

EXAMINATION OF THE COPING PROCESSES OF CAREGIVERS OF
CHILDREN WITH CANCER

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ABSTRACT

EXAMINATION OF THE COPING PROCESSES OF CAREGIVERS OF CHILDREN WITH CANCER

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The general aim of the present dissertation was to examine the coping processes of the caregivers of children with cancer. It was composed of three studies, whose aims were (1) to reveal the predictors of caregiver distress by using the Transactional Theory of Coping among the caregivers of children with cancer; (2) to identify the factors associated with caregiving process from the caregiver's perspective qualitatively; (3) to develop and implement an intervention program. Study 1 was conducted with 105 participants, who filled in the questionnaire set. The findings revealed the predictors of depressive and anxiety symptoms and dissatisfaction with life. Study 2 examined subjective experiences of the caregivers. Interviews were conducted with 20 participants and the identified themes were emotions, change, and coping. Study 3 included the development and testing the effectiveness of an intervention program. A multidimensional group intervention was planned, and applied to 16 participants. The findings indicated that the participants reported higher levels of positive affect and lower levels of negative affect after the intervention, as compared to their reports before the intervention. The possible explanations of the results were explored and the clinical and research implications were discussed. Overall, the study examined the coping process of the caregivers of children with cancer in a constructive way with the ultimate aim of facilitating adjustment, and also shed light on the important factors in the development of intervention programs.

Keywords: Caregiver, cancer, coping, qualitative, intervention

ÖZ

KANSERLİ ÇOCUKLARIN BAKIM VERENLERİNİN BAŞ ETME SÜREÇLERİNİN İNCELENMESİ

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Bu çalışmanın amacı kanserli çocuklara bakım verenlerin baş etme süreçlerinin incelenmesidir. Ana çalışma, üç alt çalışmadan oluşmaktadır. Bu çalışmaların amaçları (1) Transaksiyonel Baş Etme Teorisi kullanılarak kanserli çocukların bakım verenlerinin stres düzeylerini etkileyen etmenleri araştırmak; (2) bu süreçle ilgili etmenleri bakımverenin bakış açısından niteliksel olarak incelemek ve (3) bir müdahale programı geliştirmek ve etkililiğini test etmektir. Birinci çalışma, anket setini dolduran 105 katılımcı ile gerçekleştirilmiştir. Bulgular, depresyon ve kaygı belirtileri ve yaşam doyumunu yordayan etmenleri göstermiştir. İkinci çalışma bakım verenlerin öznel deneyimlerini incelemiştir. 20 kişi ile görüşme yapılmış ve duygular, değişim ve baş etme temaları belirlenmiştir. Üçüncü çalışma bir müdahale programı geliştirme ve etkililiğinin test edilmesinden oluşmuştur. Kanserli çocukların bakım verenleri için çok boyutlu bir program planlanmış ve 16 kişiye uygulanmıştır. Bulgular, uygulama sonrasında katılımcıların ön-test ölçümlerine oranla pozitif duygularının arttığını ve negatif duygularının azaldığını göstermiştir. Bulguların olası açıklamaları incelenmiş ve çıkarımları klinik ve araştırma yönlerinden tartışılmıştır. Sonuç olarak bu çalışma kanserli çocukların bakım verenlerinin uyum sürecini destekleme amacıyla yapılmış, baş etme süreçlerini yapısal olarak incelemiş ve ayrıca müdahale programlarının geliştirilmesinde rol oynayan önemli etmenlere ışık tutmuştur.

Anahtar kelimeler: Bakım veren, kanser, baş etme, niteliksel, müdahale

To the families I have
and I met in the course of the study

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CHAPTER 1

INTRODUCTION

1.1. Chronic Illness

As a general definition, chronic illness is a long term health problem or disability, for at least 6 months (Vickers, Parris, & Bailey, 2004). Unlike acute diseases, which are shorter in duration, respond to a specific treatment, and have an expectation with a return to the normal health prior to the illness; chronic illnesses are longer or have indefinite duration, have a risk of other accompanying symptoms such as pain, may affect physical functioning, and have uncertain future. Therefore, while acute diseases require basically following the orders of the medical team, chronic illnesses usually require an adaptation to living with the illness (Lorig et al., 2006). With the rise of the biopsychosocial model (Engel, 1977), adaptation to the illness has been in the interest of psychology. It has been acknowledged that biological, psychological and social factors interact in illnesses. Hence, the diagnosis of a chronic illness involves psychological and social (including the family) counterparts, as well as the physical part.

A chronic illness has an effect on the whole family in which there is an ill family member. The adaptation to the illness process includes not only the ill person, but also the entire family. There are changes in the dynamics, roles, and daily life to accommodate the illness and treatment process. Moreover, family members have their own concerns, reactions, and emotions for the illness, which are open to change during different phases of the treatment. Families are also important as a source of support for the ill member (Alderfer & Kazak, 2006). Therefore, the well-being of the family is important for the well-being of the ill member. The adaptation of the ill member affects the adaptation of the family, and vice versa. For this reason, family members, especially the caregivers are at the scope of this study. The

present study aims to understand how childhood cancer, a chronic illness, affects the well-being of the caregivers. Caregiving is defined as providing assistance to relatives who are unable to provide for themselves; and it includes both an affective and a behavioral expression of commitment to welfare of another person (Pearlin et al., 1990).

1.2. Cancer

“Cancer is a group of diseases characterized by the presence of new cells that grow and spread beyond control” (Brannon & Feist, 2010, p. 255). The malignant growth of cells can be examined in four main groups: Carcinomas (cancers of epithelial tissue, such as skin), sarcomas (cancers of connective tissue, such as bone), leukemias (cancers of blood, such as stem cells), and lymphomas (cancers of lymphatic system) (Brannon & Feist, 2010). Childhood cancers have their own classification system, which is International Classification of Childhood Cancer (ICCC) (National Cancer Institute, n.d.). Based on the work of Steliarova-Foucher and colleagues (2005), ICCC suggested 12 cancer groups, such as leukemias, lymphoma and gliomas. After the diagnosis, the treatment process begins, usually immediately. Treatment of childhood cancers is a multimodal process, which includes one or more of the following main treatment modes: Chemotherapy (use of drugs to attack cancer cells), bone-marrow and stem cell transplantation (use of marrow or stem cells to reverse life threatening restraint of bone marrow), radiotherapy (use of radiation to attack cancer cells), and surgery (removal of tumor) (Dixon-Woods, Young, & Heney, 2005). The treatment process is usually long-term and is accompanied by pain and side effects. The outcomes of the treatment vary depending on various factors, such as, being metastasized or not (Brannon & Feist, 2010). Thus, cancer requires a long-term and continuous care, has an uncertain and life threatening nature.

The diagnosis of cancer can be considered as a traumatic stressor. In DSM-IV-TR “Learning that one’s child has a life threatening disease” is defined as a traumatic event, which may result in post traumatic stress disorder (APA, 1994). It was suggested that every year, approximately 2.500-3000 cancer cases are expected for

0-14 age group, whereas this number is 150.000 for adults in Turkey. The most frequent types of childhood cancers were leukemia, lymphoma, and central nervous system tumors (Kutluk, 2008). According to Turkish Pediatric Oncology Group data; in 2002, 1073 childhood cancer cases were registered and one-year survival rates for these cases were 77 %. According to statistics, survival rates and successful treatment outcomes increase every year (Kutluk, 2008), and this puts further importance to the adaptation to treatment and post-treatment of both children and their families.

1.3. The Aims and Organization of the Current Dissertation

The general aim of the present dissertation was to examine the coping processes of the caregivers of children with cancer. It was composed of three studies, whose aims were (1) to reveal the predictors of caregiver distress by using Lazarus and Folkman's (1984) Transactional Theory of Coping Model among the caregivers of children with cancer; (2) to identify the factors associated with caregiving process from the caregiver's perspective qualitatively; (3) in the light of the findings of the first and second studies, to develop and implement an intervention program, and to test the effectiveness of it.

This chapter provided the theoretical background for the study. The aims, hypotheses, method, results, and discussion sections of the Study 1 were explained in Chapter 2, Chapter 3 included the aims, method, results and discussion sections of the Study 2. In Chapter 4, the intervention program was defined and the aims, method, results and discussion sections were included. The last chapter, Chapter 5, included a general discussion, in which the results of the previous three studies were integrated. The limitations of the study, implications of the findings, and the directions for further research were given in Chapter 5.

1.4. Caregiver Studies

As it was mentioned, childhood cancer affects the whole family. The caregiver is a part of the treatment process, which makes him/her experience psychological distress concerning the illness. Therefore, previous studies have examined the levels of distress, the risk factors that increase the likelihood of worse psychological outcomes and protective factors that decrease the likelihood of worse psychological outcomes. Several theoretical models integrating previous findings and evaluating caregiving a chronically ill patients as a process were developed and tested. A review of these quantitative studies, theoretical models that were used in caregiver studies, qualitative studies, and intervention studies were given in the following sections.

1.4.1. Quantitative Studies on Caregivers

Being a caregiver of an ill family member is considered as a risk factor for worse well-being. Compared to healthy control condition, parents of children with cancer had significantly higher levels of depression and anxiety symptoms, lower levels of life satisfaction, and worse health perception (Fotiadou et al., 2008). When being parent of a child with cancer was compared to other chronic illnesses, i.e. diabetes and epilepsy; a worse quality of life was reported by cancer caregivers (Goldbeck, 2001). Physical health of the caregivers was also stated to be worsened in the presence of a child's chronic condition. Holm and colleagues (2008) indicated that parents having higher levels of psychological symptoms developed more physical symptoms as time passes.

The process that ends up with a worse psychological adjustment does not merely depend on having a caregiver role. There are other variables of the caregiving process that determine caregivers' level of adjustment. The demographic characteristics of the caregivers, perception of control over health, being able to fulfill basic needs and perform daily activities in the presence of caregiving role, social support, stress appraisal, choice and use of coping strategies are some of the variables that were discussed in relation to psychological adjustment of caregivers.

1.4.1.1. Demographic Variables

In terms of the effects of demographic variables, it was found that lower income was associated with higher anticipatory grief in the parents of children with cancer (Al-Gamal & Long, 2010). Age is another demographic variable that is associated with distress. It was revealed that younger caregivers experience more distress (Matthews, Baker, & Spillers, 2003). There are contradictory findings for the effects of gender on well-being; in other words, whether there is a difference between mothers and fathers of children with cancer or not. Some studies found no difference between mothers and fathers (e.g., Al-Gamal & Long, 2010; Svavarsdottir, 2005); while other studies suggested that mothers experience higher levels of distress (e.g. Sloper, 2000; Yeh, 2002). Moreover, lower education level was related to more post-traumatic stress symptoms of fathers (Dunn et al., 2012). Thus, several demographic variables were found to be related to levels of distress experienced by families of children with cancer.

1.4.1.2. Sense of Control

Being able to predict the outcomes and the course of events was important for a person's sense of control. For the sense of control over people's health, the concept of health locus of control could be used. Health locus of control was defined as "the set of beliefs that an individual holds about personal influence over the course or outcome of an illness" (Williams & Koocher, 1998). People may believe that they themselves (internal), powerful others or chance (external) has control over health and illness situations. This concept is important for predicting people's health behaviors (Wallston, Wallston, & DeVellis, 1978) and problem solving strategies (Williams & Koocher, 1998).

In terms of chronic illnesses, sense of control is prone to change. For example, hair loss during chemotherapy can be regarded as a loss of internal locus of control (Williams & Koocher, 1998). As Lazarus and Folkman (1984) suggested, the sense of control was also related to the choice of coping strategies. Internal locus of control is associated with the choice of problem focused coping strategies, whereas

external locus of control is related to emotion focused coping or avoidance. Thus, health locus of control could be considered to affect caregivers' adjustment indirectly.

1.4.1.3. Caregiver Well-being

Caregiving a child with cancer requires some illness specific tasks, such as staying with the ill child during hospitalization, communicating with the medical team, helping the child in dealing with some painful medical procedures and their side effects, financing the treatment, and meeting the needs of the child, such as nutrition (Keene, 2002). These tasks of caregiving require the time and the energy of the caregiver. Therefore, there may be less time and energy for the needs of the caregiver himself/herself, which may result in an increase in depressive and anxiety symptoms (Demirtepe-Saygılı & Bozo, 2011a). Moreover, the caregivers can spend less time for families and friends and planned activities, which in turn result in more distress (Matthews, Baker, & Spillers, 2003). Thus, not being able to meet his/her own needs and engage in daily activities as before the illness impacted the psychological adjustment of the caregivers negatively.

1.4.1.4. Social Support

There was an agreement about the protective role of social support from stressful life events (Cohen & Willis, 1985), including caregiving a person with a chronic illness (Pearlin et al., 1990). Higher levels of perceived social support were associated with better adjustment for mothers of children with cancer (Han, 2003). Moreover, support of family members moderated the relationship between repression and adjustment (Fuemmeler et al., 2003). In other words, social support buffered the negative effects of repression on adjustment.

Social support is also important for predicting caregiver stress during stressful procedures. For example, during hematopoietic stem cell transplantation (HSCT), a procedure applied for some types of cancers, social support from spouses and family were important for mothers' adjustment level in the consequent year. Moreover, the

source of social support could vary, such as spouse, family, or friends and receiving support from a source could be replaced by support from other sources. To illustrate, the adverse effect of low spousal support was moderated by support received from family and friends, and vice versa (Rini et al., 2008). Therefore, social support was an important coping source for stressful life events, such as having a child diagnosed with cancer.

1.4.1.5. Appraisal and Coping Strategies

Cognitive appraisal is a process for the evaluation of stressfulness of an event or situation. Appraisals of the situation and sources of the person are important for the choice of coping strategies (Lazarus & Folkman, 1984). The concept of appraisal provides an explanation for individual differences in coping with stress. The situation can be appraised as a threat for some people while as a challenge for some others. Appraisal can act as a mediator between the stressors and health outcomes (Son et al., 2007). In terms of chronic illnesses, patients' appraisal of their illness related stressors were stronger predictors of adjustment, as compared to illness variables (Pakenham, 1999). There is a high level of uncertainty for most of the childhood cancer cases (Alderfer & Kazak, 2006), which may address an appraisal of threat by the caregivers of children with cancer.

Coping strategies of the caregivers have also been examined in terms of their impact on their adjustment. In the context of caregiving a family member with a chronic illness, researchers used coping strategies as a predictor or a mediator between distress and burden (e.g., Folkman & Lazarus, 1984; Pruchno & Resch, 1989). The use of problem focused coping was a predictor of better adjustment as compared to the use of emotion focused coping (Aldwin, 1994). It was found that problem focused coping is negatively related to caregiver burden (Patrick & Hayden, 1999) and depression (Elliot & Shewchuk, 2003). The use of more emotion focused coping was found to be related to higher levels of depression (Williams et al., 2002) and posttraumatic stress symptoms and general psychological distress among the parents of children with cancer (Fuemmeler, Mullins, Pelt, Carpentier, & Parkhurst, 2005). To sum up, findings on coping strategies stated that problem focused coping

is related to better adjustment, whereas the use of emotion focused coping is related to worse adjustment.

In terms of caregiving a child with cancer, a study comparing the mothers of children with cancer with the mothers of children with acute illnesses revealed that the former group reported more emotion focused coping strategies than the latter one, which can possibly be explained by the uncertainty and life-threatening nature of the cancer (Barrera et al., 2004). The use of coping strategies was studied by considering the time course, too. It was found that problem focused coping was most effective among the parents of pediatric cancer patients at the initial phase of the illness, which requires searching and learning more about the illness and treatment (Hoekstra-Weebers, Jaspers, Klip, & Kamps, 2000). The same study also revealed that changes in the coping styles were possible in the course of the treatment process and the preferred coping style influenced their distress at that particular time. In other words, the coping styles that were being used before did not have an effect on the current level of distress. Similarly, in a cross-sectional study, although it was not possible to observe the change longitudinally, mothers of leukemic children tended to use problem focused coping strategies more at the initial phase of the illness and emotion focused coping strategies at the subsequent phases of the illness (Demirtepe-Saygılı & Bozo, 2011b). The process of caregiving a child with cancer may need different coping strategies. The important point that needs to be taken into account is the coping-environment fit. Theoretically, in the case of high appraised control, problem focused coping was preferred and in case of low appraised control, emotion focused coping was used (Folkman & Moskowitz, 2004). This relationship between the situation and personal control is referred as the goodness of fit (Conway & Terry, 1992). Therefore, coping with the child's cancer may have some controllable and uncontrollable parts, which needs to be distinguished and coped with accordingly.

1.4.1.6. Affect

Caregiver studies including “affect” as a variable defined it in various ways. For example, negative affective responses were defined as having depressive and

anxiety symptoms (Frank et al., 2001). Moreover, the presence of positive affect was usually underestimated. In the present study, Watson and Tellegen's (1985) conceptualizations of positive and negative affect was used.

Watson and Tellegen (1985) studied affect as a two dimensional structure as negative and positive affect. Negative and positive affect were not conceptualized as being opposite to each other (Watson, Clark, & Tellegen, 1988). High positive affect consisted of having "high energy, full concentration and pleasurable engagement", while low positive affect included "sadness and lethargy". Moreover, while high negative affect included aversive mood states, such as anger, guilt, and fear; low negative affect was characterized by a state of "calmness and serenity" (Watson, Clark, & Tellegen, 1988).

Although negative affect is more prominent in the presence of stress, positive affect may also accompany stress, coexisting with negative affect (Folkman & Moskowitz, 2000). Positive affect in the presence of stress was studied as benefit finding (e.g., Bower et al., 2007), adoption of new skills (e.g., Fredrickson & Joiner, 2002), and perception of growth (Park, Cohen, & Murch, 1996).

Caregiving a child with cancer was accompanied by various emotions, which were usually negative. Therefore, studies usually focused on negative affect and the predictors of it. For example, it was revealed that as compared to medical variables, psychosocial variables were stronger in predicting emotional functioning after the treatment of childhood cancer (Maurice-Stam, Oort, Last, & Grootenhuis, 2008). One of these psychosocial variables was having positive expectations, which was closely associated with lower levels of negative emotions (Grootenhuis & Last, 1997).

Positive affect has not been studied in relation to caregivers of children with cancer, to the author's knowledge. As Kramer (1997) stated, in illness studies, negative affect received much more attention than positive affect. However, Robertson and colleagues (2007) suggested that caregivers experiencing high or low levels of positive and high or low levels of negative affect may have different needs.

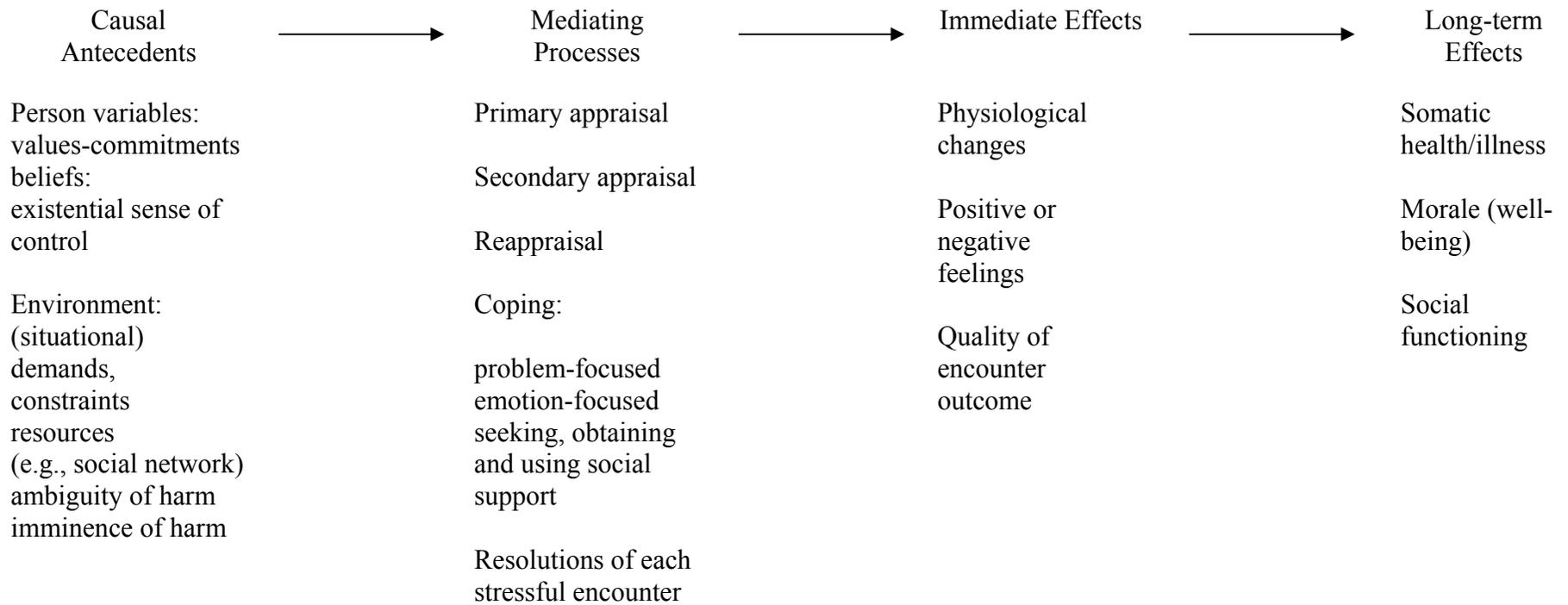
Therefore, since the interventions should be tailored in accordance with the needs of individuals who have high negative affect coupled with or without positive affect; studying positive affect in caregivers of people with chronic conditions was as important as studying negative affect.

1.4.2. The Model: Transactional Theory of Coping

The theoretical framework of the present study is the Transactional Theory of Coping (Lazarus & Folkman, 1984) (see Figure 1). Stress was defined as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his/her personal resources and endangering his/her well-being.” Coping was described as “the process through which the individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions they generate.” The relationship between stress and coping was evaluated as transactional; in other words, it is dynamic, bidirectional, and reciprocal. Cognitive appraisal and the coping strategies play an important role in this relationship. Cognitive appraisal consists of three processes, namely; primary appraisal, secondary appraisal, and reappraisal. In primary appraisal, the situation is evaluated as being irrelevant, benign-positive, or stressful. In secondary appraisal, possible responses to the situation are evaluated by taking into account the resources and potential to cope; and in reappraisal, the previous appraisal can be changed based on new information. Problem focused coping includes addressing the problem that causes stress, and making and applying plans; whereas, emotion focused coping includes ameliorating the negative emotions that are related to stress (Lazarus & Folkman, 1984). The immediate effects depend on the appraisal of the outcomes of coping. That is, when the resolution of a stressful situation is appraised as successful, positive affect can be expected. On the contrary, when the resolution is appraised as unsuccessful, negative affect can be anticipated.

The Transactional Theory of Coping (Lazarus & Folkman, 1984) has provided a framework for many studies over years (e.g. Ducharme et al., 2005). It was also adapted and used in chronic illness literature with different samples, such as siblings of children with sickle cell disease (Gold, Treadwell, Weissman, & Vichinsky,

2008), caregivers of elderlies who need homecare (Gräbel & Adabbo, 2011), and caregiver-patient dyads coping with multiple sclerosis (Pakenham, 2001). In this dissertation, the Transactional Theory of Coping (Lazarus & Folkman, 1984) was used as the theoretical framework of Study 1, which aimed at examining the predictors of caregiver distress (see Chapter 2), and Study 3, which suggested an intervention program (see Chapter 4).



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Figure 1

A theoretical schematization of stress, coping and adaptation (Lazarus & Folkman, 1984)

1.4.3. Qualitative Studies on Caregivers

The nature of the studies conducted with caregivers of children with cancer was mostly quantitative. Although using quantitative approach has many advantages such as generalization, objectivity, and reliability; it was still possible to miss some important points in quantitative studies. To illustrate, the subjective interpretations of the participant and the researcher are eliminated in quantitative research (Flick, 2002). It is the qualitative research that can make up for the weak points of quantitative approach. It can acknowledge diversities and subjective perspectives of the participants (Flick, 2002). As the aim of the second study was to examine the coping process of the caregivers from their own perspective, qualitative approach was preferred for Study 2.

Interpretative phenomenological analysis (IPA) was chosen as the theoretical orientation for the qualitative method of the present study. “The aim of IPA is to explore in detail individual personal and lived experience and to examine how participants are making sense of their personal and social world” (Smith & Eatough, 2007). It assumes that it is impossible to have a direct access to the participant’s world. Hence, it includes the perspective of the researcher, the participant, and the interaction between them (Willig, 2008). That is, it is a dynamic process in a sense that researcher’s conceptualization is in an interaction with the participant’s. IPA uses the transcripts of semi-structured interviews (Willig, 2008). Since the aim of the present study is to understand how the families evaluate living with cancer and perceive the experience of having a child with cancer, IPA was selected as the method of analysis.

As it was mentioned above, there are a limited number of qualitative studies conducted with caregivers of children with cancer and some of these qualitative studies are summarized below. Longitudinal studies tried to reveal the needs and problems of caregivers and children considering the changes in time. For example, in a qualitative study, McGrath (2001) examined support among leukemic children and their caregivers longitudinally. Partners, family, friends, employers, staff, and other caregivers were identified as the sources of support. Moreover, according to

this study, support offers declined by time although there was a continuous strong need for support. Earle and Eiser (2007) focused on leukemic children's coping and behaviors from mothers' perspective longitudinally. Mothers reported their child having more behavioral problems in older age owing to child's having more knowledge about the illness.

Fletcher, Schneider, and Harry (2010) did also focused on subjective experience of mothers' coping with their child's cancer; and their study revealed that practical and social support, faith and hope contribute to successful coping. On the other hand, the mothers reported neglecting their own health or engaging in unhealthy behaviors to cope with stress. A need to protect the family members, especially the ill child was a theme reported by the mothers, which may be a result of fear of relapse. Lastly, they emphasized a change in their daily lives, accepting a new normal and living accordingly.

There were also studies that focused on the changes in the lives of families. Fletcher (2010) investigated the costs of having a child with cancer among mothers. Finance and work, health of family members, and disruption of family life were the reported costs. Another qualitative study conducted with the mothers of leukemic children revealed that continuation of the previous life is difficult for both the child and the mother. Due to the treatment, infection risk, and potential behavior problems of the child, school attendance and social life of the child became harder. Moreover, for the mother; economic burden, problems at work, and restriction of social life made a normal life difficult to achieve. It was concluded that a rearrangement process gives better results rather than trying to continue the daily life before the diagnosis and treatment process (Earle, Clarke, Eiser, & Sheppard, 2006).

James and colleagues (2002) focused on perceptions about caregiving demands qualitatively and revealed that parents mentioned time for activities other than caregiving tasks as an unmet need, and emphasized the need for practical support, that is assistance in caregiving and household responsibilities in order to save time. Parallel to the quantitative caregiver literature (e.g. Pearlin et al., 1990), the need for emotional support was also evident in this study.

Wells, Cagle, Marshall, and Hollen (2009) examined female Mexican-American cancer caregivers and they identified themes of burden as economic problems, uncertain future, and low mood. Moreover, the caregivers mentioned experience of physical problems when they feel overwhelmed by caregiving. They also reported an emotional interdependence, that is, they feel bad when the ill family member feels bad.

The resiliency factors were also investigated by researchers qualitatively. The factors that were identified as contributing to resiliency were tolerance for a rapid change and family reorganization and being able to ask for social support from various sources such as extended family and medical team (McCubbin et al., 2002). Moreover, having a positive viewpoint, faith and religion, being able to take care of oneself and being in control were identified as factors that contribute to effective coping among mothers of children with cancer (Fletcher & Clarke, 2003).

To sum up, the qualitative studies tried to reflect caregiver perspective more directly, i.e. via interviews. The studies focused on the problems associated with the treatment process, coping, and support issues. They revealed the factors that facilitate or complicate coping. Study 2 (see Chapter 3) described the subjective experiences of caregivers of children with cancer on three topics, namely, coping, emotions, and effects of cancer.

