, psychotherapist, and dietitian work for the patients' welfare. The other role of the medical family therapist is working with the emotional themes during the tough process. They facilitate families to express their emotions, whether positive or negative. In particular, because children are one of the most valuable parts of the family system, family dynamics and the emotions experienced by family members may totally change. That is, the sick child's condition influences the system and the system's reactions influence the sick child, the family, the treatment process, relationships between health care professionals, and so on (McDaniel, Doherty, & Hepworth, 2014).

Moreover, the child with leukemia, healthy siblings, and the parents should all participate in support groups to share their personal experiences with others having the same experience. Families need appropriate information about such groups and the professionals should encourage them to participate in them. In Turkey, there are several foundations that support families with cancer, such as Lösev and Kaçuv. However, there is no foundation in

Turkey that specifically focuses on the needs of healthy siblings – although having and belonging to such a group can make the siblings of children with cancer feel better (Barrera, Neville, Purdon, & Hancock, 2018; Nolbris, Abrahamsson, Hellström, Olofsson, & Enskär, 2010). Thus, support programs like “SuperSibs!” in the USA should be established in Turkey for the siblings of children with cancer. Furthermore, the treatment process concerns not only the nuclear family but also the extended family. Accordingly, the hospital administration and hospital staff should inform all family members regarding the treatment process and create a road map together. The hospital should also be understanding about families’ questions and concerns and approach them in as friendly a manner as possible. In the present study, only one participant stated that the doctor preferred to inform the father regarding the treatment process. Instead, both parents generally learned about the diagnosis together. Thus, since all family members are affected by the treatment process, it is important to include larger systems into the health system itself.

To sum up, the importance of MFT should be highlighted more. In addition, the government should prepare a systemic leukemia treatment program to provide good physical, psychological, and social outcomes for families of children with leukemia. Lastly, the government should prepare public service announcements to raise awareness about the social stigma that children with leukemia and their families are exposed to.

6.3 Limitations

Inevitably, there are some limitations in this research study. First, the preexisting distress and conflicts within the families were not known. For instance, one mother mentioned that the night before the interview her child had a fever, so she could not sleep properly. Such events can influence the current situation. Second, one parent shared the experience of all family members with the researcher, which could introduce bias. In addition, only one father participated in the study, so the experiences of the fathers in the treatment process could not be explored in detail while I was also unable to compare the experiences of fathers and mothers. Third, several extraneous variables affected the study. For instance, the course and intensity of treatment could impact the parents' experiences, and affect the findings. To illustrate, the first participant indicated that their child was in a remission period whereas another participant stated that her child was diagnosed just 2 months before. Fourth, the data were collected at only one time point so the parents' experiences at different time points were not be determined. Fifth, all the participants were married so the narratives of other types of families were ignored. Lastly, the interview itself was time-consuming and the parents were emotionally overloaded by the need to remember the hard process. Thus, most participants had to take breaks to satisfy their own needs and check on their children.

6.4 Recommendations for Future Research

Future studies can investigate structurally diverse families and include both parents' experiences. In this way, we can gain greater understanding of family dynamics from the interviews. The data can be collected longitudinally. This will help establish cause and effect relationships and reveal changes in family relationships during the treatment process. Further studies should also include the experiences of fathers more, as they tend to be left in the background during the treatment process. I believe fathers' experiences are actually like treasure that is waiting to be discovered. Furthermore, family dynamics could be investigated more broadly through mixed design studies. Finally, future researchers should try to eliminate extraneous variables as much as possible, for example by conducting interviews during the same treatment period for different participants, or by comparing the experiences of one participant in two different treatment periods.

6.5 Conclusion

This study was a phenomenological qualitative study to investigate the changed family dynamics during childhood leukemia treatment. The study was based on systems theory and the BPSS approach. There were ten participants (9 mothers and 1 father) who all had a child diagnosed with leukemia who was attending either a state or private hospital. Seven main themes emerged from the interviews: (1) Fragmentation of the family; (2) Siblings: “Forgotten children”; (3) Changes in the children; (4) Changes in parenting; (5) Parents’ coping; (6) We are not alone versus Resentment; (7) Outsider view “finding the situation bizarre”. Further studies should try to get the fathers’ experiences during the treatment process. Finally, the government should prepare a systemic leukemia treatment program to support families who have children with leukemia physically, psychologically and socially.