1.4.4. Intervention Studies

Caregiver studies tried to reveal the risk and protective factors of the caregiving process and suggested that developing interventions are necessary to help better adjustment (e.g., Lee, 1999). However, the number of intervention studies that has been implemented is limited. Due to this limitation, in addition to studies conducted with the caregivers of children with cancer, the studies on the caregivers of children with other chronic conditions were also mentioned below. The inclusion criterion for these studies was having a theoretical background based on coping models. There are several psychosocial interventions developed for the caregivers of different populations; such as, dependent patients (Rodríguez-Sánchez et al., 2010),

dementia patients (Hosaka & Sugiyama, 2003), and palliative care patients (Hudson, Thomas, Quinn, Cockayne, & Braithwaite, 2009). Some examples of the studies examining the effectiveness of intervention programs for caregivers will be explained briefly below.

An intervention program, The FOCUS Program (Northouse, Kershaw, Mood, & Schafenacker, 2005), was developed for breast cancer patients and their families, guided by Stress Appraisal Model of Lazarus and Folkman (1984). The aim was providing information and support; decreasing uncertainty and hopelessness, and fostering appraisal and coping at short term; and an increased quality of life at long term. The program components were family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management. The results revealed that the participants (both patients and caregivers) in the intervention group reported significantly less hopelessness and less negative appraisal of the illness. However, there was no significant difference between the groups at follow up measurements of quality of life.

Another intervention program, Surviving Cancer Competently Intervention Program for Newly Diagnosed Families (SCCIP-ND), targeted the caregivers of newly diagnosed children with cancer (Stehl et al., 2009). The aim was to provide healthy adjustment to childhood cancer. The program included identifying beliefs about cancer, treatment, and the impact on family, changing those beliefs, and focusing on family growth and the future. Although the pilot study with a small number of participants revealed significant differences (Kazak et al., 2005), there was no difference between the groups in terms of their state anxiety and traumatic stress.

Still another intervention program (Sahler et al., 2005), using problem solving skills training based on the principles of problem solving therapy (D'Zurilla & Chang, 1995), had mothers of children with cancer as their participants. After 8 hours of problem solving training sessions, the intervention group reported significantly higher levels of problem solving skills and lower levels of negative affect as compared to usual care group. The effect was highest at post-test measurements and decreased gradually at 3- and 6-months follow up measurements.

Thus, intervention studies tried to help a better coping process and caregiver well-being. Drotar (2006) suggested that identifying the characteristics and the needs of the group correctly, having a theoretical background, using multiple therapeutic components concurrently (e.g., cognitive therapy + relaxation), and using standardized scripts were necessary for successful interventions for dealing with childhood chronic illnesses. The third study (see Chapter 4) was composed of designing, implementing and testing the effectiveness of a psycho-educational group intervention for the caregivers of children with cancer.

CHAPTER 2

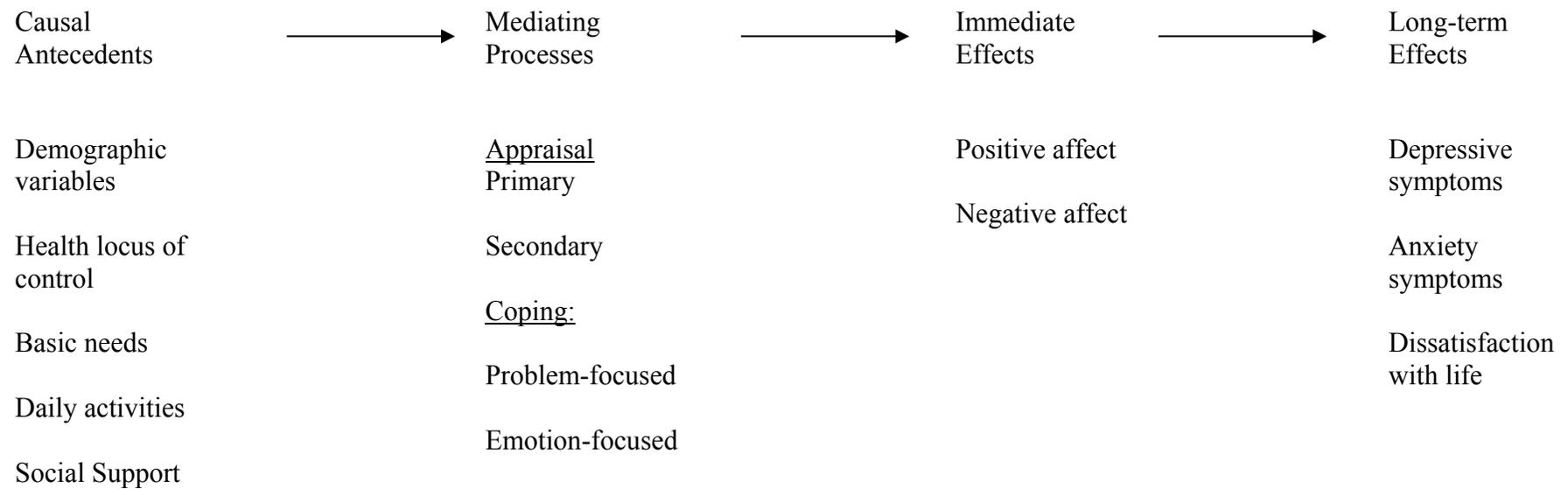
STUDY 1: PREDICTORS OF CAREGIVER DISTRESS AMONG THE CAREGIVERS OF CHILDREN WITH CANCER: A TRANSACTIONAL THEORY OF COPING PERSPECTIVE

2.1. Aim and Hypotheses

The aim of the Study 1 is to find out the predictors of caregiver distress among the caregivers of children with cancer by using Transactional Theory of Coping (Lazarus & Folkman, 1984) as a theoretical framework. The included variables were determined considering the caregiver literature, especially the caregivers of children with cancer. Caregiver distress was composed of three variables, namely, the level of depressive symptoms, anxiety symptoms and dissatisfaction with life. The model used in the present study can be seen in Figure 2.

The hypotheses are as follows: First; (1.a.) the causal antecedents (demographic variables, sense of control, basic needs, daily activities and social support) will predict depressive symptoms; (1.b.) after controlling for the effects of causal antecedents, the mediating processes (stress appraisal, problem focused coping, and emotion focused coping) will predict depressive symptoms; (1.c.) after controlling for the effects of causal antecedents and the mediating processes, immediate effects (positive and negative affect) will predict depressive symptoms. Second; (2.a.) the causal antecedents (demographic variables, sense of control, basic needs, daily activities and social support) will predict anxiety symptoms; (2.b.) after controlling for the effects of causal antecedents, the mediating processes (stress appraisal, problem focused coping and emotion focused coping) will predict anxiety symptoms; (2.c.) after controlling for the effects of causal antecedents and the mediating processes, immediate effects (positive and negative affect) will predict

anxiety symptoms. Last, (3.a.) the causal antecedents (demographic variables, sense of control, basic needs, daily activities, and social support) will predict the level of dissatisfaction with life; (3.b.) after controlling for the effects of causal antecedents, the mediating processes (stress appraisal, problem focused coping, and emotion focused coping) will predict the level of dissatisfaction with life; (3.c.) after controlling for the effects of causal antecedents and the mediating processes, immediate effects (positive and negative affect) will predict the level of dissatisfaction with life.



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Figure 2

The summary of the model used in the present study which is based on the Transactional Theory of Coping (Lazarus & Folkman, 1984)

2.2. Method

2.2.1. Participants

The participants were 105 caregivers of children with cancer. Eighty six participants were female (82 %) and 19 of them were males (18 %). The sample was composed of mostly mothers (81 %, $n = 85$), the remaining were fathers ($n = 19$, 18.1 %) and a sister ($n = 1$, 1 %). The age of the participants ranged between 18 and 52 with a mean of 34.31 ($SD = 7.46$). The majority of the sample ($n = 77$, 73 %) perceived themselves as belonging to middle income group. The remaining 22.9 % ($n = 24$) reported themselves as a member of low income group; and only 4 participants (3.8 %) constituted the upper income group. Education levels of the participants were as follows: 29.5 % primary school ($n = 31$), 13.3 % secondary school ($n = 14$), 34.3 % high school ($n = 36$), 18.1% university ($n = 19$) and 4.8 % graduate level ($n = 5$). While 37 participants were employed (35.2 %), the remaining 66 participants were unemployed (62.9 %). The distribution of the participants according to residence was as follows: 29.5 % reported living in metropolitans ($n = 31$), 45.7 % in provinces ($n = 48$), 18.1 % in towns ($n = 19$) and 6.7 % in villages ($n = 7$). Finally, the percentage of the participants who did not get help for care giving was 55.2 % ($n = 58$), and the remaining 42.9 % received help from either their husband or their mothers ($n = 45$) (see Table 1 for the demographic characteristics of the sample).

Table 1

Demographic Characteristics of the Sample of Study 1

	<i>M</i>	<i>SD</i>	<i>n</i>	<i>%</i>	<i>Min-Max</i>
Age	34.31	7.46			18-52
Relationship to the patient					
Mother			85	81	
Father			19	18.1	
Sister			1	1	

Table 1 Continued

	<i>M</i>	<i>SD</i>	<i>n</i>	<i>%</i>	<i>Min-Max</i>
Perceived family income					
Low			24	22.9	
Middle			77	73	
High			4	3.8	
Education					
Primary school			31	29.5	
Secondary school			14	13.3	
High school			36	34.3	
University			19	18.1	
Graduate			5	4.8	
Employment status					
Unemployed			66	62.9	
Employed			37	35.2	
Residence					
Metropolitan			31	29.5	
Province			48	45.7	
Town			19	18.1	
Village			7	6.7	
Receipt of help					
Help			45	42.9	
No help			58	55.2	

The age of the children ranged between 1 and 18 years ($M = 7.11$; $SD = 5.34$). The most frequent diagnosis of the children was neuroblastoma ($n = 22$), followed by bone tumor ($n = 18$) and leukemias ($n = 14$). International Classification of Childhood Cancer (ICCC) (National Cancer Institute, n.d.) criteria were used for categorization of the diagnoses (Table 2 includes the frequency of diagnoses of children). The duration of the illness of the child ranged between 1-124 months with a mean of 11.54 months ($SD = 17.89$). The children receiving chemotherapy formed

91.4 % ($n = 96$) of the sample. The other children were either receiving radiotherapy ($n = 2$, 1.9 %) or coming to the hospital for their follow-up appointments ($n = 7$, 6.7 %). Table 2 includes the characteristics of the children reported by the caregivers.

Table 2

Characteristics of Children as Reported by Their Caregivers

	<i>M</i>	<i>SD</i>	<i>n</i>	<i>%</i>	<i>Min-Max</i>
Child's age	7.11	5.34			1-18
Diagnosis					
Leukemias			14	13.3	
Lymphomas			10	9.5	
Glioma			2	1.9	
Neuroblastoma			22	20.9	
Retinoblastoma			5	4.8	
Renal and Wilms' tumor			4	3.8	
Hepatoblastoma			6	5.7	
Bone tumor			18	17.1	
Soft tissue			6	5.7	
Germinal			2	1.9	
Carcinoma			8	7.6	
Other/unknown			8	7.6	
Time since diagnosis (month)	11.54	17.89			1-124
Type of the treatment					
Chemotherapy			96	91.4	
Radiotherapy			2	1.9	
Follow up			7	6.7	

2.2.2. Measures

The questionnaire set used in Study 1 included demographic information form, Multidimensional Health Locus of Control Scale (Wallston & DeVellis, 1978), The Caregiver Well-Being Scale (Berg-Weger, Rubio, & Tebb, 2000), Multidimensional

Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988), Stress Appraisal Measure (Peacock & Wong, 1990), Ways of Coping Inventory (Folkman & Lazarus, 1980), Positive and Negative Affect Schedule (Watson, Clark, & Tellegen, 1988), Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), Beck Anxiety Inventory (Beck, Epstein, Brown, and Steer, 1988), and The Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985).

2.2.2.1. Demographic Information Form

The demographic information form used in Study 1 was used in Study 2, too. It was prepared for the caregivers of children with cancer, and it included general demographic questions about age, gender, education, occupation, marital status, and perceived family income (see Appendix B). Besides, it contained questions about the illness and the caregiving process, such as the relationship to the patient, type of diagnosis, time since diagnosis, the phase of the treatment, number of people living at home, number of other caregivers, number of children except for the ill child, and having physical and psychological illness or not.

2.2.2.2. Multidimensional Health Locus of Control Scale (MHLC)

Multidimensional health locus of control scale consists of 18 items about 3 dimensions of health locus of control, namely; internal health locus of control (IHLC), powerful others health locus of control (PHLC), and chance health locus of control (CHLC). It is a 6-point Likert type scale ranging from 0 (*strongly disagree*) to 5 (*strongly agree*). The original version of the MHLC scale was developed by Wallston and DeVellis (1978), and it was translated into Turkish by Üstündağ-Budak (1999). The Turkish version of the scale has an additional factor labeled as fate health locus of control. The Cronbach's alpha levels of the subscales ranged between .68 and .39, and it was .63 for the whole scale. The subscale scores are calculated by adding up the respective item scores, and the total score of MHLC is obtained by summing up all these subscale scores. Higher scores on this scale indicate externality (see Appendix C). The internal consistency reliability as measured by Cronbach's alpha was .60 for the present sample.

2.2.2.3. *The Caregiver Well-Being Scale (CWB Scale)*

This scale was developed in order to evaluate the well-being indicators (i.e. basic needs and daily activities) of the caregivers (Berg-Weger, Rubio, & Tebb, 2000). It measures the level of daily functioning in the presence of the caregiver role. There are two subscales of the scale; basic needs and activities of living. The basic needs subscale includes not only the physical needs like sleep and nutrition but also some other needs like expression of feelings, relaxation, and personal growth. The internal consistency reliability of this subscale was .91 (Berg-Weger, Rubio, & Tebb, 2000). Activities of living subscale includes the daily activities of the person and some additional activities that can be regarded as leisure activities, such as having a hobby. The internal consistency reliability of the activities of living subscale as measured by Cronbach's alpha was .81. The correlation coefficient between the two subscales was found .69, indicating the convergent validity of the subscales (Berg-Weger, Rubio, & Tebb, 2000).

The scale was adapted to Turkish by Demirtepe and Bozo (2009) with internal consistency reliability coefficients .93 for the basic needs subscale and .89 for the activities of living subscale. The scale did also have a strong test-re-test reliability ($r = .79, p < .001$). The correlational analyses between the caregiver well-being scale, and BDI (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) ($r = -.71, p < .01$) and Mental, Physical, and Spiritual Well-being Scale (Vella-Brodrick & Allen, 1995) ($r = .55, p < .01$) suggested that the scale has construct validity (see Appendix D). The internal consistency reliability as measured by Cronbach's alpha were .85 for basic needs subscale and .86 for daily activities subscale for the present sample.

2.2.2.4. *Multidimensional Scale of Perceived Social Support (MSPPS)*

This scale consists of 12 items aiming at assessing perceived social support. It was developed by Zimet, Dahlem, Zimet, and Farley (1988), and adapted to Turkish by Eker and Arkar (1995). The scale includes 3 subscales, namely; support from the family, friends, and significant others. The scale has a strong reliability for the

subscales and the full scale (alpha values ranged between .80 and .95) (Öner, 1994). The items are rated on a 7-point scale ranging between 1 (*disagree very strongly*) and 7 (*agree very strongly*). Higher scores on this scale mean higher levels of perceived social support (see Appendix E). The internal consistency reliability as measured by Cronbach's alpha was .92 for the present sample.

2.2.2.5. Stress Appraisal Measure (SAM)

It was developed by Peacock and Wong (1990) and adapted to Turkish by Durak and Şenol-Durak (2013). It measures the appraisal of stress via the factors of primary appraisal as a threat or a challenge, and secondary appraisal as uncontrollable, self-controlled, or other controlled. The Cronbach's alpha levels of the subscales ranged between .68 and .84 for adults (Durak & Şenol-Durak, 2013). The state form, which included 24 items, was used in the present study, and the state was defined as having a child with a medical problem (see Appendix F). The internal consistency reliability as measured by Cronbach's alpha for the subscales ranged between .53 and .78 for the present sample.

2.2.2.6. Ways of Coping Inventory (WCI)

It was developed by Folkman and Lazarus (1980) and adapted to Turkish by Siva (1991) with the Cronbach's alpha coefficient .90. The Turkish version of the scale includes 74 items. In the Gençöz, Gençöz, and Bozo study (2006), hierarchical dimensions of coping styles were examined and three factors were identified; problem focused, emotion focused, and indirect coping. The internal consistency reliabilities of the subscales were .90, .88, and .84, respectively. The problem focused and emotion focused subscales were used in the present study (see Appendix G). The internal consistency reliability as measured by Cronbach's alpha was .82 for problem focused and .76 for emotion focused coping subscales for the present sample.

2.2.2.7. *Positive and Negative Affect Schedule (PANAS)*

It was developed by Watson, Clark, and Tellegen (1988) and adapted to Turkish by Gençöz (2000). It consists of 20 items rated on a 5-point Likert-type scale, 10 of which measure Positive Affect (PA) and the other 10 measure Negative Affect (NA) (see Appendix H). Respondents are asked to rate the extent to which they experience the affective states in the last 2 weeks. Cronbach's alpha coefficients were reported as .83 and .86 for positive and negative affect, respectively; and the test-retest reliability was .40 for the negative affect and .54 for the positive affect for the Turkish version. The internal consistency reliabilites as measured by Cronbach's alpha were .78 for positive affect and .76 for negative affect in the present study.

2.2.2.8. *Beck Depression Inventory (BDI)*

BDI (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) comprised 21 multiple-choice questions measuring the moods of the participants for the previous 2 weeks. The scores obtained from each question ranged between 0 and 3, and a lower overall score (of 63) referred to a lower level of depression. The inventory was translated to Turkish by Tegin (1980) and Hisli (1988). Test-retest reliability for the Turkish version of the BDI was .65, whereas the split-half reliability was .78 for students and .61 for depressive patients. By looking at BDI's correlation with Hamilton Depression Rating Scale (Hamilton, 1960), convergent validity of the scale was calculated as .75 (Hisli, 1988; 1989) (see Appendix I). The internal consistency reliability as measured by Cronbach's alpha was .86 for the present sample.

2.2.2.9. *Beck Anxiety Inventory (BAI)*

It measures the frequency of the anxiety symptoms on a 4-point scale. It was developed by Beck, Epstein, Brown, and Steer (1988), and adapted to Turkish by Ulusoy, Şahin, and Erkmen (1998). The Cronbach's alpha for the Turkish version of the inventory was .93. The inventory includes 21 anxiety symptoms felt since last week, and higher scores on this scale indicate more anxiety (Savaşır & Şahin, 1997) (see Appendix J). The internal consistency reliability as measured by Cronbach's

alpha was .90 for the present sample.

2.2.2.10. The Satisfaction with Life Scale (SWLS)

It was developed by Diener, Emmons, Larsen, and Griffin (1985) and adapted to Turkish by Durak, Şenol-Durak, and Gençöz (2010), with an internal consistency reliability as measured by Cronbach's alpha .89. It is a 5-item measure designed to assess global judgment of life satisfaction. SWLS items are global rather than specific in nature, which allows respondents to weight domains in terms of those they individually deem most important. Statements are rated on a 5-point Likert scale. Higher scores indicate lower satisfaction with life (see Appendix K). The internal consistency reliability as measured by Cronbach's alpha was .77 for the present sample.

2.2.3. Procedure

Ethical approval was obtained from Middle East Technical University Ethical Committee, Hacettepe University Ethical Committee, and Ankara Provincial Directorate of Health. Approvals of the heads of the pediatric oncology departments of the hospitals were gathered and written informed consent (see Appendix A) was obtained from all participants.

The participants were contacted either at their child's hospital stays at the inpatient clinics, or at treatment or examination appointments in outpatient polyclinics. The participants who gave consent were included in the study. They filled in the questionnaires in their rooms or in the waiting rooms of polyclinics. Some of the participants needed the questions being read to them because of having problems in sight or reading. In that case, the questions were read and the answers of the caregivers were marked by the researcher. Although there was no time limit, it took the participants approximately 45- 55 minutes to fill in the questionnaires.

2.2.4. Data Analysis

Data were analyzed using SPSS 15. Descriptive statistical analysis (frequency, percentage, mean, median and standard deviation) was employed to describe the research sample and measures. Reliability analyses were conducted for Cronbach's alpha values of the scales. The Pearson product-moment correlation coefficient was used to describe associations among the measures. A series of hierarchical multiple regressions were used to examine the unique contributions of each individual set of predictor variables that comprised the proposed model, including the causal antecedents (demographic variables, sense of control, basic needs, daily activities, and social support), the mediating processes (stress appraisal, problem focused coping, and emotion focused coping), and immediate effects (positive and negative affect). Sets of variables were entered into the analysis based on the proposed theoretical model. The dependent measures were the level of depressive symptoms, the level of anxiety symptoms, and the level of dissatisfaction with life.

2.3. Results

2.3.1. Preliminary Analyses

In order to find out the predictive values of demographic characteristics of the caregivers (i.e., age and number of people living in the house) and caregiving related variables (the ill child's age and duration of the illness) on long term effect variables (i.e., the level of depressive symptoms, anxiety symptoms, and dissatisfaction with life), separate regression analyses were conducted. Independent samples t-tests were applied to reveal group differences in terms of demographic characteristics (the caregivers' gender, and employment status) and caregiver related variables (having other caregivers helping, presence/absence of a physical illness, and receiving any kind of treatment). Moreover, to examine the variation of the long term effect variables based on the level of education, level of perceived income, and residence, one-way ANOVAs were performed. Similarly, one-way ANOVAs were run for illness related variables (the diagnostic category and type of treatment).

Regression analyses run with the demographic variables (i.e., caregiver age and number of people living in the house) revealed no significant effect for caregiver age and number of people living in the house on the level of depressive symptoms ($R^2 = .03$, $F(2, 102) = 1.77$, $p > .05$), anxiety symptoms ($R^2 = .03$, $F(2, 102) = 1.66$, $p > .05$), and dissatisfaction with life ($R^2 = .01$, $F(2, 101) = .46$, $p > .05$) (see Table 3).

Table 3

Regression Analyses Predicting Long Term Effect Variables (the level of depressive symptoms, anxiety symptoms and dissatisfaction with life) from the Demographic Variables (Caregiver Age and the Number of People Living in the House)

Variable	Mean	SD	B	SE B	β
Depressive symptoms ($N = 105$)	18.82	10.00			
Caregiver Age	34.31	7.47	-.22	.13	-.16 ^{ns}
Number of people living in the house	4.68	2.53	.25	.39	.06 ^{ns}
Anxiety symptoms ($N = 105$)	19.31	12.17			
Caregiver Age	34.31	7.47	-.25	.16	-.15 ^{ns}
Number of people living in the house	4.68	2.53	.34	.47	.72 ^{ns}
Dissatisfaction with life ($N = 104$)	15.02	4.11			
Caregiver Age	34.37	7.47	-.05	.05	-.09 ^{ns}
Number of people living in the house	4.47	2.54	.02	.16	-.02 ^{ns}

Regression analyses run with the caregiving related variables (the ill child's age and duration of the illness) revealed the following results: The ill child's age and duration of the illness were not significantly associated with the level of depressive symptoms ($R^2 = .04$, $F(2, 102) = 2.33$, $p > .05$) and dissatisfaction with life ($R^2 = .01$, $F(2, 101) = .58$, $p > .05$). For the level of anxiety symptoms, however, the child's age ($\beta = -.26$,

$p = .01$) was a significant predictor ($R^2 = .07$, $F(2, 102) = 3.65$, $p < .05$). As the ill child's age decreased, the level of anxiety symptoms increased (see Table 4).

Table 4

Regression Analyses Predicting Long Term Effect Variables (the level of depressive symptoms, anxiety symptoms and dissatisfaction with life) from the Caregiving Related Variables (the ill child's age and duration of the illness)

Variable	Mean	SD	B	SE B	β
Depressive symptoms ($N = 105$)	18.82	10.00			
Ill child's age	7.11	5.34	-.37	.19	-.20*
Duration of the illness	11.54	17.89	-.02	.06	-.04
Anxiety ($N = 105$)	19.31	12.17			
Ill child's age	7.11	5.34	-.59	.22	-.26**
Duration of the illness	11.54	17.89	.08	.07	.12
Dissatisfaction with life ($N = 104$)	15.02	4.11			
Ill child's age	7.08	5.36	-.07	.08	-.09
Duration of the illness	11.60	11.60	.02	.02	.07

Note. * $p < .05$; ** $p < .01$

In order to examine group differences in terms of demographic characteristics (the caregivers' gender and employment status) and caregiver related variables (having other caregivers helping, the presence/absence of a physical problem, and receiving any kind of treatment), independent samples t-tests were applied.

There was a significant difference between males and females in terms of the levels of depressive ($t(103) = 2.15$, $p < .05$) and anxiety symptoms ($t(103) = 2.00$, $p < .05$), but not life satisfaction ($t(102) = .46$, $p > .05$). Males reported significantly lower levels of depressive symptoms ($m = 14.43$, $sd = 8.35$) as compared to females ($m = 19.79$, $sd = 10.12$). Similarly, as compared to females ($m = 20.41$, $sd = 12.13$), males reported significantly lower levels of anxiety symptoms ($m = 14.33$, $sd = 11.34$) (see Table 5).

Table 5

Descriptive Statistics and t-test Results for Males and Females

		<i>n</i>	<i>m</i>	<i>Sd</i>	<i>t</i>
Depressive symptoms	Male	19	14.43	8.35	2.15*
	Female	86	19.79	10.12	
Anxiety symptoms	Male	19	14.33	11.34	2.00*
	Female	86	20.41	12.13	
Dissatisfaction with life	Male	19	14.63	4.63	.46
	Female	85	15.11	4.01	

Note. * $p < .05$

As Table 6 illustrates, the differences between caregivers who were employed and who were unemployed were significant on all of the long term effect variables. For the level of depressive symptoms ($t(103) = 2.11, p < .05$), caregivers who were employed had lower scores ($m = 16.07, sd = 8.31$) than unemployed caregivers ($m = 20.32, sd = 10.58$). Similarly, for anxiety scores ($t(103) = 2.09, p < .05$), caregivers who were employed reported lower levels ($m = 16.00, sd = 11.31$) than caregivers who were unemployed ($m = 21.11, sd = 12.32$). The results of the t-tests were significant for the level of dissatisfaction with life, too ($t(102) = 2.71, p < .01$). Caregivers who were employed had significantly lower levels of dissatisfaction with life ($m = 13.59, sd = 3.68$) than the caregivers who were not ($m = 15.81, sd = 4.15$).

Table 6

Descriptive Statistics and t-test Results of Participants Employed or Unemployed

		<i>n</i>	<i>m</i>	<i>sd</i>	<i>t</i>
Depressive symptoms	Employed	37	16.07	8.31	2.11*
	Unemployed	68	20.32	10.58	
Anxiety symptoms	Employed	37	16.00	11.31	2.09*
	Unemployed	68	21.11	12.32	
Dissatisfaction with life	Employed	37	13.59	3.68	2.71**
	Unemployed	67	15.81	4.15	

Note. * $p < .05$; ** $p < .01$

The group differences in terms of caregiver related variables (having other caregivers helping, presence/absence of a physical illness, and receiving any kind of treatment) were also investigated for the depressive symptoms, anxiety symptoms and dissatisfaction with life.

Having a helper for caregiving or not did not make a difference in terms of depressive symptoms ($t(103) = .53, p > .05$), anxiety symptoms ($t(103) = -.40, p > .05$) and dissatisfaction with life ($t(102) = 1.75, p > .05$).