APPENDICES A

INFORMED CONSENT FORM

Projenin Adı: Çocukları lösemi teşhisi almış ebeveynlerin tedavi sürecindeki deneyimleri.

Proje yürütücüsünün adı ve iletişim bilgileri:

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Projenin amacı: Bu çalışmanın amacı çocukları lösemi teşhisi almış anne ve babaların süreç içindeki deneyimlerini incelemektir. Süreç içinde değişen aile dinamiklerini araştırmak hedeflenmektedir. Çalışmadan elde edilen bulgular kanser tedavisinde disiplinler arası bir sürecin gerçekleşmesine katkı sağlayacaktır.

Süreç: Gönüllü onay formunun doldurulup imzalanmasının ardından sizlerden araştırmada kullanabileceğiniz bir kod adı belirlemeniz istenecek, araştırmada kimlik bilgileriniz gizli tutulacaktır. Öncelikle demografik bilgi formunu doldurmanız beklenmektedir. Bu formun doldurulmasının ardından görüşme yapılmaya başlanacaktır. Görüşmeler projede kullanılabilmesi için ses kaydına alınacaktır.

Araştırmanın sonunda deneyimleriniz belirli temalar altında toplanacak ve bu temaların sizin deneyimlerinizi yansıtıp yansıtmadığı konusunda bilgi alınacaktır. Bu nedenle e-mail ve telefon bilgilerinizi paylaşmanız beklenmektedir. Sizinle bu şekilde iletişime geçilecektir.

Bu görüşme sonunda eğer destek almaya ihtiyacınız olduğunu düşünürseniz Özyeğin Üniversitesi Çift ve Aile Merkezi (ÖZÜÇAM) ile (549) 810 86 25 nolu telefondan ya da Bilgi Üniversitesi Psikolojik Danışmanlık Merkezi (PDM) ile pdm@bilgi.edu.tr adresinden ya da (212) 311 76 74 nolu telefondan iletişime geçebilirsiniz.

Gizlilik: Bu araştırmada gizlilik esasına bağlı kalınacaktır. Katılımcıların demografik formları, e-mail ve telefon bilgileri, görüşme dokümanları (notlar, ses kayıtları) katılımcıların kod adları ile şifre korumalı dosyalarda ve şifre korumalı bilgisayarlarda saklanacaktır.

Gönüllü Katılım: Bu projeye katılım tamamen gönüllülük temelindedir. Bu formu imzalamama ve çalışmaya katılmama hakkınız her zaman geçerlidir. Formu imzalasanız dahi kendinizi rahat hissetmediğiniz an çalışmayı bırakabilirsiniz. Katılımı reddetmek herhangi bir zarara yol açmayacaktır. Araştırma sırasında veya sonrasında herhangi bir sorunuz olursa lütfen yukarıda verdiğimiz iletişim bilgilerinden bize ulaşınız.

Bu formda anlatılan araştırmanın etik yönleriyle ve/veya araştırma detaylarıyla ilgili sorularınız, sorunlarınız veya önerileriniz varsa lütfen Özyeğin Üniversitesi Etik Kurulu ile (216) 564 9512 no'lu telefondan temasa geçiniz.

Yukarıda sözü geçen "Çocukları lösemi teşhisi almış ebeveynlerin tedavi sürecindeki deneyimleri" isimli araştırma projesinin detaylarını okudum ve bu proje ile ilgili sorularım cevaplandı. Bu çalışmaya gönüllü olarak katılıyorum. Özel nitelikli kişisel verilerimin, kişisel verilerimin, çocuğumuzun özel nitelikli kişisel verileri ile kişisel verilerinin sadece araştırma konusu ile ilgili olarak kullanılmak üzere toplanmasına, işlenmesine ve amaç ile sınırlı olarak aktarılmasına muvafakat ediyorum.

____________________________ ____________________________

İsim Soyad Tarih

E-mail Telefon

APPENDICES B

INTERVIEW QUESTIONS

1) Oğlunuza/Kızınıza bu teşhis ne zaman ve nasıl kondu? Hangi tedavilerden geçti?
2) Hastalığı öğrenme sürecinizi anlatabilir misiniz, neler düşündünüz, neler hissettiniz? (Probe: Aklınızdan neler geçti, bu duygu ve düşüncelerle neler yaptınız)
3) Eşiniz ilk öğrendiğinde ne yaptı? Siz bunların karşısında neler düşündünüz? Neler hissettiniz? Nasıl davrandınız?
4) Kardeşleri hastalığı biliyor mu? Nasıl anlattınız? Bunları anlattığınızda ne yaptılar?
5) Hastalık öncesinde hayatınız nasıldı? Teşhisten sonra hayatınızda neler değişti? (Probe: aile, iş ve sosyal hayat, hayata bakış)
6) Bu sürecin sizin için en zor tarafları neler? Nasıl başa çıkıyorsunuz?
7) Bu süreçte yanınızda kimler bulunuyor? Size nasıl destek oluyorlar?
8) Bu süreçten eşinizle olan ilişkiniz nasıl etkilendi?
9) Bu süreçten diğer çocuklarınızla olan ilişkileriniz nasıl etkilendi?
10) Teşhisten sonra çocuklarınızın arasındaki ilişkiyi öncesine kıyasla nasıl değerlendiriyorsunuz? Bu süreçten kardeş ilişkisi nasıl etkilendi?
11) “Lösemi” aile içinde nasıl konuşuluyor?
12) Teşhisten sonra aile içi ilişkilerinizde neler değişti? (Probe: sorumluluklar, iletişim şekli, birlikte geçirilen zaman)
13) Doktorlarla ve diğer sağlık personelleri ile olan ilişkilerinizi nasıl değerlendirirsiniz? (Probe: size olan yaklaşımları, bilgilendirmeleri)
14) Bu teşhisi başkalarıyla paylaştınız mı? Onlar ne yaptılar? Siz bunların karşısında ne hissettiniz, düşündünüz? Onlara karşı nasıl davrandınız? (Probe: geniş aile, arkadaşlar, iş yeri, okul)

15) Teşhisten sonra insanların size karşı tutum ve davranışlarını öncesine kıyasla nasıl değerlendiriyorsunuz? Siz bu tutum ve davranışlar hakkında ne hissettiniz, düşündünüz? Nasıl davrandınız? (Probe: yakından tanıyanların, uzaktan tanıyanların)
16) Tedavi olan çocuğunuzla beraberken tanımadığınız insanların size olan yaklaşımlarını nasıl gözlemliyorsunuz? (sokakta yürürken vs.) Siz bunların karşısında ne hissettiniz, düşündünüz? Nasıl davrandınız?
17) Bu süreçte en çok neye ihtiyacınız olduğunu hissediyorsunuz? Sizi en çok ne rahatlatıyor? (Probe: örnek)
18) Bu teşhisi yeni almış bir aileye ne tavsiye edersiniz?
19) Son olarak eklemek istediğiniz bir şey var mı?

APPENDICES C

DEMOGRAPHIC INFORMATION FORM

1) Cinsiyetiniz: __________

2) Yaşınız: __________

3) Medeni durumunuz: __________

4) Mesleğiniz: __________

5) Sosyo-ekonomik (maddi) seviyenizi nasıl tanımlarsınız?

○ Üst sınıf ○Üst-orta sınıf ○Orta sınıf ○Düşük-orta sınıf ○Düşük sınıf

6) Eğitim durumunuz (en son mezun olduğunuz okul):

○ İlkokul ○ Ortaokul ○ Lise ○ Üniversite ○ Yüksek lisans

7) Kaç çocuğunuz var, tedavi gören çocuğunuz kaçıncı çocuğunuz? __________

8) Çocuğunuz lösemi teşhisi alalı ne kadar zaman oldu? __________

9) Löseminin türü nedir? __________

10) Tedavi sürecinde olan çocuğunuzun yaşı ve cinsiyeti? __________

11) Tedavi süreci ile birlikte psikolojik tedavi arayışınız/düşünceniz oldu mu?

○ Evet ○ Hayır

12) Bu süreçle birlikte herhangi bir psikolojik ilaç kullanma arayışına girdiniz mi?

○ Evet ○Hayır

13) Çocuğunuzun lösemi teşhisi almasıyla birlikte bir destek grubuna ya da derneğe katıldınız mı?

○ Evet ○ Hayır

14) Daha önce yakın tanığınız biri kanser teşhisi almış mıydı?

○ Evet ○ Hayır

15) Evet ise, kim ve ne kanseri?

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