The presence/absence of a physical problem as reported by the caregivers or not did significantly predict the level of depressive symptoms ($t(103) = -3.19, p < .01$); caregivers who reported that they had a physical problem had higher levels of depressive symptoms ($m = 26.45, sd = 14.45$) than caregivers without a physical problem ($m = 17.65, sd = 8.66$). For anxiety symptoms ($t(103) = -2.90, p < .01$), caregivers who reported having a physical problem did also report higher levels of anxiety symptoms ($m = 27.78, sd = 13.26$) than the caregivers without any physical complaint ($m = 18.01, sd = 11.52$). Similarly, for dissatisfaction with life ($t(102) = -2.18, p < .05$), caregivers who had a physical problem did also report significantly higher levels of dissatisfaction with life ($m = 17.21, sd = 4.53$) than the caregivers who did not ($m = 14.68, sd = 3.97$). Moreover, there was a significant difference between the caregivers receiving any kind of treatment at the moment and the ones who were not ($t(103) = -2.20, p < .05$). Caregivers who were receiving treatment reported higher levels of depressive symptoms ($m = 24.98, sd = 12.05$) than the ones who were not ($m = 18.10, sd = 9.55$). However, the group differences were not significant in terms of anxiety symptoms ($t(103) = -1.06, p > .05$) and dissatisfaction with life ($t(102) = -1.06, p > .05$) (see Table 7).

Table 7

Descriptive Statistics and t-test Results of the Participants with Presence/Absence of a Physical Problem

		<i>n</i>	<i>M</i>	<i>sd</i>	<i>T</i>
Depressive symptoms	Physical problem	14	26.45	14.45	-3.19**
	No physical problem	91	17.65	8.66	
Depressive symptoms	Treatment	11	24.98	12.05	-2.20*
	No treatment	94	18.10	9.55	
Anxiety symptoms	Physical problem	14	27.78	13.26	-2.90**
	No physical problem	91	18.01	11.52	
Dissatisfaction with life	Physical problem	14	17.21	4.53	-2.18*
	No physical problem	90	14.68	3.97	

Note. * $p < .05$; ** $p < .01$

In order to examine the variation of the long term effect variables based on the level of education, level of perceived income, and the place of living, one-way ANOVAs were performed. Other one-way ANOVAs were run for illness related variables (the diagnostic category and type of treatment).

To examine the effects of education level, on the dependent variables, three separate one way ANOVA's were performed (see Table 8). The effect of education level on the level of depressive and anxiety symptoms were not significant ($F(3, 101) = 1.50$, $p > .05$ and ($F(3, 101) = .59$, $p > .05$, respectively). However, the effect of education level on dissatisfaction with life was significant ($F(3, 100) = 5.50$, $p < .01$). Post hoc

analyses using Tukey HSD test revealed that university graduates had significantly lower dissatisfaction with life scores ($m = 12.31$) than the high school graduates ($m = 16.30$), secondary school graduates ($m = 15.86$), and primary school graduates ($m = 15.27$). The other group differences were not significant.

Table 8

Descriptive Statistics, Analysis of Variance, and Tukey HSD Tests for the Long-Term Effect Variables (Depressive and Anxiety Symptoms and Dissatisfaction with Life) and Education Level

	<u>Primary</u> (<i>n</i> = 31)		<u>Secondary</u> (<i>n</i> = 14)		<u>High School</u> (<i>n</i> = 36)		<u>University and higher</u> (<i>n</i> = 24)		<u>One-way ANOVA</u>		
	<i>m</i>	<i>sd</i>	<i>m</i>	<i>sd</i>	<i>m</i>	<i>sd</i>	<i>m</i>	<i>sd</i>	<i>df</i>	<i>F</i>	<i>p</i>
Depressive symptoms	19.86	10.98	20.19	8.90	19.91	9.93	15.05	9.00	3,101	1.50	.22
Anxiety symptoms	20.02	11.65	22.43	11.31	18.91	13.03	17.17	12.24	3,101	.59	.62
Dissatisfaction with life	15.27 _a	4.39	15.86 _a	3.44	16.30 _a	4.03	12.31 _b	3.06	3,100	5.50	.002

Note. The mean scores that do not share the same subscript on the same row are significantly different from each other at .05 alpha level of Tukey's HSD test.

The variation of the level of depressive symptoms, anxiety symptoms, and dissatisfaction with life based on the categorization of the perceived family income was examined by performing a one way ANOVA (see Table 9). The results showed that the effect of perceived family income on the level of depressive symptoms was significant ($F(2, 102) = 4.81, p = .01$). When the differences among the lower, middle, and upper income groups were examined with Tukey HSD test, it was found that lower income group had significantly higher level of depressive symptoms ($m = 22.67$) than the upper income groups ($m = 7.50$). The middle income group ($m = 18.21$) was not significantly different from either low or upper income groups in terms of the level of depressive symptoms.

No significant effect of perceived family income was revealed for the level of anxiety symptoms ($F(2, 102) = 1.74, p > .05$). Similar to depressive symptoms, the effect of perceived family income on dissatisfaction with life was significant ($F(2, 101) = 13.56, p < .001$). Further post hoc analysis with Tukey HSD test revealed that lower income group ($m = 18.04$) had significantly higher scores than middle ($m = 14.35$) and upper ($m = 9.62$) income groups. The difference between people having middle and upper income groups was also significant.

Table 9

Descriptive Statistics, Analysis of Variance, and Tukey HSD Tests for the Long Term Effect Variables (Depressive and Anxiety Symptoms and Dissatisfaction with Life) and Perceived Family Income

	<u>Lower (n = 24)</u>		<u>Middle (n = 77)</u>		<u>Upper (n = 4)</u>		<u>One-way ANOVA</u>		
	<i>m</i>	<i>sd</i>	<i>m</i>	<i>sd</i>	<i>m</i>	<i>sd</i>	<i>df</i>	<i>F</i>	<i>p</i>
Depressive symptoms	22.67 _a	11.98	18.21 _{ab}	8.99	7.50 _b	4.51	2,102	4.81	.01
Anxiety symptoms	20.57	12.52	19.48	12.07	8.50	8.18	2,102	1.74	.18
Dissatisfaction with life	18.04 _a	4.43	14.35 _b	3.49	9.62 _c	1.89	2,101	13.56	.001

Note. The mean scores that do not share the same subscript on the same row are significantly different from each other at .05 alpha level of Tukey's HSD test.

The effects of place of living on the long term effect variables were also investigated. No significant difference between the caregivers living in metropolitans, provinces, towns and villages were found for the levels of depressive ($F(3, 101) = .63, p > .05$), anxiety symptoms ($F(3, 101) = .95, p > .05$) and dissatisfaction with life scores ($F(3, 100) = .53, p > .05$) were obtained.

The effects of the illness characteristics, i.e. the diagnostic category and phase of treatment were not significant on the long-term effect variables. Specifically, the diagnostic category according to ICCC classification, did not affect level of depressive ($F(11, 93) = 1.01, p > .05$) and anxiety symptoms ($F(11, 93) = .48, p > .05$), and dissatisfaction with life ($F(11, 92) = 1.13, p > .05$). The effect of phase of treatment on depressive symptoms ($F(2, 102) = 1.85, p > .05$), anxiety symptoms ($F(2, 102) = 1.56, p > .05$), and dissatisfaction with life ($F(2, 101) = .86, p > .05$) were not significant, too.

2.3.2. Descriptive Information for the Measures of the Study

The variables which took place in the model of coping proposed in the present study were examined in terms of descriptive information (see Table 10).

Table 10

Descriptive Information for the Measures of the Study 1

<i>Variable</i>	<i>Measure</i>	<i>Mean</i>	<i>SD</i>	<i>Min-Max Values</i>
<i>Causal Antecedents</i>				
Sense of control	MHLC	48.00	8.02	19-65
Caregiver well-being	CWB Scale			
Basic needs		70.55	13.31	47-102
Daily activities		64.69	13.63	38-96
Social support	MSSPS	70.55	13.31	18-84
<i>Mediating Processes</i>				
Stress Appraisal	SAM			

Table 10 Continued

<i>Variable</i>	<i>Measure</i>	<i>Mean</i>	<i>SD</i>	<i>Min-Max Values</i>
Threat		30.14	5.09	13-40
Challenge		10.93	2.57	4-15
Controlled by self		17.72	3.47	8-25
Controlled by others		12.01	4.05	4-20
Uncontrolled		11.90	3.26	4-20
Coping Strategies	WCI			
EFC		61.08	9.95	35-84
PFC		99.24	13.11	70-137
<i>Immediate Effects</i>				
Affect	PANAS			
Positive		30.43	7.36	11-48
Negative		27.53	6.94	11-43
<i>Long Term Effects</i>				
Depressive symptoms	BDI	18.82	10.00	1-52
Anxiety symptoms	BAI	19.31	12.17	0-56
Dissatisfaction with life	SWLS	15.02	4.11	7-25

3.2.3. Correlations among the Study Variables

Zero order correlation coefficients among the study variables were examined in order to investigate the relationships among the causal antecedents, mediating processes, immediate and long term effects (see Table 11). The variables which were correlated with the level of depressive symptoms were as follows: Health locus of control ($r = .30, p < .01$), basic needs ($r = -.55, p < .001$), daily activities ($r = -.49, p < .001$), social support ($r = -.46, p < .001$), challenge appraisal ($r = -.21, p < .05$), uncontrollable appraisal ($r = .38, p < .01$), self control appraisal ($r = -.48, p < .01$), other control appraisal ($r = -.51, p < .01$), problem focused coping ($r = -.55, p < .01$),

emotion focused coping ($r = .24, p < .01$), positive affect ($r = -.32, p < .001$), negative affect ($r = .51, p < .001$), anxiety symptoms ($r = .62, p < .001$), and dissatisfaction with life ($r = .44, p < .001$).

The variables which were correlated with the level of anxiety symptoms were as follows: Basic needs ($r = -.40, p < .001$), daily activities ($r = -.40, p < .001$), social support ($r = -.32, p < .001$), threat appraisal ($r = .27, p < .01$), uncontrollable appraisal ($r = .35, p < .001$), self control appraisal ($r = -.38, p < .001$), other control appraisal ($r = -.40, p < .001$), problem focused coping ($r = -.41, p < .001$), emotion focused coping ($r = .19, p < .05$), negative affect ($r = .45, p < .001$), and dissatisfaction with life ($r = .31, p < .001$).

The variables which were correlated with the level of dissatisfaction with life were as follows: Basic needs ($r = -.53, p < .001$), daily activities ($r = -.37, p < .001$), social support ($r = -.42, p < .001$), threat appraisal ($r = .31, p < .001$), challenge appraisal ($r = -.20, p < .05$), uncontrollable appraisal ($r = .33, p < .001$), self control appraisal ($r = -.30, p < .01$), other control appraisal ($r = -.36, p < .01$), problem focused coping ($r = -.24, p < .01$), positive affect ($r = -.20, p < .05$), and negative affect ($r = .27, p < .01$).

Table 11

Correlation Coefficients among the Study Variables

	1	2	3	4	5	6	7	8
1. Health locus of control	1.00							
2. Basic needs	-.07	1.00						
3. Daily activities	.01	.67***	1.00					
4. Social support	-.12	.55***	.41***	1.00				
5. Threat appraisal	-.10	-.14	-.20*	-.09	1.00			
6. Challenge appraisal	-.09	.25**	.12	.24*	.18	1.00		
7. Uncontrollable	-.02	-.28**	-.33***	-.26**	.52***	-.08	1.00	
8. Self-control	-.24*	.51***	.42***	.41***	-.03	.30**	-.24*	1.00
9. Other control	-.28**	.56***	.41***	.55***	-.04	.14	-.19	.49***
10. Problem focused coping	.27**	.60***	.42***	.37***	-.12	.37***	-.25**	.57***
11. Emotion focused coping	.21*	-.12	-.12	-.18	-.07	.06	-.02	-.23*
12. Positive affect	.05	.49***	.42***	.27**	.01	.22*	-.20*	.46***
13. Negative affect	.23*	-.25**	-.21*	-.27**	.31***	-.19	.27**	-.31***
14. Depressive symptoms	.30**	-.55***	-.49***	-.46***	.16	-.21*	.38***	-.48***
15. Anxiety symptoms	.11	-.40***	-.40***	-.32***	.27**	-.01	.35***	-.38***
16. Dissatisfaction with life	.06	-.53***	-.37***	-.42***	.31***	-.20*	.33***	-.30**

Note 1. * $p < .05$; ** $p < .01$; *** $p < .001$

Note 2. Higher scores on health locus of control indicate externality

Higher scores on basic needs indicate higher levels of fulfillment of basic needs

Higher scores on daily activities indicate higher levels of performance on daily activities

Table 11 (Continued)

	9	10	11	12	13	14	15	16
1. Health locus of control								
2. Basic needs								
3. Daily activities								
4. Social support								
5. Threat appraisal								
6. Challenge appraisal								
7. Uncontrollable								
8. Self-control								
9. Other control	1.00							
10. Problem focused coping	.45***	1.00						
43 11. Emotion focused coping	-.23*	.03	1.00					
12. Positive affect	.24*	.47***	-.02	1.00				
13. Negative affect	-.26**	-.54***	.19*	-.20*	1.00			
14. Depressive symptoms	-.51***	-.55***	.24**	-.32***	.51***	1.00		
15. Anxiety symptoms	-.40***	-.41***	.19*	-.17	.45***	.62***	1.00	
16. Dissatisfaction with life	-.36***	-.24*	.18	-.20*	.27**	.44***	.31***	1.00

Note 1. * $p < .05$; ** $p < .01$; *** $p < .001$

Note 2. Higher scores on health locus of control indicate externality

Higher scores on basic needs indicate higher levels of fulfillment of basic needs

Higher scores on daily activities indicate higher levels of performance on daily activities

3.2.4. Hierarchical Regression

Three hierarchical multiple regression analyses regressing depressive symptoms, anxiety symptoms, and dissatisfaction with life of the caregivers on the variables of the model (causal antecedents, mediating processes, and immediate effects) were run. The variables which were found as related with the long-term effect variables in the preliminary analyses were included in the hierarchical regression equations.

3.2.4.1. Predictors of Depressive Symptoms

The first hierarchical multiple regression analysis used depressive symptoms as the long term effect variable. First, demographic variables (child's age, gender, occupation, and income) were entered into the regression equation. On the second step, causal antecedents (health locus of control, basic needs, daily activities, and social support) were entered into the equation. On the third step, appraisal (challenge, uncontrollability, self-control, and other-control) and coping strategies (problem and emotion focused); and finally, on the fourth step positive and negative affect were entered into the equation.

When the demographics were entered at the first step, it was revealed that the demographic variables explained 15 % of the variance in level of depressive symptoms of the caregivers ($R^2 = .15$, $F(4, 100) = 4.50$, $p < .01$). Child's age ($\beta = -.19$, $p < .05$) and reported family income ($\beta = -.25$, $p < .01$) were negatively associated with depressive symptoms. The causal antecedents entered in the second step increased the explained variance by 32 % ($R^2 = .47$, $F(8, 96) = 10.83$, $p < .001$). The level of health locus of control was positively related to the level of depressive symptoms ($\beta = .25$, $p < .01$), meaning that external locus of control was associated with higher level of depressive symptoms. The level of daily activities ($\beta = -.28$, $p < .01$) and perceived social support ($\beta = -.20$, $p < .05$) were negatively related to the level of depressive symptoms.

Mediating processes, which were entered in the third step, increased the explained variance by 8% ($R^2 = .55$, $F(14, 90) = 8.01$, $p < .001$). Appraisal of the situation as uncontrollable was related to the level of depressive symptoms ($\beta = .20$, $p < .05$).

The immediate effects, which were entered in the last step increased the explained variance by 2 % ($R^2 = .57$, $F(16, 88) = 7.47$, $p < .001$). Negative affect was positively related to the level of depressive symptoms ($\beta = .19$, $p < .05$) (see Table 12).

Table 12

Hierarchical Regression Model Predicting Depressive Symptoms

<i>Variables in Set</i>	ΔF	<i>df</i>	<i>t</i>	β	<i>pr</i>	ΔR^2
<i>Demographic Variables</i>	4.50**	4,100				.15
Child's age		100	-2.07	-.19*	-.20	
Gender		100	-1.44	-.16	-.14	
Occupation		100	-.44	-.05	-.04	
Income		100	-2.64	-.25**	-.25	
<i>Causal Antecedents</i>	14.68***	4,96				.32
Health locus of control		96	3.25	.25**	.31	
Basic needs		96	-1.85	-.21	-.19	
Daily activities		96	-2.67	-.28**	-.26	
Social support		96	-2.13	-.20*	-.21	
<i>Mediating Processes</i>	2.71*	6,90				.08
Challenge appraisal		90	-.17	-.01	-.02	
Uncontrollability		90	2.52	.20*	.17	
Self-control		90	-.53	-.05	-.04	
Other-control		90	-1.45	-.14	-.10	
Problem focused coping		90	-1.27	-.15	.11	
Emotion focused coping		90	1.60	.13	-.09	
<i>Immediate Effects</i>	2.20*	2,88				.02
Positive affect		88	.08	.01	.01	
Negative affect		88	2.09	.19*	.22	

Note. * $p < .05$; ** $p < .01$; *** $p < .001$

3.2.4.2. Predictors of Anxiety Symptoms

The second hierarchical multiple regression analysis used anxiety symptoms as the long term effect variable. First, demographic variables (child's age, gender, and occupation) were entered into the regression equation. On the second step, causal antecedents (basic needs, daily activities and social support) were entered into the equation. On the third step appraisal (threat, challenge, uncontrollability, self-control and other-control) and coping strategies (problem focused), and finally, on the fourth step negative affect were entered into the equation.

When the demographic variables were entered at the first step, it was found that the demographic variables explained 10 % of the variance in level of anxiety symptoms of the caregivers ($R^2 = .10$, $F(3, 101) = 3.76$, $p < .05$). Child's age ($\beta = -.23$, $p < .05$) was negatively associated with anxiety symptoms. The causal antecedents entered in the second step increased the explained variance by 17 % ($R^2 = .27$, $F(6, 98) = 6.01$, $p < .001$). The level of daily activities was negatively related to the level of anxiety symptoms ($\beta = -.26$, $p < .05$).

Mediating processes, which were entered in the third step, increased the explained variance by 10% ($R^2 = .37$, $F(11, 93) = 4.99$, $p < .001$). Appraisal of the situation as controlled by others was marginally related to the level of anxiety symptoms ($\beta = -.22$, $p = .06$).

The immediate effects, which were entered in the last step increased the explained variance by 3 % ($R^2 = .40$, $F(12, 92) = 5.16$, $p < .001$). Negative affect was positively related to the level of anxiety symptoms ($\beta = .23$, $p < .05$) (see Table 13).

Table 13

Hierarchical Regression Model Predicting Anxiety Symptoms

<i>Variables in Set</i>	ΔF	<i>df</i>	<i>t</i>	β	<i>pr</i>	ΔR^2
<i>Demographic Variables</i>	3.76*	3,101				.10
Child's age		101	-2.40	-.23*	-.23	
Gender		101	-.94	-.11	-.09	
Occupation		101	-1.15	-.13	-.11	
<i>Causal Antecedents</i>	7.53***	3,98				.17
Basic needs		98	-.87	-.11	-.09	
Daily activities		98	-2.21	-.26*	-.22	
Social support		98	-1.26	-.13*	-.13	
<i>Mediating Processes</i>	3.02*	5,93				.10
Threat appraisal		93	1.47	.15	.15	
Uncontrollability		93	1.06	.11	.11	
Self-control		93	-1.25	-.14	-.13	
Other-control		93	-1.94	-.22	-.20	
Problem focused coping		93	-.56	-.07	-.06	
<i>Immediate Effects</i>	4.78*	1,92				.03
Negative affect		92	2.19	.23*	.22	

Note. * $p < .05$; ** $p < .01$; *** $p < .001$

3.2.4.3. Predictors of Dissatisfaction with Life

The last hierarchical multiple regression analysis used dissatisfaction with life as the long term effect variable. First, demographic variables (occupation, level of education, and income) were entered into the regression equation. On the second step, causal antecedents (basic needs, daily activities, and social support) were entered into the equation. On the third step, appraisal (threat, challenge, uncontrollability, self-control, and other-control) and coping strategies (problem focused); and last, on the fourth step, negative affect were entered into the equation.

When the demographics were entered at the first step, it was revealed that the demographic variables explained 24 % of the variance in level of dissatisfaction with life of the caregivers ($R^2 = .24$, $F(3, 100) = 10.47$, $p < .001$). Reported family income ($\beta = -.43$, $p < .001$) was negatively associated with dissatisfaction with life. The causal antecedents entered in the second step increased the explained variance by 17 % ($R^2 = .41$, $F(6, 97) = 11.07$, $p < .001$). The level of satisfaction with basic needs was negatively related to the level of dissatisfaction with life ($\beta = -.48$, $p < .001$).

Mediating processes, which were entered in the third step, increased the explained variance by 11% ($R^2 = .52$, $F(13, 90) = 7.57$, $p < .001$). Appraisal of the situation as threat ($\beta = .31$, $p < .001$) and as challenge ($\beta = -.24$, $p < .01$) were both related to the level of dissatisfaction with life. Moreover, problem focused coping was negatively associated with the level of dissatisfaction with life ($\beta = -.27$, $p < .01$).

The immediate effects, which were entered in the last step increased the explained variance by 1 % ($R^2 = .52$, $F(13, 90) = 7.57$, $p < .001$), however F_{change} was not significant and negative affect did not significantly predict the level of dissatisfaction with life (see Table14).

Table 14
Hierarchical Regression Model Predicting Dissatisfaction with Life

<i>Variables in Set</i>	ΔF	<i>df</i>	<i>t</i>	β	<i>pr</i>	ΔR^2
<i>Demographic Variables</i>	10.47***	3,100				.24
Occupation		100	-1.84	-.20	-.18	
Income		100	-4.73	-.25***	-.43	
Education		100	.50	-.05	-.05	
<i>Causal Antecedents</i>	9.11***	3,97				.17
Basic needs		97	-3.78	-.44***	-.19	
Daily activities		97	.54	.06	-.26	
Social support		97	-.57	-.06	-.21	
<i>Mediating Processes</i>	3.43**	6,91				.11
Threat appraisal		91	3.40	.31***	.34	

Table 14 Continued

<i>Variables in Set</i>	ΔF	<i>df</i>	<i>t</i>	β	<i>pr</i>	ΔR^2
Challenge appraisal		91	-2.81	-.24**	-.28	
Uncontrollability		91	-.57	-.50	-.06	
Self-control		91	-.41	-.04	-.04	
Other-control		91	-.99	-.10	-.10	
Problem focused coping		91	-2.81	-.27**	.25	
<i>Immediate Effects</i>	1.26	1,90				.01
Negative affect		90	1.12	.10	.12	

Note. * $p < .05$; ** $p < .01$; *** $p < .001$

The hierarchical regression analyses revealed different patterns of results for the level of depressive and anxiety symptoms and dissatisfaction with life. Table 15 includes a summary of the results of hierarchical regression models.

Table 15

Summary of the Results of Hierarchical Regression Models

	Depressive symptoms	Anxiety symptoms	Dissatisfaction with life
<i>Demographic variables</i>			
Child's age	significant	significant	
Income	significant		significant
Gender			
Occupation			
<i>Causal antecedents</i>			
Health locus of control	significant		
Basic needs			significant
Daily activities	significant	significant	
Social support	significant	significant	

Table 15 (Continued)

	Depressive symptoms	Anxiety symptoms	Dissatisfaction with life
Mediating processes			
Challenge appraisal			significant
Threat appraisal			significant
Uncontrollability	significant		
Self-control			
Other control		significant	
Problem-focused coping			significant
Emotion-focused coping			
Immediate Effects			
Positive affect			
Negative affect	significant	significant	

2.4. Discussion

The aim of the Study 1 was to examine the predictors of caregiver distress, i.e. depressive and anxiety symptoms and dissatisfaction with life, among the caregivers of children with cancer by using the Transactional Theory of Coping (Lazarus & Folkman, 1984) as a theoretical framework. As shown in Figure 2 (p. 20), it was hypothesized that the causal antecedents (demographic variables, sense of control, basic needs, daily activities and social support) will predict the outcome variables (depressive and anxiety symptoms and dissatisfaction with life). After controlling for the effects of causal antecedents, the mediating processes (stress appraisal, problem focused coping, and emotion focused coping) will predict the outcome variables. After the controlling for the effects of causal antecedents and the mediating processes, immediate effects (positive and negative affect) will predict the outcome variables. Therefore, 3 models for each of the long-term outcome variables were proposed and tested. The effects of demographic variables and the relationship between the study variables were examined, too. Before the discussion of the main analyses, the preliminary findings need to be examined.

2.4.1. The Preliminary Analyses

The effects of the demographic, illness related, and caregiving related variables on the outcome variables were examined. The effect of caregiver's age was not significant for any of the outcome variables. According to some studies (e.g. Matthews, Baker, & Spillers, 2003; Demirtepe-Saygılı & Bozo, 2011a) younger caregivers experience more distress as compared to the older ones. However, the present study did not find a significant relationship between age and any of the outcome variables.

Unlike caregiver age, child's age significantly predicted depressive and anxiety symptoms negatively. That is, the younger the child, the more the level of depressive and anxiety symptoms. This could be attributed to the perceived vulnerability of the child from the viewpoint of the caregiver. In other words, as compared to the older children, younger ones could be perceived as more vulnerable (Grootenhuis & Last, 1997).

Gender based comparisons revealed that males had lower levels of depressive and anxiety symptoms than females, as supported by the literature (Sloper, 2000). Furthermore, there is also a difference between males and females in the same direction in terms of depressive and anxiety levels in normal population (Brannon & Feist, 2010). The difference in this particular sample could be attributed to the fact that the primary caregiver was usually the mother. Fathers spent less time at the hospital, as they continued to work for financial resources. Moreover, their role seemed to be complementary rather than primary in caregiving. Therefore, their lower levels of distress than females could be attributed to their roles.

The caregivers who were employed had lower levels of depressive and anxiety symptoms as compared to unemployed ones. Being employed might mean having more resources for coping (Kim et al., 2006), and a higher level of self esteem (Feather, 1990) which resulted in a lower level of distress. Considering the overlap between level of education and income; similar results were obtained and the mechanism of their influences could be common. In terms of level of education, it was revealed that university graduates had lower levels of dissatisfaction with life as compared to people with lower degrees of education. Similar to the effect of level of education, level of income was a significant

predictor of dissatisfaction with life. Higher level of perceived income was associated with lower levels of depressive symptoms and dissatisfaction with life. This can be due to a relatively easy access to resources and being able to use problem solving (Murphy, Felgoise, Walsh, & Simmons, 2009).

Duration of the illness was not a significant predictor of any of the outcome variables. Similarly, having helpers in caregiving did not result in any differences in terms of depressive and anxiety symptoms and dissatisfaction with life. These two findings indicated the importance of perceived factors over objective ones. That is, caregivers' subjective criteria were more important to predict their distress than objective factors such as duration and having someone to help with the caregiving tasks. The importance of subjective criteria over objective ones was also supported by the literature (e.g. Nijboer et al., 1998). Similarly, perceived life threat and perceived treatment intensity were found associated with post-traumatic stress symptoms in parents of children with cancer (Kazak et al., 1998). Moreover, Burrige, Bamett, and Clavarino (2009) suggested that perceived stage of cancer could be related to caregiver depression and anxiety. Therefore, subjective appraisal of the illness could be more predictive for caregiver distress.

Reporting physical problems was associated with having higher levels of depressive and anxiety symptoms and dissatisfaction with life. This relationship could be bidirectional, that is, having physical problems, as a preceding factor, could add to the caregiving burden and result in a more negative well-being. On the contrary, having higher levels of psychological symptoms could result in having physical symptoms, as a consequence. The interaction between physical and psychological well-being was established at the times of Socrates and Hippocrates leading to the emergence of psychosomatic medicine and biopsychosocial model (Brannon & Feist, 2010). Somatic symptoms are included in the diagnostic criteria for depression in DSM-IV-TR (APA, 1994) and owing to the overlap of symptoms, the complexity of differentiation between depressive symptoms and somatic symptoms was emphasized (Dowrick et al., 2005). Moreover, in the present study, receiving medical treatment for those physical disorders was related to higher levels of only depressive symptoms, not anxiety symptoms or dissatisfaction with life, strengthening the psychosomatic explanation for the physical symptoms.

2.4.2. Discussion of the Main Findings

Three hierarchical regression models were tested by using the predictors which were significantly related to the outcome variables in the preliminary analyses. The findings suggested different patterns of relationships for each of the outcome variables (see Table 15, p. 49). This may be due to the nature of the variables. Therefore, the definitions and main characteristics of the outcome variables should be considered together with the results.

Depression mainly includes a negative view of self, world, and future (Beck, 1973); and sadness and lack of positive affect (Kring et al., 2013). The predictors of higher levels of depressive symptoms were younger child age and lower levels of perceived income as the demographic variables; external health locus of control, lower levels of daily activities and social support as the causal antecedents; higher levels of uncontrollability appraisal as mediating process; and negative affect as the immediate effect. Anxiety is characterized by “an apprehension over an anticipated problem” (Kring et al., 2013, p.175) and an initiation of a primal survival mechanism, including the feelings of unsteadiness and dizziness (Wells, 1997). A similar pattern of results were revealed for the level of anxiety symptoms. The predictors of higher levels of anxiety symptoms were younger child age as the demographic variable; lower levels of daily activities and social support as the causal antecedents; appraisal of the situation as controlled by others as the mediating process; and negative affect as the immediate effect. Supporting evidence for the predictors of depressive and anxiety symptoms were provided by the literature. To illustrate, external locus of control (Benassi, Sweeney, & Dufour, 1988); lower levels of performance on daily activities (Demirtepe-Saygılı & Bozo, 2011a); and lower levels of perceived social support (Horton & Walander, 2001) were related to higher levels of depressive and anxiety symptoms.

Life satisfaction is defined as “a global assessment of a person’s quality of life according to his chosen criteria” (Shin & Johnson, 1978, p. 478). Thus, it includes “a cognitive judgmental process” (Diener, Emmons, Larsen, & Griffin, 1985, p. 71). A slightly different pattern of results was obtained for the level of dissatisfaction with life. It was predicted by lower levels of income as the demographic variable; lower levels of

satisfaction with the basic needs as the causal antecedent; and higher levels of appraisal of the situation as a threat and lower levels of appraisal of the situation as a challenge and more use of problem focused coping as the mediating processes. Neither positive nor negative affect was a significant predictor for dissatisfaction with life. The level of income could be perceived as a means to reach goals or an availability of services, and therefore a predictor for life satisfaction (Salinas-Jimenes, Artes, & Salinas-Jimenes, 2010) and satisfaction with basic needs can also be evaluated as an extension of the level of income, resulting in life satisfaction. Furthermore, problem solving skills was related to higher levels of satisfaction with life in caregivers of patients with amyotrophic lateral sclerosis (Murphy et al., 2009). Thus, the findings on the predictors of dissatisfaction with life were supported by the literature. Moreover, negative affect was a predictor for the levels of depressive and anxiety symptoms, but not dissatisfaction with life. Thus, it can be suggested that affect is predictive at a symptomatic level specifically, not at a general life satisfaction level.

There were some unexpected findings, considering the pattern of relationships. For example, appraisal of the situation as threatening and uncontrollable was expected to predict the level of anxiety (Lazarus & Folkman, 1984; Koerner & Dugas, 2008). However, these were not significant predictors of anxiety, while only appraisal of the situation as controlled by others marginally predicted the level of anxiety. It can be explained with the belief that if the control is on others, there may be a future threat and it may result in an unpleasant future. In other words, feeling someone else's control on themselves may result in a high level of anxiety. Another interesting point that needs a focus was that primary appraisal (threat or challenge) and problem focused coping predicted only dissatisfaction with life. By considering the literature (e.g., Elliot & Shewchuk, 2003; Trask et al., 2003), it was expected that appraisal and coping play a role in depression and anxiety. However, the present study failed to confirm such a relationship. In terms of predicting dissatisfaction with life, the following explanation was proposed: Life satisfaction includes perceived standards, and a comparison between what people desire and what their current state is. Therefore, people currently evaluating themselves as trying to solve a problem appraised as a challenge may be what they desire and they achieve.

2.4.3. Implications for the Intervention

The findings of Study 1 had important implications for the development of the intervention program (Study 3). The importance of fulfillment of their basic needs and continuation of daily activities in hospital setting were discovered and therefore included in the intervention program. The appraisal of controllability and the appraisal of the situation as a threat or a challenge were important for the choice of coping strategies, which further predicted the level of distress. Defining and illustrating what could be controlled for this particular sample and providing suggestions on what to do in controllable and uncontrollable situations were included in the intervention program. Moreover, considering the positive effects of social support, being able to ask for social support -emphasizing the importance of having social relationships- was added to the intervention agenda. To sum up, owing to the findings of Study 1, basic needs, daily activities, appraisal and coping, and social support were determined as the content of the intervention program.

2.4.4. Limitations of the Present Study

Although having strengths such as being guided by a theoretical model and using valid and reliable measurement devices, the present study has several limitations. Having unequal number of participants in groups in the sample; such as, males and females, and participants having a physical disorder or not, was a limitation of the study. Therefore, these group comparisons must be treated with caution.

Another limitation stemmed from being a cross-sectional study. The Transactional Theory of Coping (Lazarus & Folkman, 1984) includes immediate effects and long term effects as the outcomes of coping with stress process. Therefore, ideally, long term effect variables should have been measured as a follow-up. However, all of the variables were measured cross sectionally in the present study. Hence, the absence of a follow up measurement of long term effect variables was a limitation.

Caregivers who were able to read, understand, and fill in the self-report inventories were included in the present study. However, there were a substantial number of people who

were illiterate or had never filled in a questionnaire before. Those people were not able to fill in the questionnaire properly, hence excluded from the study. Therefore, the results cannot represent whole caregiver population.

The study was conducted in two leading pediatric oncology departments in Ankara which have qualified medical teams and modern technology devices, making them most preferred centers. Due to the limited number of hospitals, possible differences stemming from the characteristics of the hospital may not be acknowledged. Furthermore, among the families being treated in these hospitals, some were living in Ankara, whereas more than a half had come from cities near Ankara, or from the East and South East regions of Turkey. Therefore, the cultural characteristics of different regions might not be represented.

2.4.5. Directions for Further Studies

Further longitudinal studies could more properly investigate the long term effect variables of the coping model. Furthermore, it would be possible to track changes in the child and corresponding changes in the caregiver's coping process via longitudinal studies.

The Transactional Theory of Coping (Lazarus & Folkman, 1984) includes other variables in the coping with stress process, such as resolutions of stressful encounters as a mediating process, or somatic health as a long term effect. These variables can also be investigated in future studies with similar populations. Moreover, there can be other influential variables, which were not at the scope of the present study, such as post traumatic stress symptoms, family functioning and marital relations.

CHAPTER 3

STUDY 2: QUALITATIVE ANALYSIS OF THE COPING PROCESS OF CAREGIVERS OF CHILDREN WITH CANCER

3.1. Aim and Hypotheses

The aim of the present study is to identify the factors associated with caregiving from the caregiver's perspective without being directed or limited by a specific theory. The research questions are "How are caregivers of children with cancer affected by the illness?" and "How do caregivers of children with cancer cope with the illness process?" The questions covered three topics, namely, the emotions, coping, and the effects of cancer.

Semi-structured interview was chosen as the method for the qualitative research, consistent with Interpretative Phenomenological Analysis (IPA). In semi-structured interviews, the researcher has a set of open ended and non-directive questions but the interview is not strictly bounded by the questions, it is rather guided by them (Smith & Eatough, 2007). The interviewee is free to answer in his/her own way as s/he understands and interprets. The participant shares his/her personal experiences of the examined phenomenon with the researcher (Willig, 2008). Therefore, it is more open and flexible. As it is less structured, the questions can be tailored. It has room for probing (Burman, 1994). It allows for an interaction between the researcher and the participant. The current semi-structured interview is explained in detail in the Method section.

3.2. Method

3.2.1. Participants

Twenty caregivers (15 mothers, 5 fathers) of children with cancer participated in the study. The age of the participants ranged between 27 and 52 with a mean of 36.55 ($SD =$

7.80). All of the participants were married. Perceived family income per month was categorized into 3 as low, middle, and high. People who defined themselves as belonging to lower income group constituted 15 % of the sample ($n = 3$). The remaining 75 % were members of either middle ($n = 15$) or high income individuals ($n = 2$, 10 %). Education levels of the participants were as follows: 20 % primary school ($n = 4$), 5 % secondary school ($n = 1$), 40% high school ($n = 8$), and 35 % university ($n = 7$). The percentage of the participants who did not get help for care giving was 50 % ($n = 10$), and the remaining 50 % received help from either their husbands or their mothers ($n = 10$). Eight people (40 %) reported that they have to look after only the ill child, whereas 12 people (60 %) reported they were responsible for other family members' care, such as other children or own parents. Finally, 2 people (10 %) had psychiatric diagnoses and reported medication use.

The diagnoses of the children were various including organ tumors such as kidney, brain; tissues, such as sarcomas; or blood, such as leukemia. The length of the illness of the child ranged between 1-20 months with a mean of 5.84 months. The caregivers whose children were having chemotherapy formed 75 % ($n = 16$) of the sample. The others were a control ($n = 1$), a radiotherapy ($n = 1$), a chemotherapy and radiotherapy ($n = 1$), and a complication ($n = 1$) patients. The age of the children ranged between 10 months and 17 years ($M = 7.55$; $SD = 5.20$) (see Table 16 for the demographic characteristics of the sample).

Table 16
Demographic Characteristics of the Sample of Study 2

	<i>M</i>	<i>SD</i>	<i>n</i>	<i>%</i>	<i>Min-Max</i>
Age	36.55	7.80			27-52
Relationship to the patient					
Mother			15	75	
Father			5	25	
Perceived family income					
Low			3	15	
Middle			15	75	

Table 16 Continued

	<i>M</i>	<i>SD</i>	<i>n</i>	<i>%</i>	<i>Min-Max</i>
High			2	10	
Education					
Primary school			4	20	
Secondary school			1	5	
High school			8	40	
University			7	35	
Employment status					
Housewife/unemployed			11	55	
Employed			9	45	
Child's age	7.55	5.20			
Type of the treatment					
Chemotherapy			16	75	
Radiotherapy			2	10	
Other (control and complications)			2	10	
Time since diagnosis (month)	5.84	6.17			1-20

3.2.2. Measures

The measures of Study 2 included demographic information form and open-ended interview questions.

3.2.2.1. Demographic Information Form

The demographic information form, which was prepared for the caregivers of children with cancer, included general demographic questions about age, gender, education, occupation, marital status, and perceived family income (see Appendix B). Besides, it contained questions about the illness and the caregiving process, such as the relationship to the patient, type of diagnosis, time since diagnosis, the phase of the treatment, number

of people living at home, number of other caregivers, number of children except for the ill child, and having physical and psychological illness or not.

3.2.2.2. Interview Questions Form

This form included open ended questions about the process of caregiving beginning from the diagnosis continuing after treatment ends. The questions were about three topics namely, emotions, coping, and effects of cancer. The answers were evaluated with content analysis (see Appendix L).

3.2.3. Procedure

Ethical approval was obtained from Middle East Technical University Ethical Committee, Hacettepe University Ethical Committee, and Ankara Provincial Directorate of Health. Approvals of the heads of the pediatric oncology departments of the hospitals were gathered; and written informed consent (see Appendix A) was obtained from all participants.

After the recruitment of the participants, the rationale of the study was explained and a written consent was obtained. In addition, the reason of recording the interviews was explained and with the approval of the participants, each interview was audio-recorded.

In order to provide a warm up and a rapport between the interviewee and the interviewer, the semi-structured interview began with demographic questions which were more objective and easier to answer. The first question served the same purpose, as well (see Appendix L). The interviews lasted for approximately 30 minutes. The interviews were conducted in the meeting room or the psychologist's office of pediatric oncology department.

Due to translation problems, the question about perceived control was not understood by the interviewees correctly, therefore, it was removed from the interview and the process continued with 11 questions.

3.2.4. Data Analysis

Data were analyzed by MAXQDA 11. As suggested by Smith and Osborn (2003), the following steps were followed for the analysis of the data. After the audio-recorded interviews were transcribed verbatim, each case was read and reread by the researcher. Initial thoughts, associations, uses of language and descriptions were formed for each case. The subthemes were identified, inspected for connections and combined into clusters of themes. In this way, the subjective experiences of the participants were merged with the interpretations of the researcher. Then, themes and subthemes were explained including representative quotations. Furthermore, the distribution of the themes among the cases, the pattern of the themes, the relationship among the demographic characteristics of the cases, and the frequency of the themes were examined. The results are presented below and the numbers in parentheses represent the number of each theme's appearance during the interviews.

3.3. Results

Themes were investigated under three topics, namely; the emotions, change and coping. The numbers in parentheses represent the number of segments coded with the theme.

3.3.1. Theme 1: Emotions

The emotions felt and reported by the participants were mostly negative, including sadness, anxiety and guilt. The first reaction reported by the families was shock ($n = 6$) at the time of diagnosis.

Subtheme 1: Sadness ($f = 25$)

The most common emotion felt about the child's illness was sadness. It was mentioned as a natural part of the illness, and particularly intense through diagnosis. Seeing the child as unhealthy, observing him/her hurt by some painful procedures evoked sadness in parents. It could be evaluated as a part of the process and it did not necessarily mean the treatment is going bad. They experienced a loss of time, relationships, plans and future in the

process of cancer, which may bring about sadness. Moreover, helplessness, devastation, fear and disappointment accompanied sadness.

“It was the end of the world, then...” [Dünyanın sonu gelmişti o zaman...]

“When you see your child in that situation, you feel down and devastated.” [Çocuğu o şekilde gördüğünüzde sizin de moraliniz bozuluyor, yıkılıyorsunuz.]

Subtheme 2: Anxiety ($f=11$)

The diagnosis of cancer can be perceived as an unexpected event in people’s lives. Moreover, there was a perception of an ambiguous future, which may stir up anxiety. Some people also need to arrange the hospital life and family life together by themselves, which also made them feel anxiety for catching up.

“Will we be all right, will it relapse, when will it end, does the medication work? These are what I have been thinking of for days.” [İyi olacak mıyız, bir daha tekrarlayacak mı, ne zaman bitecek, vücuduna ilaçlar iyi geldi mi? Bunlar hep günlerce düşündüğüm şeyler.]

“In case of even minor vomiting or headache, question marks come to my mind whether it will relapse.” [En ufak bir kusmada, başağrısında bir soru işareti oluyor acaba tekrarlayacak mı diye.]

Subtheme 3: Guilt ($f=11$)

There were various points in which guilt was evident. Focusing on the ill child usually meant ignoring the other child(ren) and this was reported with a guilt ($f=8$).

“I feel so sorry about being apart from my younger child. I feel as if I am unfair to and excluding him/her...” [Küçüğümden ayrırım ona çok üzülüyorum. Ona haksızlık etmiş gibi oluyorum, sanki onu dışlamış gibi...]

“We ignored him at a critical time that needs much attention.” [Çok ilgilenilmesi gereken bir dönemde biz onu (diğer çocuğu) boş bıraktık.]

“We put aside the other children and we do not pay attention to them at all.” [Öteki çocukları kenara koyduk onlarla hiç ilgilenemiyoruz.]

Having time for oneself was also associated with guilt because it was evaluated as a time spent without the child

“I was very impressed when I went out for the first time... It is very hard to leave.” [Dışarı ilk çıktığımda çok etkilendim... bırakıp gitmek zor.]

Regret can also be considered as connected to guilt. Some parents see themselves as responsible for not noticing the symptoms early enough, not taking their child to the right doctors and losing time, etc.

Subtheme 4: Emotion suppression ($f = 14$)

The parents sometimes used suppression of their emotions ($f = 8$). They usually believe that they need to “seem” OK in order for their child to feel OK.

“I sometimes feel like crying, but I gulp it back so as not to make him feel that.” [İçimden ağlamak geliyor, kendimi sıkıyorum oğlum hissetmesin diye.]

Fathers mentioned this by comparing them with their wives. One of the fathers perceived not displaying emotions as a positive attribution:

“I can behave more patient because I am a man. I do not react, like crying or expressing sadness, but I feel them inside.” [Erkek olduğum için daha sabırlı davranabiliyorum. Ağlamak üzölmek gibi tepki göstermiyorum ama bunları içimde yaşıyorum.]

On the contrary, another father attributed a negative meaning to emotion display:

“Mothers are more emotional, but fathers repress their feelings instead of acting them out.” [Anneler daha duygusal, babalar içe veriyor, kendini dışa vuramıyor.]

Being emotional/sensitive (duygusal) was mostly reported as a weak point ($f=6$). It was actually used to describe not being able to repress sadness and crying.

“I am too emotional and this is affecting me so much. *How does it affect you?* I feel sad all the time I see my daughter.” [Benim duygusallığım çok fazla. O beni baya etkiliyor. *Nasıl etkiliyor?* Sürekli kızımı gördükçe üzülüyorum.]

“I am excessively sentimental, I cry easily.” [Aşırı duygusalım, hemen ağlıyorum.]

It should be noted that 3 people did not mention their emotions in their answers to the questions about emotions, which may suggest that they were not aware of their emotions or they did not know how to describe or name them.

“It made me feel so many things that I cannot tell. Sometimes we cannot express, it is too hard.” (with pauses) [Yani o kadar çok şey hissettirdi ki anlatamıyorum bir türlü. Bazen kendimizi bile ifade edemiyoruz. Çok zor. (duraksamalar ile)]

3.3.2. Theme 2: Change

Change is an indispensable part of cancer diagnosis and treatment process. The participants mentioned the change of the ill child, interdependence, psychosocial change, and positive change.

Subtheme 1: Change of the ill child ($f=37$)

Although there was not a direct question about the ill child, the participants talked about the child in their answers. Some of them, who were mothers, used words “us”, “our father” (babamız) while talking about their stories which address a union of mother-child. The families talked about the child in various ways in terms of the behaviors ($f=15$), the emotions ($f=10$), future and normal life ($f=7$), and the symptoms ($f=5$) of the child.

“His manner also began to change because of too much attention, but it’s not a big deal.” [Aşırı ilgiden bir anda huyu da değişmeye başladı ama tabi onlar önemli değil.]

Subtheme 2: Interdependence ($f = 16$)

The participants reported that they focus on only the ill child and depend their well-being on the child's well-being, which can be regarded as an emotional interdependence between the ill child and the caregivers. It was evaluated as a change in the mother-child relationship.

“We were all right as long as he/she is all right.” [O iyi olduđu sürece biz de iyi olduk.]

“I do not feel strong at all, but I get better when he/she says he/she feels good.” [Şu an kendimi hiç güçlü hissetmiyorum da işte o iyiyim deyince ben de iyi oluyorum.]

The interdependence seemed to work in a bidirectional way. In other word, some participants mentioned trying to seem OK in order for the child to be OK.

“You take care of yourself so that he/she will be OK.” [Sen kendine iyi bak da o da iyi olsun.]

“My child is extremely affected from me. He/she understands when I shed tears or feel down.” [Çocuğum benden aşırı etkileniyor, o, benim gözümünden akan yaş olsun, moralim bozuk olsun, anlıyor.]

Subtheme 3: Psychosocial change ($f = 24$)

The psychosocial change included social and daily life ($f = 11$), and disruptions in spousal relationship ($f = 4$). Moreover, physical and cognitive problems ($f = 9$) such as being tired, sleep problems, and memory problems were also mentioned as problematic changes in daily life.

“Our social environment does not exist anymore. We have difficulty in communicating with people comfortably due to the illness. Because, children undergoing chemotherapy are very sensitive.” [Bizim sosyal ortamımız bitti, çevreyle rahat bir iletişim kurmakta zorlanıyoruz hastalık nedeniyle. Çünkü kemoterapi gören çocuklar çok hassas.]

“We have intolerance between me and my spouse that we cannot control. We concluded that it is a trace of the illness.” [...eşimle aramızdaki tahammülsüzlük, aslında kendi elimizde değil bu, onun (hastalığın) bıraktığı bir iz olduğu kanısına vardık.]

“I vent my peevishness on my spouse. I do not want to upset my kids” [Bütün hırçınlığımı ondan (eşimden) çıkarıyorum. Çocuklarımı üzmem istemiyorum.]

Subtheme 4: Positive change ($f = 24$)

Although the diagnosis and treatment process is mostly dominated by negative emotions, uncertainty, some painful procedures and being in hospital for an uncertain time; some participants mentioned change of the following attributes in a positive way: Optimism ($f = 6$), growth ($f = 6$), awareness of positive attributions ($f = 10$), family union and attachment ($f = 2$).

“I always try to see the glass half full.” [Ben bardağın hep dolu tarafını görmeye çalışıyorum.]

“I used to get crossed easily and cry like a kid, but now I feel as I have grown up and I am more woman...” [Önceden her şeye küserdim ağlardım çocuk gibi, şimdi daha büyümüş bir insan gibi hissediyorum daha kadın gibi...]

“I am standing on my feet and I can struggle with it.” [Ayaktayım, mücadele edebiliyorum.]

3.3.3. Theme 3: Coping

The participants mentioned their coping strategies both directly and indirectly while talking about other issues.

Subtheme 1: Avoidance ($f = 10$)

Two people reported that they did not want to remember how they felt at the time of diagnosis. As they found it disturbing, they chose not to focus on the negatives. However, when we consider these interviews were conducted with volunteer participants, it can be

thought that people who used avoidance as a coping strategy might not have volunteered to participate. Therefore, it could be suggested that the rates of avoidance were not properly represented in this study.

“I try not to answer the phone calls. I feel like crying when I hear the voice of the people I love.” [Telefonlara o zaman bakmamaya özen gösteriyorum. Sevdiğim insanların sesini duyunca içimden ağlamak geliyor.]

As a response to the question about the effect of the illness, one of the participants stated: “I have not thought about it that much, you are influenced of course...” [Çok fazla oturup düşünmedim, etkileniyorsunuz tabi...]

As a general impression of the use of language, it was noteworthy that the families avoid using the word “cancer” or “tumor” and this was also evaluated as a form of avoidance. They tend to prefer more indirect ways to describe the illness, such as “mass” [kitle], “it was malignant” [kötü huylu]. Three people used the word cancer. The name of the illness was evaluated by two mothers in this way:

“This is a bad illness. The name of this illness is bad...” [Bu kötü bir hastalık. Adı kötü hastalığın...]

“The name of the illness is very bad, that is why it is too difficult. It is hurting... I cannot ascribe it to him/her because he/she is too little... I have never put that name into words.” [Hastalığın ismi çok kötü, ondan zor geliyor. Zoruma gidiyor... yakıştıramıyorum çünkü daha çok küçük...o ismi ben daha hiç telaffuz etmedim.]

“It seems like headache or toothache unless that name is used. I shiver at the time it is used” [İsmini kullanmadıkça baş ağrısı, diş ağrısı gibi geliyor. İsmi kullanıldığı an ürperiyorum.]

Subtheme 2: Religion ($f = 31$)

The religious beliefs of the participants were not directly asked. However, religious beliefs were mentioned by the participants in terms of their attributions about the illness

and the cure, and as a way of coping. They mentioned faith, God, and prayer as helping sources ($f=12$).

“First God, and then the doctors will help.” [Önce Allah, sonra doktorlar yardım edecek.]

“I believe that it comes from God. God gave the trouble and the remedy will be given by God, too” [Allahtan geldiğine inanıyorum. Derdi veren O ise şifayı verecek de O.]

“I am praying, I have nothing else to do.” [Dua ediyorum, başka yaptığım hiçbir şey yok.]

“My faith helps me to cope with it.” [Başetmeme inanç yardımcı oluyor.]

Some reported that they believed the illness is God-given ($f=5$).

“It is the will of God”, “It is given by God.” [Takdir-i İlahi, Allah’tan geldi.]

Three people stated that they were being tested by God with the child’s illness.

“It is a different thing, having been tested on your child.” [Çocuğunuzla imtihan olmak farklı birşey.]

“I am upset but I am being tested and I am going to pass, come over it.” [Üzülüyorum ama ben sınavdayım ya, geçeceğim atlatacağım yani.]

Three people mentioned good [hayır] in bad. They also used thankfulness (şükür) ($f=11$). The word “inşallah” was used very often by the participants.

Patience was a concept that was sometimes associated with God.

“God gave the patience.” [Allah sabrını verdi.]

Subtheme 3: Comparison ($f = 10$)

The participants reported that they compare their child with other ill children whom they interact with at the hospital. They use downward comparison and feel better. That is, they compare their situation with those who were worse and conclude that their child's condition was not that serious or hopeless.

“When I see them (other children), my morale is unavoidably recovering. Every bad has its worse.” [Onları görünce (diğer çocukları) ister istemez moral açısından bir düzelme oluyor, beterin beteri var.]

“When we see the children at the hospital, we say it is always insufficient no matter how much we are grateful for our situation.” [Hastanedekileri görünce biz kendi halimize ne kadar şükretsek az diyoruz.]

Subtheme 4: Locus of interest ($f = 11$)

Caregiving a child with cancer sometimes meant devoting oneself to the child and not putting anything else on the agenda. This can be evaluated as connected with interdependence theme mentioned above. The participants mentioned their focus on only the ill child ($f = 4$), not thinking about the future after the hospital life ($f = 3$). Four people answered the question “what would help you” as “the child's getting better”

“There is nothing else. Everything is of secondary importance.” [Başka hiçbir şey yok. Herşey ikinci planda.]

“The kid and the hospital were the only things that I focused on. I could not devote myself to anything else.” [Tek odaklandığım çocuktü, hastaneydi, kendimi başka hiçbirşeye veremedim.]

Subtheme 5: Acceptance ($f = 12$)

Living with the presence of the illness required acceptance of the situation. The participants talked about getting used to the illness (alışma) ($f = 9$) and acceptance (kabullenme) ($f = 3$).

“Although I could not get used to it, I have to do so, because I know it has come.”

[Alışmasam da alışmak zorundayım, geldiğini biliyorum çünkü.]

“We need to proceed in a certain way. It is going to be hard of course. I believe in that. I made myself accept this.” [Belli bir yol katetmemiz gerekiyor. O yolu katederken zorlanacağız tabi. Buna inanıyorum. Kendimi kabullendirdim.]

Patience (sabır) ($f=9$) was reported subsequent to acceptance. It was mentioned as a positive attribute in the treatment process by the participants.

“I am patient, I hope it will be gone.” [Sabrediyorum geçeceğini umuyorum.]

“Patient” (as an answer to the question about strengths) [Sabırlı] (güçlü yönleriniz sorusuna cevap)

Subtheme 6: Hope ($f=21$)

They reported that they have hope for the cure of the child. While interpreting this finding, it should be noted that the families of children who were in active treatment or at the ends of a successful completion of the treatment were included in the study.

“I consider he/she is going to recover; I have that glimmer of hope inside me.” [İyileşecek gözüyle bakıyorum, içimde bir ışık var.]

“I believe that he/she will get better.” [Onun iyi olacağına inanıyorum.]

Subtheme 7: Trust in the medical team ($f=18$)

Trust in doctors and believing that they would help them to get over the illness is mentioned by the participants ($f=9$). Getting help from the psychologist for themselves ($f=5$) and the hospital environment and staff ($f=4$) were the other sources of help.

“I believe he/she will recover thanks to the doctors.” [Doktorlar sayesinde iyileşeceğini düşünüyorum.]

Subtheme 8: Information seeking ($f = 7$)

The participants mentioned that they search for and read about the illness. They stated having information as a positive attribute and a way to maintain control.

“We had information about the illness, this vitalizes us a little.” [Hastalıkla ilgili bilgi sahibi olduk, o biraz güç veriyor.]

“I am also reading about this issue. I am reading the stories of people who already overcome this disease.” [Bu konuda kitap da okuyorum. Hastalığı yenmiş kişilerin hikayelerini okuyorum.]

Subtheme 9: Support ($f = 17$)

Social support from family and friends was mentioned as a way of alleviating negative emotions.

“You become happy when everyone accompanies you. We thought that we are not alone then.” [Herkes yanında olduğu zaman mutlu oluyorsun... demek ki yalnız değilmışiz diye düşündük.]

“They often call to support; I always feel that they experience there the same things that I go through here.” [Destek için çok arıyorlar, sürekli hissediyorum benim burda yaşadıklarımın aynısını orda yaşıyorlar.]

Although it is not in the scope of the present study, a theme that came up from the participants was *communication with the ill child*. The participants ($f = 8$) mentioned that they did not talk about the illness with the child and lie to him/her about the symptoms and the reason of being in the hospital.

“We lie to them because they are kids.” [Çocuk oldukları için yalan da söylüyoruz.]

“He/she has not known his/her illness yet, we do not want him/her to be affected” [Şu an hastalığını bilmiyor, etkilensin istemiyoruz.]

The summary of the themes, subthemes and their frequencies are provided in Table 17.

Table 17
Summary of the Results of Study 2

Theme	Subtheme	<i>F</i>
Emotions	Sadness	25
	Anxiety	11
	Guilt	11
	Emotion suppression	14
Change	Change of the ill child	37
	Interdependence	16
	Psychosocial change	24
	Positive change	24
Coping	Avoidance	10
	Religion	31
	Comparison	10
	Locus of interest	11
	Acceptance	12
	Hope	21
	Trust in the medical team	18
	Information seeking	7
Support	17	

3.4. Discussion

The aim of Study 2 was to investigate the subjective experiences of the caregivers of children with cancer from Interpretative phenomenological analysis (IPA) perspective, with a research question “How do caregivers of children with cancer cope with the illness

process?” Semi-structured interview transcripts were analyzed and described under 3 themes, namely emotions, change, and coping.

3.4.1. Emotions

The subthemes of emotions are presented and discussed one by one below. However, it should be noted that emotions are usually not felt by themselves; they coexist and are in an interaction with each other (Oatley & Duncan, 1992). The most evident emotion reported by the caregivers was sadness. Considering sadness as a result of the experience or witness of loss of an object or a goal which the person attributes different levels of importance (Power, 1999), the caregivers experience the loss of health and a normal life. Moreover, having an ill child who is struggling with cancer make the families feel sad, combined with pity. Crying during the interviews was also coded, together with helplessness, with sadness. Therefore, it was expected and found that sadness is one of the leading emotions in caregiving situation.

Generally, anxiety is a state of mood characterized by a danger or threat (Ekman, 2003). Because of an uncertain future, it is another emotion felt during the treatment process. In the present study, anxiety was particularly about a possible relapse and prolonged effects of the illness on the child's future life. Thus, anxiety was associated with the caregiving process, during which they perceive an uncertain future and threat of a bad prognosis.

Guilt is a self-conscious emotion, which can be felt after a self evaluation process. It is expected when people feel responsible from a violation of standards (Tangney, 1999). In case of caregiving a child with cancer, the caregivers reported feeling of guilt when they thought they were ignoring their healthy children. Moreover, they ruminated about whether they did something “wrong” and had a share in the illness situation, which could result in feelings of guilt. In addition, guilt was also felt when the caregivers spent time for other things, rather than being with their ill child. During the interviews, guilt was either reported directly or indirectly beneath other negative emotions, such as sadness. Thus, guilt was another emotion coupled with some negative thoughts including a negative self evaluation.

Emotion regulation is the process people have, experience, express, and deal with emotions, automatically or not and consciously or unconsciously (Gross, 1998). It is needed for adaptive interpersonal relationships and a consistent self image (Thompson, 1991). Considering emotional expression as a part of emotion regulation; suppression of emotions could be defined as the lack of expression of emotions. The suppression of emotions was reported directly by the participants or noticed indirectly by the interviewer from the absence of or difficulty in talking about the emotions. There was an assumption that expressing emotions is a bad thing, a weakness or it is something that would make the child feel bad. Koch (1985) also mentioned that emotional expression is perceived as overwhelming the other family members. When the consequences of suppressing emotions were investigated, it was found that inhibition of emotional expression, or repression, was associated with a worse health (Denollet et al., 1996; Jensen, 1987). On the contrary, expressing emotions resulted in a better well-being. For example, a guided written disclosure intervention, which aimed to increase emotional expression, resulted in a lower level of post-traumatic stress symptoms in caregivers of children with cancer (Duncan et al., 2007). Similarly, in the present study, a few participants provided the feedback that the interview made them relieved and thanked for it. This can be interpreted as a need to ventilate emotions and share their experiences. Thus, considering the negative effects of suppressing the emotions, finding ways to express them was important for the caregivers.

Anger was another negative emotion that might be felt by the caregivers about the illness and treatment situation. According to appraisal-based explanations of anger, it is an emotion felt as a result of perceiving an event as offense or mistreatment (Berkowitz, 1999). It was also suggested to be experienced for aversive events, such as pain (Berkowitz, 1993). Furthermore, anger was one of the stages of dealing with loss in Kübler Ross's 5 stages of grief model (1969). Moreover, it was suggested that feeling anger was accepted as normal in caregiving a child with cancer (Woznick & Goodheart, 2002). Nevertheless, it was not reported by the participants of the present study. Only one participant expressed anger within a question "why them?" and immediately blocked that emotional expression not to be rebellious to God ("Bir anne olarak haykırmak istedim Allah'ım bu niye başımıza geldi diye yani ben isyan etmek için değil de Allah'ım niye bu böyle oldu"). Therefore, anger could be considered as an underreported or unexpressed

emotion. In other words, it could be a part of emotion suppression. Moreover, anger felt for the situation could also be displaced, such that having problems with spouse (a subtheme under psychosocial change) was reported by some participants. The problems with the spouse was attributed to the illness process and the problems with the children. Although the participants did not mention anger much, just like the other emotions it was acknowledged as a part of the caregiving process.

3.4.2. Change

After the diagnosis, due to treatment requirements change in people's lives was inevitable. Change was reported in four subthemes, namely, change of the ill child, interdependence, psychosocial change, and positive change.

Although there was not a direct question about the change of the ill child, the caregivers most frequently mentioned the changes in their child, especially behavioral change. The caregivers perceived the child's getting better as a priority and ignored his/her behavioral problems. The interdependence between the mother and the child was considered as a change in the relationship. A mother-child unity seemed to be formed and if the child's feels better, then the mother feels well, as well, and vice versa. The literature suggested that in terms of psychological symptoms, the well-being of child both influence and was influenced by the well-being of the caregiver (Roddenbery & Renk, 2008).

Similar to the findings in the literature (e.g., Fletcher, 2010), the caregivers mentioned change in their daily lives, social relationships, and family relations. Especially the caregivers staying at the hospital abandon their own needs and this adds to the burden of having an ill child (Matthews, Baker, & Spillers, 2003). Thus, change in daily life was an inevitable part of the process.

Positive changes and attributes were directly asked in the interview and it was revealed that the caregivers were able to concentrate on and think of positive sides, such as an optimistic point of view, growth, awareness of positive attributions, family union, and attachment. A general impression of the participants was that they were optimistic about the course of the treatment and future. When growth is examined as suggested by

Tedeschi and Calhoun (2004), posttraumatic growth is an experience of growth after a traumatic life event. It includes changes in beliefs and schemas about the world. Even being able to answer this question could be considered as a change in the point of view and being able to focus on the positives, because not all of the participants answered it in an expected way. There were participants who answered this question as “nothing positive” or “when the treatment is going well, it is a positive effect for us”. Moreover, a change of importance attributed to daily events, being able to unite as a family, and considering oneself as a successful manager of the situation were reported by the participants were also interpreted as signs of growth.

3.4.3. Coping

The participants were asked about their ways of coping and managing their lives with this illness. The subthemes were avoidance, religion, acceptance, comparison, locus of interest, hope, trust in the medical team, information seeking and support.

Avoidance of thinking about the illness, talking to others and spelling the name “cancer” were reported by the participants. The caregivers who did not agree to conduct an interview might have also been avoiding a situation in which they were asked to think and talk about their child’s illness. Therefore, the rates of avoidance could not be represented in the present study. In illness situations, avoidance of the problem hinders the person from looking for treatment requirements, which brings the risk of worsening of the situation (Lazarus & Folkman, 1984). Considering that it results in a worse psychological well-being (Park et al., 2008), overcoming avoidance showed up as an important issue for the caregivers of children with cancer.

The effects of religion can be various. It may affect appraisal (Park & Cohen, 1993), responses to external events (Seybold & Hill, 2001), and it is specifically used as a coping strategy (Folkman & Moskowitz, 2004). Studies revealed both helpful and harmful effects of religion on health variables. In stressful situations it can provide a sense of meaningfulness, belongingness, and identity. On the other hand, it may result in more distress when people’s religious beliefs were shattered (Pargament, 2011).

As a factor affecting appraisal, it provided a causal explanation for some of the participants. Some caregivers attributed the reason of having cancer as “God’s will”; therefore, expected the cure from God; whereas some others evaluated having a child with cancer as a test of God and if they pass the exam, they would be rewarded. Although it was not one of the attributions reported by the participants of the present study, religion rarely resulted in an attribution of a punishment of God (Burish et al., 1987). In that case it could be evaluated as having harmful effects on people. When religion was used as a source for power or control, it helps coping. However, when it resulted in a passive waiting, it hinders coping (Pargament, 2011). Prayer, which can be regarded as a coping strategy, was also reported by the participants. This finding was also supported by the studies having various samples, such as breast cancer patients (Aquino & Zago, 2007) and dementia caregivers (Morano & King, 2010). Therefore, depending on their attributions, religion has a role on the caregivers’ coping processes either positive or negative.

When the use of problem focused coping is evaluated as suggested by Lazarus and Folkman (1984), it includes addressing the problem that causes stress, and making and applying plans. Subsequent to this definition, it can be interpreted that the subthemes “acceptance” and “information seeking” were problem focused coping strategies. Acceptance of the situation was an important part of the process. It could be interpreted within the appraisal process, coming before coping and affecting the choice of appropriate coping strategies. The participants did not mention engaging in problem solving activities. Nevertheless, the following themes were mentioned only once: Learning about similar cancer cases, which were positive, reading books, investigating the illness, and a need for a guide. Moreover, some participants mentioned they searched for treatment options, and after deciding on the hospital, they had trust in the medical team. According to Lazarus and Folkman (1984), the appraisal of the situation was related to the choice of coping strategies. Therefore, the participants might have not considered the situation as controllable, and as a result, might have not used problem focused strategies.

The use of emotion focused coping suggested by Lazarus and Folkman (1984) includes dealing with the negative emotions emerged from the problem situation. The subthemes

avoidance, religion, downward comparison, and locus of interest were deemed to be the ways of emotion focused coping. As the themes under emotion focused coping were more frequently mentioned than the themes under problem focused coping, it was interpreted that the former one was more commonly used as compared to the latter one. Using downward comparison was suggested as an emotion focused coping, as it aimed to relieve negative emotions by comparing one's own situation with worse ones (Lazarus & Folkman, 1984). Locus of interest, that is, focusing on only the ill child and ignoring anything else could also be interpreted as a way of emotion focused coping, as it meant ignoring one's own negative emotions. Thus, emotion focused coping was frequently used by the caregivers of children with cancer.

Having hope for a cure and being optimistic was common among the caregivers. Similarly, it was reported that parents did usually have positive expectations about the treatment (Grootenhuis & Last, 1997). Hope was reported as a resilience factor for the mothers of children with chronic physical conditions, too (Horton & Wallender, 2001). Hence, hope was a protective factor for the caregivers of children with cancer.

3.4.4. Implications for the Intervention

Similar to Study 1, Study 2 was also beneficial for developing an intervention program. It helped the author in clarifying the needs and priorities of the caregivers. The findings of Study 1 that acknowledged the importance of basic needs and daily activities was further supported by Study 2. That is, fulfilling the needs and creating time for recreational activities were necessary for caregivers to renew resources even in the hospital. Furthermore, to promote emotion expression, normalization of the emotions and providing a way of ventilating them, and explaining the benefits of paying attention to and revealing emotions were decided to be a part of the intervention program. Moreover, it was observed that they devoted themselves to their ill child and they tended not to focus on themselves, their own problems and needs. Therefore, the importance of their own well-being, and the interaction between the caregiver and the child should be emphasized in the intervention program, that is, "a better caregiving of the child" could be motivated.

3.4.5. Limitations of the Present Study

The present study was intended to examine the subjective experiences of the caregivers of children with cancer. Using a qualitative method provided an opportunity to reach that aim. However, it also brought the limitations of the method, that is, problems with generalizability and objectivity. The study was conducted with a limited number of participants, and the interviews included subjectivity of the participants, subjectivity of the researcher, and the interaction between them. Moreover, a limitation of using IPA, as reported by Willig (2008), was not having information on the causes of the perceptions and explanations. In other words, using a qualitative method, helped the author to examine the explanations of the phenomena as experienced by the participants. However why and how those perceptions were formed could not be observed. Therefore, the generalizability of the findings was limited, and the causal pathways of the experiences were uncertain.

Moreover, although the questions were checked in terms of their understandability by asking people from different education and socioeconomic levels, there was still a problematic question which was about controllability. Perceived control over the situation could be an important part of the whole picture. However, due to the problem with the relevant question, the perception of control over the situation could not be investigated. It was thought that culture and language contributed to this problem. Furthermore, similar to Study 1, having unequal number of mothers and fathers hindered the examination of gender differences.

3.4.6. Directions for Future Studies

The findings of the present study focused on the coping process mainly. Moreover, the importance of post traumatic growth, religious coping, and the interdependence and communication between caregiver-child dyad were demonstrated. Future studies could address these topics. Post traumatic growth is a growing field of study, which was important for the caregivers of children with cancer, too. Some families experienced growth after the traumatic event, i.e., the diagnosis of a family member with cancer (Youngmee, Schulz, & Carver, 2007). The predictors and means of growth could be

studied. Religious coping was another field of study that could be focused on. The present study was conducted in a mostly Muslim population. To the author's knowledge, there is limited number of studies conducted with this population in their own cultural circumstances. Although general religious coping studies seem to be applicable, as discussed above, there may be some differences stemming from the characteristics of different religious beliefs.

Further studies should also include communication with the ill child, because the families usually did not have an open communication with the child. This might be difficult for the child trying to make meaning of his/her situation; that is, being in the hospital away from home and school, changing physically, and having some painful procedures. Therefore, the attributions of the children in relation with parental explanations of the illness should be studied.

CHAPTER 4

STUDY 3: THE EFFECTIVENESS OF A PILOT PSYCHO-EDUCATIONAL GROUP INTERVENTION FOR CAREGIVERS OF CHILDREN WITH CANCER

4.1. Aim and Hypotheses

The aim of the Study 3 was to develop and test the effectiveness of an intervention program to facilitate better adjustment, which was defined as having a lower level of distress, of caregivers of children with cancer. It was proposed an application of the implications derived from the results of the combination of the first and the second studies, previous studies (e.g., Demirtepe-Saygılı & Bozo, 2011c) and the findings from the literature. The Transactional Theory of Coping (Lazarus & Folkman, 1984) was used as a framework for coping in this study, too. The variables of the model, especially appraisal and coping, were included in the intervention; and positive and negative affect, which were the immediate effect variables in the model, were used as the outcome variables in the current study.

Specific objectives of the intervention program were to promote normalization, to provide an environment to express and share emotions and experiences, to give information about stress and coping, to develop awareness about the coping strategies that has been used, to increase more active and conscious use of coping strategies, and to promote self care. The most frequently used format of intervention studies conducted with cancer caregivers between the years 2001 and 2010 was group (Harding et al., 2011). In order to facilitate normalization process, make use of social support, model adaptive behaviors, facilitate expression and validation of emotions, and reduce the feelings of isolation (Harding, 2005); group format is preferred in the present study. By considering the effectiveness of using multiple components in an intervention program (Drotar, 2006) and considering the caregiving as a stress process including interactions (Lazarus & Folkman, 1984), breathing exercise training was added to the coping focused intervention. To sum up, a

psychoeducational group intervention, named “family support group” (aile destek grubu) was prepared, applied and tested.

It was hypothesized that the participants will report (a) more positive affect and (b) less negative affect after the intervention as compared to their reports before the intervention.

The planned intervention faced with some problems in application, such as participant recruitment and attrition. Therefore, the intervention program was modified two times. The first version of the intervention addressed caregivers living in Ankara. It was supposed to last for 6 weeks, including weekly sessions and homeworks between sessions. It was also intended to include a waiting list control group, in order to observe group differences. The pre-test measures would be the questionnaire set used in Study 1, negative and positive affect would be the post-test measures, and the long term effect variables of the model, i.e. depressive and anxiety symptoms and dissatisfaction with life would be the follow-up measures. The second version, which was planned for the caregivers staying at the hospital, was thought as a two-day program (two morning and two afternoon sessions). The final version, which was also planned for the caregivers staying at the hospital, included only one session and lasted for one afternoon. In order to guide future studies including applications of intervention programs with similar groups, the problems and modifications made were mentioned in detail below.

4.2. Method

4.2.1. Participants

4.2.1.1. Participant Recruitment

Trial 1

After completing the permission and ethical committee approvals, the recruitment phase started. First, weekly appointment lists were obtained from the department secretary. Approximately 500 patient names from 35 days of appointment lists were gathered. Except for the redundant names, 450 patients were examined in terms of their place of

residence. Nearly 100 patients living in Ankara were identified and they were contacted by phone or during their hospital visits. They were informed about the study and asked for participation. Moreover, approximately 50 families were contacted in person during their hospital visits or stays, except for the lists. The rejection rate was approximately 91.3 %. The responses of the contacted caregivers were presented in Table 18. While examining the rates and answers, it is better to keep in mind that these are the reported reasons for nonparticipation.

Table 18
The Recruitment Process for Trial 1

The Answer	<i>N</i>
1. The number of families that could not be contacted	20
2. "I will attend"	13
who attended	4
who did not attend	5
willing to attend but have an uncertain situation	2
3. "I won't attend" (No reported reason)	50
Reported reasons:	
"I have child/ren to take care for", "I have a baby",	
"I can't leave my child alone"	12
"I don't need to attend such a program" "We got over it"	3
"My house is far away from the hospital"	3
"I will attend if I am here" (I won't come regularly)	12
"I need to think then I will contact you"	5
"I don't want to attend"	4
"I can't attend"	8
"I don't want to talk about it"	2
"I have no time for this"	10

The caregivers who volunteered for the study were given appointments for pre-tests. The intervention started as soon as the group size reached the sufficient number, i.e. 8 participants. Because of the problems in the recruitment phase and the limited number of

eligible participants, some changes were needed about the study design. First, the control group was called off. Then, eligibility criteria were loosened (such as education level). However, the number of volunteer participants could not be increased.

When the intervention started, the participants were informed about time and place and they were asked for attendance on the phone. One participant reported that she will not be able to come to the first meeting, and 3 people did not participate without informing of their absence. Therefore, there were 4 people at the first meeting. Although a reminder call was given to the participants a day before the arranged day, this number was reduced to 3 at the second meeting. Since there would be 2 participants in the session, the third week was canceled. In the 4th week, which would be the 3rd session, there was only 1 participant. Then it was decided to cancel the planned intervention.

In this process, there were some noteworthy points: The participants never said “I can come”. The answers included “I hope”, “if nothing bad happens”, “hopefully” [inşallah] etc. These answers were interpreted as an artifact of coping with illness process. As the process included some unexpected events, they might have needed to always consider a possibility of something (bad) may happen. Therefore, they might try not to make promises or strict plans.

As a result, the planned 6-week intervention could not be applied successfully, because of unforeseen circumstances, i.e. the problems in recruitment and attrition of participants. Instead, considering the difficulties in attending the program, an alternative intervention was planned, which was more compact and shorter. In this way, it was aimed at including people coming from other places of living and people who were already staying at the hospital for treatment, as well.

Trial 2

Two consecutive sessions were planned. That is, instead of 1.5 hours in 6 consecutive weeks; 8 hours in 2 days were arranged. The homeworks, planned in Trial 1, were cancelled. The pre-tests would be the questionnaire set used in Study 1 and post-tests were planned to include PANAS at the end of each day and BDI, BAI and life satisfaction

scale 1 month later. In the recruitment phase 6 people were met and their pre-tests were completed. On the intervention day, 4 people attended the first session (morning), but the second session (afternoon) was not conducted due to the absence of the participants. Therefore, the trial 2 was failed to be completed, too.

Trial 3

By considering the difficulties faced with in the first two trials, the intervention was modified again. A total of 21 participants attended to the intervention program; however, 16 of them completed both pre- and post-test measures and attended fully to the session. Thus, 16 caregivers constituted the participant group of the final version of the program. The characteristics of the program are included in the Materials section below.

4.2.1.2. Participants

Sixteen mothers of children who were being treated in the pediatric oncology departments for at least 3 weeks were included in the study. The age of the participants ranged between 20 and 50 ($M = 31.26$, $SD = 8.26$). All of the participants were married. The distribution of the participants according to perceived family income was as follows: People who defined themselves as lower income group constituted 25 % of the sample ($n = 4$), 68.8 % of the participants defined themselves as being in middle income group ($n = 11$) and 1 person reported being an upper income individual (6.3 %). Education levels of the participants were as follows: 31.3 % primary school ($n = 5$), 25 % secondary school ($n = 4$), 37.5 % high school ($n = 6$), and 6.3 % university ($n = 1$). The participants were mostly unemployed, except for 1 participant, who was a nurse. The age of the children ranged between 1 year and 17 years ($M = 7.06$; $SD = 5.57$). The length of the illness of the child ranged between 1-27 months with a mean of 9.56 months ($SD = 8.33$). The type of the illness was various (5 leukemias, 2 retinoblastoma, 9 others) (see Table 19 for the demographic characteristics of the sample).

Table 19

Demographic Characteristics of the Sample of Study 3

	<i>M</i>	<i>SD</i>	<i>n</i>	<i>%</i>	<i>Min-Max</i>
Age	31.26	8.26			20-50
Perceived family income					
Low			4	25	
Middle			11	68.8	
High			1	6.3	
Education					
Primary school			5	31.3	
Secondary school			4	25	
High school			6	37.5	
University			1	6.3	
Employment status					
Housewife/unemployed			15	93.7	
Employee			1	6.3	
Child's age	7.06	5.57			1-17
Diagnosis					
Leukemias			5	31.3	
Lymphomas			1	6.3	
Glioma			1	6.3	
Neuroblastoma			1	6.3	
Retinoblastoma			2	12.5	
Renal and Wilms' tumor			1	6.3	
Hepatoblastoma			1	6.3	
Bone tumor			1	6.3	
Soft tissue			1	6.3	
Germinal			1	6.3	
Carcinoma			1	6.3	
Duration of the illness (month)	9.56	8.33			1-27

4.2.2. Materials

4.2.2.1. Positive and Negative Affect Schedule (PANAS)

PANAS was used to measure changes in positive and negative affect before and after the intervention. It was developed by Watson, Clark, and Tellegen (1988) and adapted to Turkish by Gençöz (2000). It consists of 20 items rated on a 5-point Likert-type scale, 10 of which measure positive affect (PA) and the other 10 measure negative affect (NA). Cronbach's alpha coefficients were reported as .83 and .86 for positive and negative affect, respectively; and the test-retest reliability was .40 for the negative affect and .54 for the positive affect for the Turkish version. The internal consistency reliabilites as measured by Cronbach's alpha were .58 for both positive and negative affect subscales in the present sample. The participants were asked to rate the extent to which they experience the affective states "in the last 2 weeks" in the pre-test measurements, and "at the moment" in the post-test measurements. (see Appendix H).

4.2.2.2. The Intervention

The characteristics of the intervention program, which was called "Family Support Group", are presented in Table 20. An interventionist's treatment manual was prepared to ensure fidelity.

Table 20

The Characteristics of the Intervention Program

Aim	To facilitate adjustment of caregivers of children with cancer
Objectives	To promote normalization, to provide an environment to express and share, emotions and experiences, to promote self care, to give information about stress and coping, to develop awareness about the coping strategies, that has been used, to increase more active and conscious use of coping strategies.
Learning Outcomes	Learning ways for a better self care Being able to name the emotions Being able to recognize physical symptoms of stress Learning how to do breathing exercises
Expectations / Outcome measurement	Higher levels of positive affect and lower levels of negative affect
Duration	3 hours, with 3 breaks for 10 minutes each
Place	Play room of the pediatric oncology department
Methodology	Explanations, interaction, showing visual materials, examples, and metaphors
Materials	Participants: Handouts, paper and pencil Interventionist: Treatment manual, visual materials, paper and pencil
Interventionist	The researcher, having a Master's Degree in Clinical Psychology, acted as the interventionist
Participants	Anonymous participants whose children were being treated for cancer at pediatric oncology department

Table 20 (Continued)

Sources	Lazarus, R. S. & Folkman, S. (1984). <i>Stress, Appraisal and Coping</i> . New York: Springer; Woznick L. A. & Goodheart, C. D. (2002). <i>Living with Childhood Cancer: A Practical Guide to Help Families Cope</i> . Washington: APA Publications; the results of Study 1 and Study 2.
Content/outline	<i>1st part</i> Definition of the caregiver The diagnosis and adaptation (suggestions for adaptation) How to promote self care (time management, assertiveness) Emotions, what to do with them <i>2nd part</i> Definition of stress How do we understand that we feel stress Factors that help coping with stress Defining controllable and uncontrollable Suggestions for controllable and uncontrollable Summary Breathing exercises

4.2.3. Procedure

The intervention program was applied in a different pediatric oncology clinic than the previous two trials. The participants were contacted and informed about the intervention by the interventionist and the physician responsible for the inpatient service. The ones that were interested and gave consent to attend to the intervention were administered pre-test measure. The interventions were applied in the play room of the pediatric oncology department of the hospital within the inpatient department, which had a table that participants sat around. The participants were easily accessed by the medical team and

they had easy access to their children. Three breaks were given so that they could check their children. After the intervention, a hand-out, including summary and key points, was given to the participants (see Appendix O for sample parts of the hand-out). Four group sessions were administered with people ranging in number 4 and 8. The ones who were able to finish the intervention were administered the post-test measure. The analysis was conducted with the participants who attended and completed the intervention and filled in the pre- and post-test measures.

4.3. Results

The participants of Study 3 were also administered the questionnaires of Study 1. In other words, they were included in Study 1, too. In this way, possible pre-test differences between the participants who were able to participate in the intervention program were compared with the entire sample. There was not a significant difference in any of the variables included in Study 1 in terms of their means. The results for positive and negative affect, in particular were as follows: There was not a significant difference between the participants who participated in the intervention ($m = 30.49$) and who did not participate ($m = 30.42$) in terms of their positive affect scores ($t(103) = -.03, p > .05$). Similarly, no significant difference was revealed between the participants who participated in the intervention ($m = 28.25$) and who did not participate ($m = 27.40$) in terms of their negative affect scores ($t(103) = -.45, p > .05$) at the beginning.

In order to observe the change in pre-test and post-test in positive and negative affect, Wilcoxon Signed Ranks Tests were performed. There was a significant difference between the pre-test and post-test measurements of both positive (*Wilcoxon* $z = -2.80, p < .01$) and negative affect (*Wilcoxon* $z = -2.19, p < .05$) (see Table 21).

Table 21

Descriptive Statistics for Pre-test and Post-test Measurements of Positive and Negative Affect

	Pre-test		Post-test		<i>z</i>
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>	
Positive affect	30.86	5.78	35.21	6.16	-2.80**
Negative affect	28.69	7.75	23.36	8.26	-2.19*

Note. * $p < .05$; ** $p < .01$

Further analyses were conducted to examine which specific items of PANAS were significantly different in pre-test and post-test comparisons. For this reason, paired sample t-tests were conducted for the items of PANAS. The results revealed that there were significant differences between pre-test and post-test measurements in “interested”, “strong”, “enthusiastic”, “inspired”, and “active” from positive affect items; and “distressed” and “upset” from negative affect items, all in expected direction (see Table 22).

Table 22

t-test Results for the Items of PANAS

		<i>M</i>	<i>SD</i>	<i>t</i>
1 Interested	Pre-test	3.31	1.01	-2.80**
	Post-test	4.25	.77	
2 Distressed	Pre-test	4.07	1.39	4.56***
	Post-test	2.53	1.30	
3 Excited	Pre-test	2.69	1.25	1.14
	Post-test	2.31	1.01	
4 Upset	Pre-test	3.87	1.50	2.93**
	Post-test	2.53	1.50	
5 Strong	Pre-test	3.37	1.02	-2.20*
	Post-test	4.06	1.12	
6 Guilty	Pre-test	2.00	1.50	.55
	Post-test	1.75	1.00	

Table 22 (Continued)

7 Scared	Pre-test	2.50	1.46	1.95
	Post-test	1.94	1.00	
8 Hostile	Pre-test	1.31	.70	-.37
	Post-test	1.37	.72	
9 Enthusiastic	Pre-test	2.94	.93	-3.10**
	Post-test	3.56	1.31	
10 Proud	Pre-test	3.50	1.59	-.44
	Post-test	3.62	1.31	
11 Jittery	Pre-test	3.31	1.25	1.91
	Post-test	2.56	.96	
12 Alert	Pre-test	3.00	1.19	.19
	Post-test	2.93	1.16	
13 Ashamed	Pre-test	2.00	1.21	.25
	Post-test	1.93	1.29	
14 Inspired	Pre-test	2.00	1.32	-4.47***
	Post-test	3.00	1.15	
15 Nervous	Pre-test	3.69	1.62	1.93
	Post-test	2.87	1.02	
16 Determined	Pre-test	3.62	1.02	-1.38
	Post-test	4.00	.97	
17 Attentive	Pre-test	3.75	1.29	-.64
	Post-test	3.94	1.81	
18 Irritable	Pre-test	3.12	1.63	1.51
	Post-test	2.69	1.35	
19 Active	Pre-test	2.53	1.06	-3.17**
	Post-test	3.40	1.12	
20 Afraid	Pre-test	2.94	1.65	-.76
	Post-test	3.12	1.78	

Note. * $p < .05$; ** $p < .01$; *** $p < .001$

Subjective evaluations of the participants, including the content of the intervention sessions provided by them, such as their feelings, experiences and questions, verbal feedback given by the participants after the intervention, and the observations of the interventionist were included in Appendices M and N.

4.4. Discussion

The aim of the Study 3 was to develop a group based intervention program to address the special needs of the caregivers of children with cancer. As suggested by Drotar (2006), a multidimensional intervention was planned, including an educational part, expressing emotions and sharing experiences part, and breathing exercise training part. It was hypothesized that after the intervention the participants would report (a) more positive affect and (b) less negative affect as compared to the measurement prior to the application of the intervention.

4.4.1. The Recruitment Process

Before the discussion of the findings, the recruitment process needs elaboration. One possible reason for not attending a psychosocial intervention could be lack of knowledge, in general. Such programs are not common in Turkey. Moreover, people usually were not aware of the role of psychology and psychologists in the process of treatment for cancer. Although the study was intended to be applied in one of the most advanced pediatric oncology departments in Turkey, having a psychologist as a team member, the families were usually not aware of the importance of the psychological aspect. One mother responded to the invitation for the intervention by saying “what else can be good for me except for my child’s getting better?” [Çocuğumun iyileşmesi dışında ne bana iyi gelebilir?]

In addition to a general lack of knowledge about the role of psychology in the treatment process, some people might have considered no need for an intervention for themselves, because of not focusing on themselves, their inner processes, and emotions.

Transtheoretical Model (Prochaska, DiClemente, & Norcross, 1992; Prochaska, Norcross, & DiClemente, 1994), which was a stages-of-change model, provided a framework for

this explanation. The caregivers might have been at the stage of precontemplation, who perceived no problem and had no intention to change. Therefore, people who were in precontemplation stage might not have preferred to attend such programs. On the other hand, the caregivers who were at the stage of contemplation, that is the caregivers who were aware of their problems but did not make a decision to change, and people who were at the stage of preparation, i.e. the ones who accept that their problems and intent to change, might be more willing to attend the intervention program.

Another factor that might have affected the attendance to the program was the referral of the physician. The last trial of the intervention was conducted in another hospital and this trial was different from the previous ones in terms of the referral from the physician who was responsible for the inpatient clinic. It was observed that the caregivers were more ready to accept the intervention program if their physicians suggested them to join.

4.4.2. The Characteristics of the Intervention

After many unsuccessful trials, the nature of the program was changed. At the beginning, the program was planned to be longer (six sessions), including three components, namely, sharing, psychoeducation, and relaxation training that are supported by homeworks. However, there were some problems with attendance, such as allowing time and priority. Considering that they did not have much time for intervention for themselves, the duration of the intervention was shortened. The psychoeducation part had to be shorter, therefore, more directive. Moreover, relaxation training had to be replaced by breathing exercise training, which was shorter. With the help and guidance of the results of Study 1 and 2 and previous experiences, an emphasis on normalization of emotions and emotion expression and some practical suggestions that can be accomplished in hospital settings were replaced by an emphasis on problem solving. Therefore, a bottom up process, beginning from the needs and characteristics of the specific target population was merged with a top down approach, including a theoretical framework and findings from the literature. That is, an integration of the theoretical knowledge with target needs, considering the context was important for applicable and effective intervention programs.

4.4.3. Discussion of the Findings

When the findings of the applied intervention were examined, the following points were considered as remarkable. There was no group difference between the participants who volunteered for the intervention and those who did not in terms of the study variables of Study 1 (see Figure 2, p. 20). This could be interpreted in two ways. First, it could be suggested that the volunteers were representative of the whole sample, which was appropriate for research. Second, on the other hand, this meant that willingness for participation could not be predicted by the variables of the first study. Therefore, further investigation is necessary to answer the question what characteristics predict intervention participation.

Acceptance of the situation was an important part of the coping process. It was observed that people having problems with acceptance tend not to participate in the intervention program. Although there was a section about accepting the situation in the agenda of the intervention program, it was thought that the program was not suitable for confrontation, as it was short and held in a group format. For example, as derived from Study 2, the word “cancer” was not used by the interventionist.

There was a significant difference between the pre-test and post-test measurements for the intervention, meaning that the intervention resulted in more positive and less negative affect. Therefore, the hypotheses of Study 3 were supported by the findings. Moreover, the item based analyses of PANAS revealed significant changes in “interested”, “strong”, “enthusiastic”, “inspired”, and “active” items from positive affect subscale, and “distressed” and “upset” items from negative affect subscale. The items from positive affect pointed out readiness and motivation for action or preparation for coping. The function of the increase in positive affect was explained by researchers in the following ways: First, Lazarus, Kanner, and Folkman (1980) acknowledged the role of positive affect in stressful situations, which were characterized by negative emotions. Positive emotions provide a break, build up coping, and reload the sources used by stress. Then, Fredrickson’s (1998) “broaden-and-build model” for positive emotions suggested that positive emotions broadened the person’s attentional focus and behavioral repertoire and built resources that were used by the negative emotions in stressful situations.

Although significant differences were obtained in the expected direction, their interpretations were not that simple and obvious. There were some confounding factors that could not be controlled during the process. For example, during the sessions some participants arrived late, or had to leave and check their children when called. Although they came back, they missed some parts of the already short session. Moreover, only one interventionist applied all four intervention sessions, meaning that the characteristics of the interventionist might have played a role in the results, too. In other words, the effects of non-specific factors for the intervention might have been influential on the outcomes. The effects of therapist's characteristics and therapeutic alliance on the outcomes were important variables that were studied by researchers over years (e.g., Corso et al, 2012; Horvath & Luborsky, 1993). To illustrate, it was mentioned in the second study that participants provided a feedback that it made them feel good, although the interviewer did only ask questions and listen to the answers and did nothing else specifically to make them feel better. Thus, the participants might be affected by the fact that they were being interested in, paid attention, cared, and valued. Thus, other factors than the intervention itself might have influenced the participants, and therefore the results.

The intervention program was composed of 3 main parts, which were psychoeducation, sharing, and breathing exercise. The effectiveness of each part was supported by the literature. First, the effect of psychoeducation was examined. A meta-analytic review (Van Daele et al., 2012) was conducted including psychoeducation programs whose aim was to reduce stress and facilitate gaining insight in various populations between the years 1900-2010. They concluded that despite small effect size, psychoeducational programs resulted in lower levels of stress. Moreover, women benefit from these psychoeducational interventions more than men, and programs which were shorter in duration were more effective than the longer ones (Van Daele et al., 2012). When the effects of psychoeducation was examined in caregivers in particular, it was revealed that psychoeducational intervention resulted in a higher level of disease related knowledge in the caregivers of children with sickle cell disease (Kaslow et al., 2000). Similarly, a brief problem solving intervention for caregivers of people with advanced cancer resulted in a better emotional well-being (Cameron, Shin, Williams, & Stewart, 2004).

Second, the stress alleviating effects of expressing emotions and relaxation training were also supported by the literature. For example, emotional disclosure interventions resulted in less distress in older adults after losing a spouse (Segal, Bogaards, Becker, & Chatman, 1999). For relaxation training; it was revealed that after completing an intervention including relaxation training, the participants reported more use of relaxation exercises themselves (Boise, Congleton, & Shannon, 2005). Breathing exercise training was added to the intervention schedule as a complementary part in the present study, as it was also found that relaxation training works better when presented as a part of a multicomponent program (Astin, 2004). Therefore, the effectiveness of the components of the intervention program was supported by the literature.

4.4.4. Clinical Implications

The present study provided some clinical implications that can be useful for clinicians/researchers who would apply similar interventions. The recruitment process revealed that the caregivers could be unaware of their psychosocial problems, possible contributors to their well-being, and the relationship between their own distress and the ill child's. It is now a well-known fact that the well-being of the caregiver worsens as well as the patient (Fotiadou et al., 2008), and the well-being of the caregiver has an influence on the well-being of the patient (Williamson et al., 2002). Therefore, this information can be shared with the caregivers to increase awareness and to prevent a worse well-being. Moreover, they could be unaware of possible benefits of psychosocial interventions. Thus, in addition to providing information on the process of caregiving, information about the role of a psychologist in the process and the benefits of such interventions can be given.

Another important implication of the present study was that it emphasized the importance of psychologist as a member of the treatment team. The presence of a psychologist in the inpatient clinic for continuous care was important for successful interventions. Moreover, physician referral was an important contributor for the completion of the study. Thus, a treatment protocol, that addresses biological, psychological, and social parts of the illness, is important for successful treatment outcomes, as suggested by the biopsychosocial model (Engel, 1977).

4.4.5. Limitations of the Present Study

Although the present study had several strengths, such as combining the results of previous qualitative and quantitative studies, and integrating the needs of the caregivers with theoretical background; it also had several limitations. The most important limitation of the study was not having follow-up measurements. Because of practical reasons it was not possible to communicate with the participants for follow-up measurements.

Therefore, it was not possible to observe the long-term effects of the intervention. The changes in affect could be short term and influenced by contextual factors (Zautra, Potter, & Reich, 1997). According to Lazarus and Folkman (1984), for immediate effect variables, that is affect, to be operative in the long run, there should be consistency in appraisal of and coping with the situation.

Not having a control group was another limitation of the present study. Having control groups were necessary for validity (Kazdin, 2002). However, using control groups in intervention studies was criticized by being unethical, as it meant making people in need wait. In the present study, it was thought that making a limited number of volunteer participants wait was not practical and ethical. Therefore, the absence of a control group was considered as a limitation.

Still another limitation was that as the program had composed of several parts, it was not possible to differentiate especially which part was more influential in alleviating negative affect and facilitating positive affect. Therefore, further studies are needed that use constructive strategy (Kazdin, 2002).

4.4.6. Directions for Further Studies

This study was a pilot study, conducted with a small sample, aiming at developing a feasible and effective intervention program for the caregivers of children with cancer. As further studies, the same protocol should be applied to a larger number of participants, by different interventionists using the treatment manual.

Group coherence, trust, and genuine relationships in the group would give a better result. In this way, the group members would feel more comfortable to open themselves and share feelings. However, to do this, more than one session was necessary, and this was not possible for this study.

In conclusion, the identification of the target needs and priorities correctly, working in accordance with the medical treatment team, arranging appropriate timing and place to apply the intervention, and being familiar with the cultural circumstances of the target population were the most important points that were identified in the present study for successful interventions.

CHAPTER 5

GENERAL DISCUSSION

The aim of the present study was to examine the coping processes and the aftermaths of their coping of caregivers of children with cancer, comprehensively. Three studies were conducted to serve this aim. The first study revealed the predictors of caregiver distress by using the Transactional Theory of Coping (Lazarus & Folkman, 1984). The study examined the coping process of the caregivers of children with cancer and clarified both facilitators and complicators of coping that determine the level of distress experienced by them. Three hierarchical regression models were tested and the different patterns for the level of depressive and anxiety symptoms and dissatisfaction with life were explored. The second study examined subjective experiences of the caregivers qualitatively. By this way, it was tried to complete the missing parts of Study 1, which was a self-report and theory driven study. Moreover, by creating a chance to observe and pay attention to nonverbal cues, the interaction between the interviewer and the interviewee was included. Three themes were identified, namely emotions, change, and coping. The findings of Study 2 both supported the findings of Study 1 and indicated further important themes, such as the relationship between caregiver and child and religion. The third study aimed at developing a feasible and effective intervention program addressing the needs of the caregivers with the guidance of the relevant literature and the findings of Study 1 and Study 2. After the proposed intervention was adjusted according to the characteristics and the needs of the caregivers, and the intervention context, it was applied to four groups. The effect of the intervention was tested by the change in their positive and negative affect before and after the intervention session. An increase in positive affect and a decrease in negative affect were found. The findings were discussed in detail for each study in relevant section. This chapter included general characteristics of the participants and the role of culture, research and clinical implications, directions for further research, and conclusions.

5.1. General Characteristics of the Participants and the Role of Culture

The participants were mostly females in the present study. Similarly, caregiver studies mostly included women participants, because it is the women who fill the caregiver role in families with a chronically ill member (Pinquart & Sorensen, 2006). In the present study, there were a limited number of male participants who reported that they shared the caregiving role. Thus, similar to the caregiver literature, the participants of the present study were women, mostly mothers as the caregivers of their ill children.

The study should be evaluated in a cultural context, as it is important for the use of coping strategies (Wong, Wong, & Scott, 2006), definitions of self and social roles, that is, the interaction between the caregivers and their social environment (Markus & Kitayama, 1991), expression of emotions (Davis et al., 2012), and the characteristics of the social context (Kağıtçıbaşı, 2010). The present study was conducted in Turkey, a non-Western country, in which material independence but emotional interdependence is valued (Kagitcibasi, 1996). The findings can be examined in the light of cultural context. For example, it can be suggested that the “interdependence” theme found in Study 2 can be an extension of this cultural characteristic. That is, it might have already existed in the relationship between the mother and the child before the illness, but reinforced by the presence of the illness and expressed itself clearly after this diagnosis. Hence, cross-cultural studies can clarify culture-specific characteristics and universal commonalities.

A general impression regarding the participant group was that they tended to devote themselves to caregiving, focused on only the ill child, believed that their child will survive, and attributed highest importance to this. They tried not to focus on themselves and wanted to be fine only in order to take better care of the ill child. To conclude, the only motivation was the ill child. Therefore, although they reported psychological symptoms, many of them seemed reluctant to do something about it. The effects of devoting themselves on caregiving role can be explained in relation to the concept of self-complexity. Self-complexity means having a number of self aspects, i. e., having multiple roles. The other roles can provide sources for the problems of one role (Linville, 1985). As a result, the more roles the person has, the less physical symptoms and depression s/he experiences. That is, it has a stress-buffering effect (Linville, 1987). In terms of

caregiving a child with cancer, women were mostly left with only one role, i.e. caregiving an ill child, which included fulfilling his/her needs and make him/her get better. Their other roles such as being a wife or an employee were not there any more. Therefore, when there was something wrong about this role, their other roles do not exist as a source to be used for buffering that stress.

5.2. Research Implications

The first area of research with this population is studying caregiving stress that is important for the well-being of the caregivers. There are studies focusing on the identification of protective and risk factors for the caregivers, which can further guide interventions. These studies are mostly quantitative and there is a limited number of qualitative studies. Both approaches have their own strengths and limitations and can be preferred according to the purpose of research. Besides, the well-being of the ill child is also affected by the well-being of the caregiver. To illustrate, parenting stress was related to worse child adjustment (Wolfe-Christensen et al, 2010). For this reason, the studies on well-being of the caregiver, measurement of its effects on the ill child and clarifying the pathways are important.

The second area of caregiver research is intervention studies to alleviate caregiver stress and facilitate coping. Those studies are usually based on the findings of descriptive and predictive studies (e.g., Sahler et al., 2009). In caregiver interventions, it is important to merge theoretical background with practical factors, such as hospital environment and timing of the intervention. The timing of the intervention should be adjusted according to hospital routines, especially to the sleep time of children. Similarly, an appropriate place, i.e. close to but apart room from the children's room, should be chosen for the intervention. Furthermore, the identification of the target needs and priorities correctly in the cultural context is also important. By evaluating the process of intervention study, it can be suggested that an intervention study should include a team and sufficient financial resource to be successfully completed. A team including different interventionists and researchers and a division of labor between the team members would ease the process. Moreover, the supply of financial resources should be arranged to ease the process.

In order to conclude that an intervention, as a clinical trial, is effective; randomized pre-test post-test control group designs are necessary (Kazdin, 2002). However, in the present study, it was hard to implement an intervention program with these criteria and control the effects of confounding variables at the same time. Therefore, it can be stated that an anticipation of possible problems and a readiness for unforeseen factors is necessary for the researchers.

5.3. Clinical Implications

The adjustment of the caregivers is as important as the adjustment of the children with cancer. Focusing on the child alone, the caregiver alone, and both of them as a unit are necessary in clinical applications. As it was mentioned before, having a psychologist as an active team member in a pediatric oncology clinic is important for the well-being of the families coping with cancer. Several steps can be followed by the member of the team who is responsible for the psychosocial side of the treatment. First, information should be given to the caregivers about the caregiving process, emphasizing the interaction between the well-being of the caregiver and the ill child at a group level. Second, after giving information, a screening for risk and protective factors at an individual level is necessary to predict future well-being. In this way, help at an individual level can be provided to the people in need. Third, by including common points, group level interventions can be applied. Group interventions are needed beyond individual interventions, because in group sessions individuals can make use of each other's experiences and decrease isolation (Harding, 2005). Last, follow-up sessions after the treatment ends in the period of returning to normal life can be conducted for people with successful treatment results. Moreover, interventions or referrals can be made for the caregivers who lost their children and are in a period of mourning.

5.4. Directions for Future Studies

In addition to the specific directions for future studies presented in each discussion section, there are still some other suggestions derived from the present study. First, future longitudinal studies can illuminate the progress of coping in the phases of diagnosis, active treatment, and follow-up. It will also help clarifying the change in caregiver needs

at specific points, such as a surgery, or a bad prognosis. Second, intervention studies can be conducted after the treatment ends, aiming at going back to “normal life”. As the caregivers focus on the child and the treatment during hospitalization, they seem to need an adaptation to their normal life after a successful treatment outcome. Third, the siblings of children with cancer can be another research area, because some parents reported involuntarily ignoring their healthy children. They also reported that their healthy children sometimes complained about being ignored. Therefore, the experiences and attributions of siblings of children with cancer is another research area. Fourth, the effects of caregiver well-being and interventions on the child’s well-being can be examined by including child reports and caregiver reports. Last, but not the least, the content of further interventions needs to be analyzed qualitatively. This was not conducted in the present study, however, the subjective evaluations of the interventionist and the participants were examined and some important points were included in Appendices M and N. The participants’ contributions and questions should be given importance while shaping intervention programs.

5.5. Conclusion

The present study examined the coping processes of the caregivers of children with cancer using a step-by-step approach, with the ultimate aim of facilitating adjustment. First, the predictors of caregiver distress were revealed using the Transactional Theory of Coping (Lazarus & Folkman, 1984) as a theoretical framework. Second, the coping process was investigated using a qualitative method. Last, a psycho-educational group intervention was developed and tested in terms of its effectiveness as measured by the change in negative and positive affect. Several implications were suggested which are crucial for both researchers and practitioners working with similar samples. Such studies combining the quantitative and qualitative approaches, aiming at facilitating adjustment by means of intervention programs, and using researcher and practitioner roles at the same time are very rare. Therefore, the study is thought to be a leading example for future studies by clarifying the coping process, revealing important factors in the development of intervention programs, and presenting clinical and research implications.

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APPENDICES

Appendix A Informed Consent Form Gönüllü Katılım Formu

Sayın Katılımcı;

Bu çalışma ODTÜ Psikoloji Bölümü Klinik Psikoloji Doktora Programı kapsamında Uzm. Psk. Dilek Demirtepe Saygılı tarafından yürütülmekte olan bir doktora tez çalışmasıdır. Tez danışmanı, ODTÜ Psikoloji Bölümü Öğretim Üyesi Doç. Dr. Özlem Bozo'dur. Çalışmanın amacı pediatrik onkoloji bölümünde tedavi gören bir çocuğa sahip anne-babalar için hazırlanmış olan psiko-sosyal destek programının etkinliğinin test edilmesidir.

Çalışma 2 bölümden oluşmaktadır. İlk bölüm değerlendirme amaçlı bir görüşme ve anket çalışmasıdır. Anketin her bölümdeki ölçeğinin nasıl cevaplanacağı konusunda, ilgili bölümün başında bilgi verilmiştir. Anketin cevaplanması yaklaşık 45 dakika sürmekte olup herhangi bir süre kısıtlaması bulunmamaktadır.

İkinci bölüm ise psiko-sosyal destek programı uygulamasıdır. Bu program 6-8 kişilik gruplardan oluşacak ve 2 gün sürecek. Programın içeriğini paylaşım, stres ve başa çıkma konularında psikoeğitim ve gevşeme egzersizi oluşturmaktadır. Programın hemen ardından ve 1 ay sonrasında değişimin değerlendirilmesi amacıyla ölçeklerin bir kısmı tekrar uygulanacaktır. Program, yeterli sayıya ulaşıldığında katılımcılara uygun yer ve zaman belirlenerek ayarlamalar yapıldıktan sonra başlayacaktır. Programın başlangıcı araştırmacı tarafından size bildirilecektir. Bu nedenle iletişim bilgileriniz istenmektedir. Programa katılmak istediğinizi aşağıdaki kutuyu işaretleyerek belirtiniz.

Çalışmaya katılım tamamıyla gönüllülük esasına dayanmaktadır. Anket ve psiko-sosyal destek programı genel olarak, kişisel rahatsızlık verecek içeriğe sahip değildir. Ancak, katılım sırasında herhangi bir nedenden ötürü kendinizi rahatsız hissederseniz, çalışmaya katılımınızı istediğiniz anda bırakmakta serbestsiniz. Verdiğiniz bilgiler gizli tutulup, bu çalışma dışında hiçbir amaçla kullanılmayacaktır. Katılımınız için şimdiden teşekkür ederiz.

Sorularınız için;

Uzm. Psk. Dilek Demirtepe Saygılı

Tel: 0505 226 08 53

E-posta: ddemirtepe@gmail.com

Bu çalışmaya tamamen gönüllü olarak katılıyorum ve istediğim zaman yarıda kesip çıkabileceğimi biliyorum. Verdiğim bilgilerin bilimsel amaçlı yayımlarda kullanılmasını kabul ediyorum. (Formu doldurup imzaladıktan sonra uygulayıcıya geri veriniz).

Düzenlenecek olan psiko-sosyal destek programına katılmak istiyorum.

İsim Soyad

Tarih

İmza

Tel: _____

----/----/-----

Appendix B Demographic Information Form

1. Yaşınız: _____
2. Cinsiyetiniz: ____ Kadın ____ Erkek
3. Eğitim Durumunuz: ____ İlkokul ____ Ortaokul ____ Lise
____ Üniversite ____ Üniversite üstü
4. Mesleğiniz: _____
5. Şu anki evlilik durumunuz: ____ Bekar ____ Evli
____ Boşanmış ____ Eşi vefat etmiş
6. Aylık gelir miktarınız: ____ Düşük ____ Orta ____ Yüksek
7. Nerede yaşıyorsunuz? (Hangi Şehir, İlçe, Köy)
8. Hastanızın hastalığı/tanısı nedir?
9. Tanı ne zaman kondu? (Hangi ay,yıl)
10. Tedavi şu anda hangi aşamada?
11. Hastanın nesi oluyorsunuz?
12. Hastanızın yaşı?
13. Evinizde siz dahil kaç kişi yaşıyor?
14. Hastanızın bakımını üstlenen başka biri var mı? (varsa kim olduğunu belirtiniz)

15. Sizin bakımını üstlendiğiniz kaç kişi var? (kimler olduğunu belirtiniz)

16. Herhangi bir fiziksel rahatsızlığınız var mı? (varsa belirtiniz)
17. Herhangi bir psikolojik rahatsızlığınız var mı? (varsa belirtiniz)
18. Fiziksel ya da psikolojik tedavi görüyor musunuz? / Yardım alıyor musunuz? (varsa tedavi şeklini belirtiniz)

Appendix C: Multidimensional Health Locus of Control Scale

	kesinlikle katılmıyorum	katılmıyorum	katılmama eğilimindeyim	katılma eğilimindeyim	katılıyorum	kesinlikle katılıyorum
1- Hasta olursam çabuk iyileşmek benim kendi davranışlarıma bağlıdır.	0	1	2	3	4	5
2- Ne yaparsam yapayım, hasta olacaksam, olurum.	0	1	2	3	4	5
3- Hastalıklardan kaçınmanın en güzel yolu düzenli olarak doktorumu görmektir.	0	1	2	3	4	5
4- Sağlığımı etkileyen çoğu şey kaza ile başıma gelir.	0	1	2	3	4	5
5- Kendimi iyi hissetmediğimde bir sağlık uzmanına başvurmalıyım.	0	1	2	3	4	5
6- Sağlığımın iyi olup olmaması benim kontrolümdedir.	0	1	2	3	4	5
7- Ailemin hasta olmam veya sağlıklı kalmam ile büyük ilgisi vardır.	0	1	2	3	4	5
8- Hastalandığım zaman suçlanacak kişi benimdir.	0	1	2	3	4	5
9- Bir hastalıktan toparlanmamda şansın büyük bir payı vardır.	0	1	2	3	4	5
10- Sağlık durumumun iyi olup olmaması doktorlara bağlıdır.	0	1	2	3	4	5
11- Sağlığımın iyi olması büyük ölçüde şans işidir.	0	1	2	3	4	5
12- Sağlığımı etkileyen esas şey benim kendi yaptıklarımıdır.	0	1	2	3	4	5
13- Kendime iyi bakarsam hastalıklardan kaçınabilirim.	0	1	2	3	4	5
14- Bir hastalığı atlattım çoğunlukla doktor, hemşire, aile fertleri ve arkadaşlar gibi başka insanların bana iyi bakıyor olmasından kaynaklanır.	0	1	2	3	4	5
15- Ne yaparsam yapayım hastalanma ihtimalim vardır.	0	1	2	3	4	5
16- Kaderde varsa sağlıklı olurum.	0	1	2	3	4	5
17- Eğer doğru hareket edersem sağlıklı olurum.	0	1	2	3	4	5
18- Sağlığım konusunda sadece doktorumun bana yapmamı söylediklerini yaparım.	0	1	2	3	4	5

Appendix D: Caregiver Well-being Scale

Basic Needs Subscale

Aşağıda bazı temel ihtiyaçlar sıralanmıştır. Her bir ihtiyaç için hayatınızın son 3 ayını düşünün. Bu süre içinde her bir ihtiyacın ne ölçüde karşılandığını belirtiniz. Aşağıda bulunan ölçeği kullanarak sizin için uygun sayıyı yuvarlak içine alınız.

- 1 hiçbir zaman
- 2 nadiren
- 3 ara sıra
- 4 sık sık
- 5 her zaman

1. Yeterli paraya sahip olmak	1	2	3	4	5
2. Dengeli beslenmek	1	2	3	4	5
3. Yeterince uyumak	1	2	3	4	5
4. Fiziksel sağlığınıza dikkat etmek (doktora, dış hekimine gitmek vs.)	1	2	3	4	5
5. Kendinize vakit ayırmak	1	2	3	4	5
6. Sevildiğini hissetmek	1	2	3	4	5
7. Sevginizi ifade etmek	1	2	3	4	5
8. Öfkenizi ifade etmek	1	2	3	4	5
9. Neşenizi ve keyfinizi ifade etmek	1	2	3	4	5
10. Üzüntünüzü ifade etmek	1	2	3	4	5
11. Cinsellikten keyif almak	1	2	3	4	5
12. Yeni beceriler öğrenmek	1	2	3	4	5
13. Kendini değerli hissetmek	1	2	3	4	5
14. Başkaları tarafından takdir edildiğini hissetmek	1	2	3	4	5
15. Ailenizden hoşnut olmak	1	2	3	4	5
16. Kendinizden hoşnut olmak	1	2	3	4	5
17. Gelecekle ilgili kendinizi güvende hissetmek	1	2	3	4	5
18. Yakın arkadaşlara sahip olmak	1	2	3	4	5
19. Bir eve sahip olmak	1	2	3	4	5
20. Gelecekle ilgili planlar yapmak	1	2	3	4	5
21. Sizi düşünen birilerinin olması	1	2	3	4	5
22. Hayatınızın bir anlamı olması	1	2	3	4	5

Activities of Living Subscale

Aşağıda herbirimizin yaptığı ya da birilerinin bizim için yaptığı bazı yaşamsal faaliyetler sıralanmıştır. Her bir faaliyet için yaşamınızın son 3 ayını düşünün. Bu süre içinde, her bir faaliyetin ne derecede karşılandığını düşünüyorsunuz? Aşağıda bulunan ölçeği kullanarak sizin için uygun sayıyı yuvarlak içine alınız.

- 1 hiçbir zaman
- 2 nadiren
- 3 ara sıra
- 4 sık sık
- 5 her zaman

1. Yiyecek satın almak	1	2	3	4	5
2. Yemek hazırlamak	1	2	3	4	5
3. Evi temizlemek	1	2	3	4	5
4. Evin çekip çevirilmesiyle ilgilenmek	1	2	3	4	5
5. Ulaşım kolaylığına sahip olmak	1	2	3	4	5
6. Kıyafet alış verişi yapmak	1	2	3	4	5
7. Kıyafetleri yıkamak ve giydiklerine özen göstermek	1	2	3	4	5
8. Gevşemek/ rahatlamak	1	2	3	4	5
9. Egzersiz/spor yapmak	1	2	3	4	5
10. Bir hobiden keyif almak	1	2	3	4	5
11. Yeni bir ilgi alanı ya da hobi edinmek	1	2	3	4	5
12. Sosyal etkinliklere katılmak	1	2	3	4	5
13. Herhangi bir konu hakkında derinlemesine düşünmek için zaman ayırmak	1	2	3	4	5
14. Manevi ve ilham verici faaliyetlere zaman ayırmak	1	2	3	4	5
15. Çevredenizdeki güzelliklerinin farkına varmak	1	2	3	4	5
16. Arkadaşlar ya da aileden destek istemek	1	2	3	4	5
17. Arkadaşlar ya da aileden destek almak	1	2	3	4	5
18. Gülmek/ kahkaha atmak	1	2	3	4	5
19. Kendinize iyi davranmak veya kendinizi ödüllendirmek	1	2	3	4	5
20. Kariyerinize/ işinize devam etmek	1	2	3	4	5
21. Kişisel temizlik ve dış görünüşünüze zaman ayırmak	1	2	3	4	5
22. Aile ya da arkadaşlarla hoşça vakit geçirmek için zaman ayırmak	1	2	3	4	5

Appendix E Multidimensional Scale of Perceived Social Support

Aşağıda 12 cümle ve her birinde de cevaplarınızı işaretlemeniz için 1 den 7ye kadar rakamlar verilmiştir. Her cümlede söyleneni sizin için ne kadar çok doğru olduğunu veya olmadığını belirtmek için o cümle altındaki rakamlardan yalnız bir tanesini daire içine alarak işaretleyiniz. Bu şekilde 12 cümlenin her birinde bir işaret koyarak cevaplarınızı veriniz.

1. İhtiyacım olduğunda yanımda olan özel bir insan var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

2. Sevinç ve kederimi paylaşabileceğim özel bir insan var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

3. Ailem bana gerçekten yardımcı olmaya çalışır.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

4. İhtiyacım olan duygusal yardımı ve desteği ailemden alırım.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

5. Beni gerçekten rahatlatan bir insan var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

6. Arkadaşlarım bana gerçekten yardımcı olmaya çalışırlar.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

7. İşler kötü gittiğinde arkadaşlarıma güvenebilirim.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

8. Sorunlarımı ailemle konuşabilirim.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

9. Sevinç ve kederlerimi paylaşabileceğim arkadaşlarım var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

10. Yaşamımda duygularıma önem veren özel bir insanım.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

11. Kararlarımı vermede ailem bana yardımcı olmaya isteklidir.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
------------------	---	---	---	---	---	---	---	-----------------

12. Sorunlarımı arkadaşlarımla konuşabilirim.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet
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Appendix F: Stress Appraisal Measure

Bu anket, **sağlık problemi olan bir çocuğa sahip olma** hakkındaki düşüncelerinizle ilgilidir. Doğru ya da yanlış cevap yoktur. Lütfen durum hakkındaki **şu anki** düşüncelerinize göre değerlendirme yapınız. Lütfen tüm soruları cevaplayınız. Her bir soruyu sizin için uygun rakamı daire içine alarak değerlendiriniz.

		Hiç	Çok az	Orta Düzeyde	Oldukça	Aşırı Düzeyde
1.	Bu, tamamen çaresiz bir durum mu?	1	2	3	4	5
2.	Bu, sonuçlarından hiç kimsenin kaçamayacağı bir durum mu?	1	2	3	4	5
3.	İhtiyaç duyduğumda yardım isteyebileceğim herhangi bir kişi ya da destek talep edebileceğim bir uzman (psikolog, doktor, vb.) var mı?	1	2	3	4	5
4.	Bu durum beni endişelendiriyor mu?	1	2	3	4	5
5.	Bu durumun benim için önemli sonuçları var mı?	1	2	3	4	5
6.	Bu durumun benim üzerimde olumlu bir etkisi olacak mı?	1	2	3	4	5
7.	Bu sorunla uğraşmak için ne kadar hevesliyim?	1	2	3	4	5
8.	Bu durumun sonuçlarından ne kadar etkileneceğim?	1	2	3	4	5
9.	Öncesine göre, bu problem sayesinde ne kadar daha güçlü bir kişi olabilirim?	1	2	3	4	5
10.	Bu durumun sonuçları olumsuz olur mu?	1	2	3	4	5
11.	Bu durumla başa çıkabilecek yeteneklere sahip miyim?	1	2	3	4	5
12.	Bu durumun benim yaşamımda ciddi etkileri olacak mı?	1	2	3	4	5
13.	Bu durumla baş etmek için gerekli niteliklere sahip miyim?	1	2	3	4	5
14.	Bu sorunla baş etmek için bana yardım edebilecek bir kaynağım var mı?	1	2	3	4	5
15.	Bu sorunla baş etmede bana yardım sağlayabilecek uygun ve yeteri kadar kaynağım var mı?	1	2	3	4	5
16.	Bu durumla ilgili bir şey yapabilmek herhangi bir kişinin gücünü aşar mı?	1	2	3	4	5
17.	Bu durumun olumlu sonuçlarının da olabileceğini düşünmek beni ne kadar heyecanlandırıyor?	1	2	3	4	5
18.	Bu, ne kadar tehdit edici bir durum?	1	2	3	4	5
19.	Bu, herhangi bir kişinin çözemeyeceği bir sorun mu?	1	2	3	4	5
20.	Bu durumla baş edebilir miyim?	1	2	3	4	5

21.	Bu sorunun üstesinden gelmem için bana yardım edebilecek herhangi biri var mı?	1	2	3	4	5
22.	Bu durumda başarılı sonuçlar elde etmek için gerekli becerilere sahip miyim?	1	2	3	4	5
23.	Bu durumun benim için uzun vadeli sonuçları var mı?	1	2	3	4	5
24.	Bu durumun benim üzerimde olumsuz bir etkisi olacak mı?	1	2	3	4	5

Appendix G The Ways of Coping Inventory

Aşağıda, verilen her cümleyi dikkatle okuyunuz. Çocuğunuzun hastalığı ve buna bağlı ortaya çıkan sorunlarla başa çıkmak için, bu cümlelerde anlatılanları ne sıklıkla kullandığınızı size uygun gelen kutuyu (X) ile isaretleyiniz. Hiçbir cümleyi cevapsız bırakmamaya çalışınız. Her cümle ile ilgili yalnız bir cevap kategorisini isaretleyiniz.

	Hiç uygun değil	Pek uygun değil	Uygun	Oldukça uygun	Çok uygun
1. Aklımı kurcalayan şeylerden kurtulmak için değişik işlerle uğraşırım					
2. İyimser olmaya çalışırım					
3. Bazı seyleri büyütmemeye üzerinde durmamaya çalışırım					
4. Sakin kafayla düşünmeye ve öfkelenmemeye çalışırım					
5. Olayın değerlendirmesini yaparak en iyi kararı vermeye çalışırım					
6. Problemin kendiliğinden hallolacağına inanırım					
7. Ne olursa olsun kendime direnme ve mücadele etme gücü hissederim					
8. Kendime karşı hoşgörülü olmaya çalışırım					
9. Olanları unutmaya çalışırım					
10. Telaşımı belli etmemeye ve sakın olmaya çalışırım					
11. “Başa gelen çekilir” diye düşünürüm					
12. Problemin ciddiyetini anlamaya çalışırım					
13. Kendimi kapana sıkışmış gibi hissederim					
14. “Her işte bir hayır vardır” diye düşünürüm					
15. Dua ederek Allah’tan yardım dilerim					
16. Olanla yetinmeye çalışırım					
17. Olanları kafama takıp sürekli düşünmekten kendimi alamam					
18. Mutlaka bir yol bulabileceğime inanır, bu yolda uğraşırım					
19. Sanki bu bir sorun değilmiş gibi davranırım					
20. “İş olacağına varır” diye düşünürüm					
21. Neler olabileceğini düşünüp ona göre					

davranmaya çalışırım					
22. İşin içinden çıkamayınca “elimden bir şey gelmiyor” der, durumu olduğu gibi kabullenirim					
23. Her şeye yeniden başlayacak gücü bulurum.					
24. Problemin çözümü için adak adarım					
25. Olaylardan olumlu bir şey çıkarmaya çalışırım					
26. Alın yazısına ve bunun değişmeyeceğine inanırım					
27. Soruna birkaç farklı çözüm yolu ararım					
28. Başıma gelenlerin herkesin başına gelebilecek şeyler olduğuna inanırım					
29. “Olanları keşke değiştirebilseydim” derim					
30. “Her şeye rağmen elde ettiğim bir kazanç vardır” diye düşünürüm					
31. Gururumu koruyup güçlü görünmeye çalışırım					
32. Problemi adım adım çözmeye çalışırım					
33. Elimden hiçbir şeyin gelmeyeceğine inanırım					
34. Problemin çözümü için hocaya okunurum					
35. Her şeyin istediğim gibi olmayacağına inanırım					
36. Bu dertten kurtulayım diye fakir fukaraya sadaka veririm					
37. Ne yapılacağını planlayıp ona göre davranırım					
38. Mücadeleden vazgeçerim					
39. Sorunun benden kaynaklandığını düşünürüm					
40. Olaylar karşısında “kaderim buymuş” derim					
41. “Keşke daha güçlü bir insan olsaydım” diye düşünürüm					
42. Nazarlık takarak, muska taşıyarak benzer olayların olmaması için önlemler alırım					
43. Ne olup bittiğini anlayabilmek için sorunu enine boyuna düşünürüm					
44. “Benim suçum ne” diye düşünürüm					
45. “Allah’ın takdiri buymuş” diye					

kendimi teselli ederim					
46. Temkinli olmaya ve yanlış yapmamaya çalışırım					
47. Çözüm için kendim bir şeyler yapmak istemem					
48. “Hep benim yüzümden oldu” diye düşünürüm					
49. Mutlu olmak için başka yollar ararım					
50. Hakkımı savunabileceğime inanırım					
51. Bir kişi olarak iyi yönde değiştiğimi ve olgunlaştığımı hissederim					

Appendix H Positive and Negative Affect Schedule

Bu ölçek farklı duyguları tanımlayan bir takım sözcükler içermektedir. Son iki hafta nasıl hissettiğinizi düşünüp her maddeyi okuyun. Uygun cevabı her maddenin yanında ayrılan yere (puanları daire içine alarak) işaretleyin. Cevaplarınızı verirken aşağıdaki puanları kullanın.

1. Çok az veya hiç
2. Biraz
3. Ortalama
4. Oldukça
5. Çok fazla

1. İlgili _____ 1 2 3 4 5
2. Sıkıntılı _____ 1 2 3 4 5
3. Heyecanlı _____ 1 2 3 4 5
4. Mutsuz _____ 1 2 3 4 5
5. Güçlü _____ 1 2 3 4 5
6. Suçlu _____ 1 2 3 4 5
7. Ürkmüş _____ 1 2 3 4 5
8. Düşmanca _____ 1 2 3 4 5
9. Hevesli _____ 1 2 3 4 5
10. Gururlu _____ 1 2 3 4 5
11. Asabi _____ 1 2 3 4 5
12. Uyanık _____ 1 2 3 4 5
13. Utanmış _____ 1 2 3 4 5
14. İlhamlı _____ 1 2 3 4 5
(yaratıcı düşüncelerle dolu)
15. Sinirli _____ 1 2 3 4 5
16. Kararlı _____ 1 2 3 4 5
17. Dikkatli _____ 1 2 3 4 5
18. Tedirgin _____ 1 2 3 4 5
19. Aktif _____ 1 2 3 4 5
20. Korkmuş _____ 1 2 3 4 5

Appendix I Beck Depression Inventory

Aşağıda gruplar halinde bazı sorular yazılıdır. Her gruptaki cümleleri dikkatle okuyunuz. Bugün dahil, geçen hafta içinde kendinizi nasıl hissettiğinizi en iyi anlatan cümleyi seçiniz. Seçmiş olduğunuz cümlelerin yanındaki numaranın üzerine (X) işareti koyunuz.

- | | |
|-----|---|
| 1. | (a) Kendimi üzgün hissetmiyorum.
(b) Kendimi üzgün hissediyorum.
(c) Her zaman için üzgünüm ve kendimi bu duygudan kurtaramıyorum.
(d) Öylesine üzgün ve mutsuzum ki dayanamıyorum. |
| 2. | (a) Gelecekte umutsuz değilim.
(b) Geleceğe biraz umutsuz bakıyorum.
(c) Gelecekte beklediğim hiçbir şey yok.
(d) Benim için bir gelecek yok ve bu durum düzelmeyecek. |
| 3. | (a) Kendimi başarısız görmüyorum.
(b) Çevremdeki birçok kişiden daha fazla başarısızlıklarım oldu sayılır.
(c) Geriye dönüp baktığımda, çok fazla başarısızlığım olduğunu görüyorum.
(d) Kendimi tümüyle başarısız bir insan olarak görüyorum. |
| 4. | (a) Her şeyden eskisi kadar zevk alabiliyorum.
(b) Her şeyden eskisi kadar zevk alamıyorum.
(c) Artık hiçbir şeyden gerçek bir zevk alamıyorum.
(d) Bana zevk veren hiçbir şey yok. Her şey çok sıkıcı. |
| 5. | (a) Kendimi suçlu hissetmiyorum.
(b) Arada bir kendimi suçlu hissettiğim oluyor.
(c) Kendimi çoğunlukla suçlu hissediyorum.
(d) Kendimi her an için suçlu hissediyorum. |
| 6. | (a) Cezalandırıldığımı düşünmüyorum.
(b) Bazı şeyler için cezalandırılabilirim hissediyorum.
(c) Cezalandırılmayı bekliyorum.
(d) Cezalandırıldığımı hissediyorum. |
| 7. | (a) Kendimden hoşnutum.
(b) Kendimden pek hoşnut değilim.
(c) Kendimden hiç hoşlanmıyorum.
(d) Kendimden nefret ediyorum. |
| 8. | (a) Kendimi diğer insanlardan daha kötü görmüyorum.
(b) Kendimi zayıflıklarım ve hatalarım için eleştiriyorum.
(c) Kendimi hatalarım için çoğu zaman suçluyorum.
(d) Her kötü olayda kendimi suçluyorum. |
| 9. | (a) Kendimi öldürmek gibi düşüncelerim yok.
(b) Bazen kendimi öldürmeyi düşünüyorum, fakat bunu yapmam.
(c) Kendimi öldürebilmeyi isterdim.
(d) Bir fırsatını bulsam kendimi öldürürdüm. |
| 10. | (a) Her zamankinden daha fazla ağladığımı sanmıyorum.
(b) Eskisine göre şu sıralarda daha fazla ağlıyorum.
(c) Şu sıralarda her an ağlıyorum.
(d) Eskiden ağlayabilirdim, ama şu sıralarda istesem de ağlayamıyorum. |

11. (a) Her zamankinden daha sınırlı değilim.
(b) Her zamankinden daha kolayca sinirleniyor ve kızıyorum.
(c) Çoğu zaman sinirliyim.
(d) Eskiden sinirlendiğim şeylere bile artık sinirlenemiyorum.

12. (a) Diğer insanlara karşı ilgimi kaybetmedim.
(b) Eskisine göre insanlarla daha az ilgiliyim.
(c) Diğer insanlara karşı ilgimin çoğunu kaybettim.
(d) Diğer insanlara karşı hiç ilgim kalmadı.

13. (a) Kararlarımı eskisi kadar kolay ve rahat verebiliyorum.
(b) Şu sıralarda kararlarımı vermeyi erteliyorum.
(c) Kararlarımı vermekte oldukça güçlük çekiyorum.
(d) Artık hiç karar veremiyorum.

14. (a) Dış görünüşümün eskisinden daha kötü olduğunu sanmıyorum.
(b) Yaşlandığımı ve çekiciliğimi kaybettiğimi düşünüyor ve üzülüyorum.
(c) Dış görünüşümde artık değiştirilmesi mümkün olmayan olumsuz değişiklikler olduğunu hissediyorum.
(d) Çok çirkin olduğumu düşünüyorum.

15. (a) Eskisi kadar iyi çalışabiliyorum.
(b) Bir işe başlayabilmek için eskisine göre kendimi daha fazla zorlamam gerekiyor.
(c) Hangi iş olursa olsun, yapabilmek için kendimi çok zorluyorum.
(d) Hiçbir iş yapamıyorum.

16. (a) Eskisi kadar rahat uyuyabiliyorum.
(b) Şu sıralarda eskisi kadar rahat uyuyamıyorum.
(c) Eskisine göre 1 veya 2 saat erken uyanıyor ve tekrar uyumakta zorluk çekiyorum.
(d) Eskisine göre çok erken uyanıyor ve tekrar uyuyamıyorum.

17. (a) Eskisine kıyasla daha çabuk yorulduğumu sanmıyorum.
(b) Eskisinden daha çabuk yoruluyorum.
(c) Şu sıralarda neredeyse her şey beni yoruyor.
(d) Öyle yorgunum ki hiçbir şey yapamıyorum.

18. (a) İştahım eskisinden pek farklı değil.
(b) İştahım eskisi kadar iyi değil.
(c) Şu sıralarda iştahım epey kötü.
(d) Artık hiç iştahım yok.

19. (a) Son zamanlarda pek fazla kilo kaybettiğimi sanmıyorum.
(b) Son zamanlarda istemediğim halde üç kilodan fazla kaybettim.
(c) Son zamanlarda istemediğim halde beş kilodan fazla kaybettim.
(d) Son zamanlarda istemediğim halde yedi kilodan fazla kaybettim.

Daha az yemeye çalışarak kilo kaybetmeye çalışıyorum. Evet () Hayır ()

20. (a) Sağlığım beni pek endişelendirmiyor.
(b) Son zamanlarda ağrı, sızı, mide bozukluğu, kabızlık gibi sorunlarım var.
(c) Ağrı, sızı gibi bu sıkıntılarım beni epey endişelendirdiği için başka şeyleri düşünmek zor geliyor.
(d) Bu tür sıkıntılarım beni öylesine endişelendiriyor ki, artık başka hiçbir şey düşünemiyorum.

21. (a) Son zamanlarda cinsel yařantımda dikkatimi eken bir Őey yok.
(b) Eskisine oranla cinsel konularla daha az ilgileniyorum.
(c) Őu sıralarda cinsellikle pek ilgili deęilim.
(d) Artık cinsellikle hibir ilgim kalmadı.

Appendix K: Life Satisfaction Scale

Aşağıdaki ifadelerin size ne kadar uyduğunu belirtiniz.

		Çok Uygun	Uygun	Belirsiz	Uygun Değil	Hiç Uygun Değil
1.	Bir çok bakımdan hayatım idealime yakın.					
2.	Yaşam koşullarım mükemmel.					
3.	Hayatımdan memnunum.					
4.	Şimdiye kadar hayatta istediğim önemli şeyleri elde ettim.					
5.	Eğer hayatımı yeniden yaşasaydım hemen hiçbir şeyi değiştirmezdim.					

Appendix L Interview Questions

Görüşme Soruları

1. Çocuğunuzda ilk belirtiler ne zaman görüldü, ne kadar zaman sonrasında tanı kondu?
2. Tanı döneminde neler hissettiniz?
3. Şu anda nasıl hissediyorsunuz?
4. Hastalığın sizin üzerinizdeki etkileri nelerdir?/Hastalık sizi nasıl etkiledi?
5. Hastalık hayatınızı kötü yönde nasıl etkiledi, Neler değişti?
6. İyi yönde değişiklikler oldu mu, neler değişti?
7. Başetmenize yardımcı olan etmenler neler?/ Başetmenize neler yardımcı oldu?
8. Sizce sizin güçlü yanlarınız neler?
9. Sizce sizin zayıf yanlarınız neler?
10. Bakım verdiğiniz süreçte durumun ne kadar kontrolünüzde olduğunu düşünüyorsunuz?
11. Sizce size ne yardımcı olur?
12. Geleceğe dair düşünceleriniz nelerdir?

Appendix M Evaluation of the Intervention: Interventionist's Perspective

The contributions of the participants to the content of the intervention sessions and some observations of the interventionist during the sessions were important for a complete evaluation of the intervention program. However, it should be noted that subjective opinions of the interventionist, which include individual differences that cannot be generalized, were represented here. Four important topics were identified (i.e., caregiving role, social environment, communication problems, and the emotion “guilt”) and presented below.

The effects of having a caregiving role was mentioned before, however, there was a specific incident about the caregiving role. At the beginning of the session when I said “I know that you know each other, you see each other in the corridors. However, let's begin with introducing yourself”, they looked at each other and told that they know each other's faces but not names. They had known each other as “...’s mother”. This was an important detail meaning that their identities, even names become indistinct in the hospital settings and they had only one role left, being a caregiver. Moreover, a mother, whose child overcame cancer and was no longer receiving active treatment, reported that she did not focus on herself during the treatment and now she was looking back and perceived what a great problem was that she was trying to manage. She continued by saying “Now we are back at home, and it is my turn to recover.”

There was a topic that was reported as annoying, which was what others say about the illness. Complaints were mentioned about what people from their social environment tell them in reaction to the illness such as “you are young, can have other children”, “how couldn't you notice it”, “you were incumbent upon him that's why it happened”, etc. The participants reported that others' sayings were not helpful, besides they were annoying. Some participants reported a better dealing with those comments but some others felt more vulnerable and they could not cope with that. The attributions (such as not having correct information) and suggestions on how to respond were mentioned in the sessions. Therefore, in addition to the benefits of support and communication, the other side of support network, that is, nonsupportive relationships was another important topic for this sample. They also emphasized that only the people who experience the same problem are

able to understand them, others cannot know what it was like. This “others” sometimes applied to me, which held me back in trying to reach them.

The communication problems with social environment sometimes applied to the medical team. They sometimes complained about having communication problems with physicians and nurses. They mentioned that they were not provided with sufficient information, hesitate to ask questions and even reported looking in the physician’s eyes to understand the child’s condition. The intervention session served as a means to express their anger. Suggestions were included for this; such as not to generalize negative experiences or how and when to ask something.

The process of devoting themselves to the treatment of the child was related to feeling guilty for the time spent apart from the child. In addition to the findings of Study 2 on guilt, it was observed several times that after joining the intervention some participants did something for the child, such as buying something to their child or cooking something what s/he wanted, as if they were trying to compensate for the time spent away from his/her. Guilt was also reported by a mother in session who said that she loved drinking tea and she was punishing herself by not drinking tea in the hospital with her ill daughter. The intervention aimed at normalizing the negative emotions including guilt. It is thought that guilt needs to be focused on as much as sadness and anxiety.

Appendix N Evaluation of the Intervention: Participants' Perspective

The participants of the intervention program were asked to give verbal feedback at the end of the session. Moreover, as the treatment process is long-lasting, former participants were met during the hospital visits and conversations were made with them. The participants' perspective included their questions and comments, which were investigated under three topics, namely, change in affect, application of what was learned, and demands and questions asked.

After the session ended, the participants were asked to fill in PANAS and some of them reported that their answers changed after the session. This may mean that they were aware of their emotions before the session and felt the change in their emotions due to the intervention. They also reported feeling "relieved", "better" and reported a wish that it would repeat or be longer.

Another former participant mentioned that she once felt an increase in her heartbeat, she applied the breath exercise and it worked, she turned back to normal, meaning that the breath exercise training was helpful to her.

The illness was important in all the caregivers' lives; however, it meant something more for some of the participants. Some participants, coming from small towns, reported that it was their first time in Ankara, a metropolitan, and learned to survive here. They told that they had difficulties in talking to doctors, completing paper work, and even finding the hospital, but now they were masters of everything and felt confident that they can manage things by themselves. That is, it was a source of self-esteem for them.

There were questions asked in the session about the medical aspects of their child's illness, such as the rate of a good prognosis, the causes of the illness etc. This can be due to avoidance or hesitation of asking the doctors, or a need to approve the information from a different source. Some participants wanted me to pray for them. Some others expressed a need for a psychologist for their child; wanted me to talk to their child. These examples demonstrated the importance of competency and ethical conduct of the psychologist.

It is important to know one's boundaries and to be careful with your words as an interventionist.

In the application phase of questionnaires of Study 1, the participants were asked to fill in the questionnaires and also informed and suggested to attend a future intervention program. Most participants volunteered for filling in the questionnaires but not attending the intervention. They reported that they do not want to or do not need to attend a program, but willing to fill in the questionnaires "to help the study" or "to contribute to research". It was interesting to experience that a request is more readily accepted than an offer of service.

Appendix O Sample Parts of the Hand-Out for the Intervention
Aile Destek Programı

Bakımveren kimdir?

(...)

Bu uyum sürecini kolaylaştırmak için,

- Tedavi ekibine güvenmek ve onlarla iyi bir ilişki kurmak
- Umutlu olmak,

(...)

Yetişkin bir insanın ihtiyaç duyduğu herşey bakımverenler için de geçerlidir. Ancak, bakımveren rolü üstlenildiğinde bu ihtiyaçlar yeteri kadar karşılanamaz, çünkü kişinin neredeyse tüm ilgisi, zamanı ve enerjisi hasta olan çocuğa aktarılır. (...)

Ne yapılabilir?

- Zaman planlaması (kendine zaman ayırabilme)

(...)

Hastalıkla başetme süreci olumsuz duyguları da içeren bir süreçtir. (...)

Ne yapılabilir?

- Olumsuz duygudan kaçmayın, kabul edin, isimlendirin

(...)

Stres nedir?

(...)

Stresli olduğumuzu nasıl anlarız?

Fiziksel belirtiler

Olumsuz düşünceler

Olumsuz duygular

Stresle başetmede yardımcı olan kaynaklar nelerdir?

- Aile, sosyal çevre desteği
- Çözüme dair umut, inanç
- Enerji, güç

(...)

Note. The author should be contacted for the full version of the hand-out.

Appendix P Turkish summary

Literatür Özeti

Kronik hastalık, en az 6 ay olmak üzere uzun süreli bir sağlık sorunu ya da engeli anlamına gelmektedir (Vickers, Parris, Bailey, 2004). Uzun süreli olması nedeniyle hastalığa bir uyum süreci gerektirir (Lorig ve ark., 2006). Biyopsikososyal modelin (Engel, 1977) yükselişi ile birlikte bu uyum süreci psikolojinin de ilgi alanları arasında yer almaktadır. Bu modele göre kronik hastalıkların biyolojik, psikolojik ve sosyal yönleri bulunmaktadır. Bu yönlerden biri de ailedir. Kronik hastalığa sahip bir bireyi olan ailelerde de bir uyum süreci gereklidir, çünkü hastalık; roller, işleyiş, ve günlük hayat gibi etmeler üzerinde etkilidir. Bu çalışmanın amacı çocukluk çağı kanserleri tanısı almış çocukların aile bireylerinin, özellikle bakımverenlerin, uyum süreçlerini incelemektir. Bakım verme, hastalık nedeniyle hayatlarını kendi kendine yerine getiremeyen aile üyelerine yardımcı olmak olarak tanımlanmaktadır ve bu durum hasta kişinin sağlık durumuna duygusal ve davranışsal bir kendini adamayı da içermektedir (Pearlin ve ark., 1990). Kanser tanısı ise travmatik bir stres kaynağı olarak kabul edilmektedir.

Bu çalışmanın genel amacı kanserli çocukların bakımverenlerinin baş etme süreçlerinin incelenmesidir. Ana çalışma, 3 alt çalışmadan oluşmaktadır. İlk çalışmanın amacı Transaksiyonel Baş Etme Teorisi (Lazarus & Folkman, 1984) kullanılarak kanserli çocukların bakımverenlerinin stres düzeylerini etkileyen etmenleri araştırmak; ikinci çalışmanın amacı bu süreçle ilgili etmenleri bakımverenin bakış açısından niteliksel olarak incelemek ve üçüncü çalışmanın amacı bir müdahale programı geliştirmek ve etkililiğini test etmektir. Çalışmaların ayrıntılarına geçilmeden önce literatürde bulunan çalışmalar özetlenmiştir.

Bugüne kadar yapılmış olan çalışmalar bakımverenlerin yaşadığı stres düzeyi ve psikolojik belirti düzeylerini ölçme, yüksek belirti düzeyini yordayan risk faktörlerini ve düşük belirti düzeyini yordayan koruyucu faktörleri inceleme amaçlarını taşımaktadır. Ayrıca, bakım vermeyi bir süreç olarak inceleyen çeşitli teorik modeller de

önerilmektedir. Aşağıda, bu çalışmada incelenen değişkenler ve bir teorik modelden kısaca bahsedilmiştir.

Yapılan niceliksel çalışmalarla yaş, eğitim durumu ve sosyoekonomik durum gibi demografik değişkenler, kontrol algısı, iyi oluş, sosyal destek, stres algısı ve başa etme yolları ve duygular gibi değişkenlerin bakımverenler üzerindeki etkileri incelenmiştir. Bu değişkenlerin bir arada ve birbirileri ile etkileşim içinde incelenmesine imkan veren teorik bir model Transaksiyonel Baş Etme Teorisi'dir (Lazarus & Folkman, 1984). Bu modele göre stresle baş etme, dinamik ve karşılıklı etkileşimin olduğu bir süreçtir ve bu süreçte yer alan değişkenler, öncü değişkenler (demografik değişkenler, kontrol algısı, sosyal destek gibi), aracı süreçler (algı ve baş etme yolları), kısa süreli sonuçlar (olumlu ve olumsuz duygular) ve uzun süreli sonuçlardır (sağlık, iyi oluş gibi). Stres, kişinin iyilik halini tehdit eden ve sahip olduğu kaynakları zorlayıcı olarak algılanan bir çevre-k kişi ilişkisi olarak tanımlanmaktadır. Baş etme ise stresli olarak algılanan ve olumsuz duygulara neden olan bir durumda çevre-k kişi ilişkisinin gereklerini yerine getirme süreci olarak tanımlanmaktadır. Bu tanımlar bir arada değerlendirildiğinde aracı süreçler olan algı ve başa çıkma süreçlerinin önemi ortaya çıkmaktadır. Kişinin durumu kendisi ile ilgisiz, kendisi için olumlu ya da stresli olarak algılaması (birincil algı); kişinin kendi kaynaklarını değerlendirerek durumun kontrol edilebilirliği hakkında karara varması (ikincil algı) ve gelen yeni verileri değerlendirerek kararı üzerinde durması (yeniden değerlendirme) algı sürecini oluşturmaktadır. Bu süreçten sonra gelen baş etme süreçleri ise problem odaklı ya da duygu odaklı olarak iki türde gerçekleşmektedir. Problem odaklı baş etme stres yaratan problemin çözümüne yönelmek ve plan yapıp uygulamak gibi süreçleri içerirken duygu odaklı baş etme stresli durumun beraberinde getirdiği olumsuz duyguları azaltmaya yönelik süreçleri içermektedir (Lazarus & Folkman, 1984). Bu model yıllardır farklı gruplarla test edilmiş ve geçerliliği farklı türde hastalıklar ve bakımverenler (örn. Pakenham, 2001; Gold, Treadwell, Weissman, & Vichinsky, 2008) için de kanıtlanmıştır.

Bakımverenlerle yürütülen niceliksel çalışmaların yanı sıra daha az sayıda niteliksel çalışma da bulunmaktadır. Niteliksel yaklaşım bireyler arası farklılıkları ve öznel bakış açılarını içermesi bakımından önemlidir (Flick, 2002). Niceliksel yaklaşım genellenebilirlik, nesnellik ve güvenilirlik gibi güçlü yanlara sahip olmasına rağmen

kişisel farklılıkları yakalama konusunda daha zayıf kalmaktadır ve bu zayıf yön niceliksel çalışmalarla tamamlanabilir. Bu nedenle İkinci Çalışma'da niceliksel yaklaşım kullanılmıştır. Bu çalışmada kullanılan teorik yönelim Yorumlayıcı Fenomenolojik Analizdir. Bu analizin amacı kişisel deneyimleri ve kişilerin kendilerini ve sosyal çevrelerini nasıl anlamlandırdıklarını detaylı bir biçimde incelemektir (Smith & Eatough, 2007). Yaklaşımın bir diğer özelliği araştırmacının ve katılımcının bakış açılarının ve bu ikisi arası etkileşimin dahil edilmesidir (Willig, 2008). Bu nedenle analiz için yarı-yapılandırılmış görüşme dökümleri kullanılmaktadır. Kanserli çocukların aileleri ile yapılmış niceliksel çalışmalar tedavi sürecinin beraberinde getirdiği sorunlar, baş etme ve sosyal destek gibi konuları ayrıntılı bir biçimde incelemektedir (örn. Fletcher, Schneider, & Harry, 2010; James ve ark., 2002).

Bakımverenlerle yürütülen ve amacı bu süreçteki risk ve koruyucu faktörleri belirlemek olan çalışmaların sonucunda az sayıda müdahale programı geliştirme ve etkililiğini test etme çalışması yapılmıştır (örn., Northouse, Kershaw, Mood, & Schafenacker, 2005). Kronik hastalıklara sahip çocukları olan aileler için geliştirilecek müdahale çalışmalarının sahip olması önerilen özellikler şunlardır (Drotar, 2006): Grubun özelliklerinin ve ihtiyaçlarının doğru bir şekilde tespit edilmesi, teorik bir çerçeveye dayalı olması, farklı terapötik bileşenlerin bir arada kullanılması (örn. Bilişsel terapi + gevşeme egzersizi) ve standart yazılı metinlerin kullanılması. Üçüncü çalışmada aktarılan müdahale programı geliştirilirken bu öneriler dikkate alınmıştır.

1. Çalışma: Kanseli Çocukların Bakımverenlerinde Stresi Yordayan Etmenler: Bir Transaksiyonel Baş Etme Teorisi Perspektifi

Amaç ve Hipotezler

Bu çalışmanın amacı Transaksiyonel Baş Etme Teorisi (Lazarus & Folkman, 1984) kullanılarak kanserli çocukların bakımverenlerinin stres düzeylerini etkileyen etmenlerini incelemektir. Modelde yer alan değişkenler, bakımverenlerle yapılmış olan çalışmalar incelenerek belirlenmiştir. Sonuç değişkenleri olarak ise depresif belirtiler, kaygı belirtileri ve yaşam doyumu kullanılmıştır. Çalışmanın hipotezleri şunlardır: (1. a.) öncü değişkenler (demografik değişkenler, kontrol algısı, temel ihtiyaçlar, günlük aktiviteler ve

sosyal destek) depresif belirti düzeyini yordayacak; (1.b.) öncü değişkenlerin etkileri kontrol edildikten sonra aracı süreçler (stres algısı, problem odaklı baş etme ve duygu odaklı baş etme) depresif belirti düzeyini yordayacak; (1.c.) öncü değişkenlerin ve aracı süreçlerin etkileri kontrol edildikten sonra kısa süreli sonuçlar (olumlu ve olumsuz duygular) depresif belirti düzeyini yordayacak; benzer şekilde, (2.a.) öncü değişkenler (demografik değişkenler, kontrol algısı, temel ihtiyaçlar, günlük aktiviteler ve sosyal destek) kaygı belirtileri düzeyini yordayacak; (2.b.) öncü değişkenlerin etkileri kontrol edildikten sonra aracı süreçler (stres algısı, problem odaklı baş etme ve duygu odaklı baş etme) kaygı belirtileri düzeyini yordayacak; (2.c.) öncü değişkenlerin ve aracı süreçlerin etkileri kontrol edildikten sonra kısa süreli sonuçlar (olumlu ve olumsuz duygular) kaygı belirtileri düzeyini yordayacak; ve son olarak (3.a.) öncü değişkenler (demografik değişkenler, kontrol algısı, temel ihtiyaçlar, günlük aktiviteler ve sosyal destek) yaşam doyumu düzeyini yordayacak; (3.b.) öncü değişkenlerin etkileri kontrol edildikten sonra aracı süreçler (stres algısı, problem odaklı baş etme ve duygu odaklı baş etme) yaşam doyumu düzeyini yordayacak; (1.c.) öncü değişkenlerin ve aracı süreçlerin etkileri kontrol edildikten sonra kısa süreli sonuçlar (olumlu ve olumsuz duygular) yaşam doyumu düzeyini yordayacaktır.

Yöntem

Katılımcılar

Kanser tanısı almış bir çocuğa sahip 86 kadın (% 82) ve 19 erkek (% 18) olmak üzere toplam 105 kişi bu çalışmanın katılımcı grubunu oluşturmuştur. Katılımcıların yaş ortalaması 34.31'dir. Çocukların yaşları ortalaması ise 7.11'dir. Tanı kategorileri çok çeşitli olmakla birlikte en sık rastlanan tanımlar nöroblastom ($n = 22$), kemik tümörü ($n = 18$) ve lösemidir ($n = 14$). Hastalık süresi 1-124 ay arası değişmektedir ($M = 11.54$). Çocukların % 91.4'ü kemoterapi almakta iken geri kalan % 1.9 radyoterapi tedavisi görmekte ve % 6.7'si kontrol için hastanede bulunmaktaydılar.

Veri Toplama Araçları

Çalışmada kullanılan test bataryasında demografik bilgi formu, Çok Yönlü Sağlık Kontrol Odağı Ölçeği (Wallston & DeVellis, 1978), Bakıcı İyilik Ölçeği (Berg-Weger, Rubio, & Tebb, 2000), Çok Yönlü Algılanan Sosyal Destek Ölçeği (Zimet, Dahlem, Zimet, & Farley, 1988), Stres Algısı Ölçeği (Peacock & Wong, 1990), Baş Etme Stratejileri Ölçeği (Folkman & Lazarus, 1980), Pozitif ve Negatif Duygu Skalası (Watson, Clark, & Tellegen, 1988), Beck Depresyon Envanteri (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), Beck Kaygı Envanteri (Beck, Epstein, Brown, and Steer, 1988) ve Yaşam Doyumu Ölçeği (Diener, Emmons, Larsen, & Griffin, 1985) bulunmaktadır.

Demografik Bilgi Formu: Bu form kanserli çocukların bakımverenleri için hazırlanmıştır ve yaş, cinsiyet gibi genel özelliklerin yanısıra hastaya yakınlık derecesi, tedavi süresi gibi duruma özgü değişkenleri de içermektedir.

Çok Yönlü Sağlık Kontrol Odağı Ölçeği: Wallston ve DeVellis (1978) tarafından geliştirilmiş olan ölçek Türkçe'ye Üstündağ-Budak (1999) tarafından uyarlanmıştır. Alınan yüksek puanlar dış kontrol odağına, düşük puanlar ise iç kontrol odağına işaret etmektedir. Bu çalışmada bulunan iç tutarlılık katsayısı .60'tır.

Bakıcı İyilik Ölçeği: Berg-Weger, Rubio ve Tebb (2000) tarafından geliştirilmiş olan ölçek Türkçe'ye Demirtepe ve Bozo (2009) tarafından uyarlanmıştır. Ölçek temel ihtiyaçlar ve günlük aktiviteler olmak üzere iki altölçekten oluşmaktadır. Her iki altölçekte alınan yüksek puanlar daha yüksek bir iyilik düzeyine işaret etmektedir. Bu çalışmada bulunan iç tutarlılık katsayısı temel ihtiyaçlar altölçeği için .85, günlük aktiviteler altölçeği için .86'dır.

Çok Yönlü Algılanan Sosyal Destek Ölçeği: Zimet, Dahlem, Zimet ve Farley (1988) tarafından geliştirilmiş olan ölçek Türkçe'ye Eker ve Arkar (1995) tarafından uyarlanmıştır. Alınan yüksek puanlar algılanan sosyal desteğin yüksek olduğu anlamına gelmektedir. Bu çalışmada bulunan iç tutarlılık katsayısı .92'dir.

Stres Algısı Ölçeği: Peacock ve Wong (1990) tarafından geliştirilen ölçek Türkçe'ye Durak ve Şenol-Durak (2013) tarafından uyarlanmıştır. Ölçek, stres kaynağının tehdit ya da zorlayıcı olarak algılanmasını içeren birincil algı ve kontrol edilemez, başkaları tarafından kontrol edilen ve kendisi tarafından kontrol edilen olarak algılanmasını içeren ikincil algıyı ölçmeyi amaçlamıştır. Bu çalışmada bulunan iç tutarlılık katsayısı tüm altölçekler için .53 ile .78 arasında değişmiştir.

Baş Etme Stratejileri Ölçeği: Folkman ve Lazarus (1980) tarafından geliştirilen ölçek Türkçe'ye Siva (1991) tarafından uyarlanmıştır. Problem odaklı başa çıkma ve duygu odaklı başa çıkma altölçekleri bu çalışmada kullanılmış ve iç tutarlılık katsayıları aynı sıra ile .82 ve .76 olarak bulunmuştur.

Pozitif ve Negatif Duygu Skalası: Watson, Clark ve Tellegen (1988) tarafından geliştirilen ölçek Türkçe'ye Gençöz (2000) tarafından uyarlanmıştır. Pozitif ve negatif duygular olmak üzere iki altölçekten oluşmaktadır ve iç tutarlılık katsayıları aynı sıra ile .78 ve .76 olarak bulunmuştur.

Beck Depresyon Envanteri: Beck ve arkadaşları (1961) tarafından geliştirilen ölçek Türkçe'ye Tegin (1980) ve Hisli (1988) tarafından uyarlanmıştır. Artan puanlar depresif belirtilerin artışı anlamına gelmektedir. Bu çalışmada bulunan iç tutarlılık katsayısı .86'dır.

Beck Kaygı Envanteri: Beck, Epstein, Brown ve Steer (1988) tarafından geliştirilen ölçek Türkçe'ye Ulusoy, Şahin ve Erkmen (1998) tarafından uyarlanmıştır. Artan puanlar kaygının fiziksel belirtilerinin artışı anlamına gelmektedir. Bu çalışmada bulunan iç tutarlılık katsayısı .90'dır.

Yaşam Doyumu Ölçeği: Diener, Emmons, Larsen ve Griffin (1985) tarafından geliştirilen ölçek Türkçe'ye Durak, Şenol-Durak ve Gençöz (2010) tarafından uyarlanmıştır. Artan puanlar azalan yaşam doyumuna işaret etmektedir. Bu çalışmada bulunan iç tutarlılık katsayısı .77'dir.

İşlem

Gerekli etik komite izinlerinin alınmasından sonra pediatrik onkoloji bölüm başkanlarından da onay alınmıştır. Çalışmaya katılmak için gönüllü olan bakımverenlere bilgilendirilmiş onam formu imzalatılmıştır. Yatan hasta bölümünde ve poliklinik randevularını bekleme sırasında katılımcılara test bataryası uygulanmıştır. Katılımcıların anketleri kendileri okuyup işaretleyerek ya da araştırmacılar tarafından okunup işaretlenerek yaklaşık 45-55 dakikada uygulamaları tamamlanmıştır.

Bulgular

Ön analizlerde şu bulgulara ulaşılmıştır: Yaş, yaşanan yer, hastalık süresi, tanı ve kişinin birlikte yaşadığı kişi sayısı ve bakımverme görevlerinde ona yardımcı kişilerin varlığının etkileri hiçbir sonuç değişkeni (depresif belirtiler, kaygı belirtileri ve yaşam doyumu) için anlamlı değildir. Hasta çocuğun yaşının ise anlamlı bir etkiye sahip olduğu bulunmuştur. Çocuğun yaşı küçüldükçe bakımverenin hissettiği depresif belirti ve kaygı belirtileri düzeyi artmaktadır. Sonuç değişkenleri cinsiyet farkı açısından incelendiğinde, kadınların erkeklere oranla daha yüksek düzeyde depresif belirti ve kaygı belirtileri yaşadığı sonucuna ulaşılmıştır. Katılımcıların çalışma durumlarının sonuç değişkenlerinin tamamı için farklı olduğu görülmüştür. Çalışan katılımcıların depresif belirti ve kaygı belirtileri çalışmayan katılımcılara oranla daha düşük ve yaşam doyumları daha yüksektir. Ayrıca, fiziksel bir rahatsızlığı olduğunu rapor eden katılımcıların anlamlı olarak daha yüksek depresif belirti ve kaygı belirtilerine ve düşük yaşam doyumuna sahip oldukları bulunmuştur. Gelir düzeyi açısından değerlendirildiğinde depresif belirti düzeyi ve yaşam doyumu üzerindeki etki anlamlıdır. Gelir düzeyi yüksek olanlar, diğer gruplara göre daha düşük düzeyde depresif belirtilere ve daha yüksek yaşam doyumuna sahiptirler. Eğitim düzeyinin etkisi yalnızca yaşam doyumu için anlamlıdır ve üniversite mezunlarının yaşam doyumu diğer gruplara göre daha yüksektir. Değişkenler arası ilişkilere korelasyon ile bakılmış ve oluşan ilişki örüntüsü incelenmiştir.

Her bir sonuç değişkeni için üç farklı hiyerarşik regresyon modeli oluşturulmuş ve bu modellerde ön analizlerde anlamlı ilişkilere sahip olduğu bulunan değişkenler içerilmiştir. Buna göre sonuçlar şu şekildedir: Depresif belirtiler için ilk basamakta girilen demografik

değişkenler varyansın % 15'ini açıklamıştır. Çocuğun yaşının küçüldükçe ve gelir düzeyinin azaldıkça depresif belirti düzeyinin arttığı bulunmuştur. İkinci basamak açıklanan varyansı % 32 artırmıştır. Dış sağlık kontrol odağının ve düşük düzeyde günlük aktivitenin ve düşük düzeyde sosyal desteğin daha yüksek depresif belirti düzeyi ile ilişkili olduğu görülmüştür. Üçüncü basamakta aracı değişkenler, açıklanan varyansı % 8 artırmıştır. Durumu kontrol edilemez olma algısı arttıkça depresif belirti düzeyi de artmıştır. Dördüncü ve son basamakta girilen kısa süreli sonuç değişkenleri açıklanan varyansı % 2 artırmıştır. Negatif duygular arttıkça depresif belirtilerin de arttığı sonucuna ulaşılmıştır.

Kaygı belirtileri için ilk basamakta girilen demografik değişkenler varyansın % 10'unu açıklamıştır. Çocuğun yaşının küçüldükçe kaygı belirtilerinin arttığı bulunmuştur. İkinci basamakta girilen öncü değişkenler açıklanan varyansı % 17 artırmıştır. Düşük düzeyde günlük aktivitenin ve sosyal desteğin daha yüksek kaygı belirtileri düzeyi ile ilişkili olduğu görülmüştür. Üçüncü basamakta aracı değişkenler, açıklanan varyansı % 10 artırmıştır. Durumu başkalarının kontrolünde algılama düzeyi arttıkça kaygı belirtileri düzeyi de sınırdan anlamlı düzeyde artmıştır. Dördüncü ve son basamakta girilen kısa süreli sonuç değişkenleri açıklanan varyansı % 3 artırmıştır. Negatif duygular arttıkça kaygı belirtilerinin de arttığı sonucuna ulaşılmıştır.

Yaşam doyumu için ilk basamakta girilen demografik değişkenler varyansın % 24'ünü açıklamıştır. Gelir düzeyi azaldıkça yaşam doyumu da azalmaktadır. İkinci basamakta girilen öncü değişkenler açıklanan varyansı % 17 artırmıştır. Buna göre, temel ihtiyaçların karşılanma düzeyi azaldıkça yaşam doyumu da azalmaktadır. Üçüncü basamakta aracı değişkenler, açıklanan varyansı % 11 artırmıştır. Durumu tehdit olarak algılama arttıkça, bunun aksine durumu zorlayıcı olarak algılama azaldıkça ve problem odaklı baş etme düzeyi arttıkça yaşam doyumu da artmaktadır. Dördüncü ve son basamakta girilen kısa süreli sonuç değişkenleri açıklanan varyansı % 1 arttırmasına rağmen bu değişim anlamlı değildir.

Tartışma

Çalışmanın bulguları literatürdeki bulgularla desteklenmektedir. Örneğin, çocuğun yaşının etkisi (Grootenhuis & Last, 1997) bu çalışmada da doğrulanmıştır. Bu etki küçük çocukların daha kırılgan ve zarar görmeye daha açık olmaları algısına atfedilebilir. Cinsiyet farkının ise kadın ve erkeklerin bakımverme sürecinde sahip oldukları rollerle açıklanabileceği düşünülmüştür. Yani çocuğun bakımını birincil olarak üstlenen genelde anne, tedavinin sürmesini sağlamak için dışarda çalışan genellikle babadır ve bu durumda babanın hastane dışında geçirdiği vakit daha çok ve kaynaklara erişimi daha rahat olabilmektedir. Gelir düzeyinin, eğitim durumunun ve bir işe sahip olmanın düşük belirti düzeyleri ile ilişkili olmasında ise kaynaklara erişimin kolaylığı ve kendini ifade edebilecek yeterli becerilere ve ortama sahip olunması etkili olabilir. Ana analizlerin bulguları değerlendirildiğinde her bir sonuç değişkeni için farklı bir örüntü ortaya çıkmıştır ve bu durum değişkenlerin tanımları ile birlikte değerlendirilmiştir. Bulgular literatürdeki sonuçlar ile uyumludur (örn. Benassi, Sweeney & DuFour, 1988; Horton & Walender, 2001).

Bu çalışmanın, üçüncü çalışma kapsamında gerçekleştirilen müdahale programı için önemli katkıları bulunmaktadır. Örneğin, alınan sosyal desteğin, temel ihtiyaçları karşılamanın ve günlük aktiviteleri sürdürmenin bakımverenler için iyi sonuç vereceği, dolayısıyla desteklenmesi ve artırılması gerektiği sonucuna varılmıştır. Bunun yanısıra algının, kontrol konusunun ve problem çözmenin olumlu etkileri göz önünde bulundurularak müdahale programına eklenmesine karar verilmiştir.

Çalışmanın kısıtlılıkları bazı grupların (örneğin cinsiyet) eşitsizliği grup karşılaştırmaları sonuçlarının geçerliliğini kısıtlamıştır. Kesitsel bir çalışma olması, baş etmeyi uzun bir süreç olarak gören Transaksiyonel Baş Etme Modeli açısından kısıtlayıcıdır. Bu nedenle boylamsal çalışmalarla kısa ve uzun süreli etkiler araştırılmalıdır. Çalışmanın yalnızca anket doldurabilme yetisine sahip gönüllü kişilerle ve yalnızca 2 merkezde tamamlanmış olması genellenebilirliği kısıtlayan diğer etmenlerdir. İlerde yapılacak çalışmalarda boylamsal ölçüm kullanmanın yanısıra, modelde yer alan fiziksel sağlık gibi diğer değişkenler de incelenebilir.

2. Çalışma: Kanserli Çocuklara Bakımverenlerin Baş Etme Süreçlerinin Niteliksel Olarak İncelenmesi

Amaç ve Hipotezler

Bu çalışmanın amacı, bakımverenlerin yaşadıkları süreçle bağlantılı etmenleri herhangi bir teori tarafından yönlendirilmeden ve kısıtlanmadan ortaya çıkarmaktır. Araştırma sorusu “kanserli çocukların bakımverenleri hastalık süreci ile nasıl baş eder?”dir. Sorular üç konuyu içermektedir, bunlar duygular, baş etme ve kanserin etkileridir. Yarı yapılandırılmış görüşmeler yapılmış ve açık uçlu sorular kullanılmıştır.

Yöntem

Katılımcılar

On beş anne ve beş baba olmak üzere 20 kişi katılımcı grubunu oluşturmuştur. Katılımcıların yaş ortalaması 36.55'tir. Katılımcıların yarısı ($n = 10$) bakım verme konusunda kendilerine yardımcı olan birinin var olduğunu, diğer yarısı ise olmadığını ($n = 10$) rapor etmiştir. Çocukların hastalık süresi 1 ile 20 arasında değişmektedir ($M = 7.55$). Alınan tedavi konusunda çocukların 16'sının kemoterapi gördüğü, diğerlerinin ise radyoterapi ($n = 1$), kontrol ($n = 1$) ve komplikasyon ($n = 1$) sürecinde bulunduğu bilgileri edinilmiştir.

Veri Toplama Araçları

Bu çalışmanın veri toplama araçları demografik bilgi formu ve açık uçlu görüşme soruları formundan oluşmaktadır.

Demografik Bilgi Formu: Bu form kanserli çocukların bakımverenleri için hazırlanmıştır ve yaş, cinsiyet gibi genel özelliklerin yanısıra hastaya yakınlık derecesi, tedavi süresi gibi duruma özgü değişkenleri de içermektedir.

Görüşme Soruları Formu: Tanıdan başlayıp tedavi sonrasına kadar uzanan bir süreci içeren soruları kapsayan bir form hazırlanmıştır.

İşlem

Gerekli izinlerin alınmasından sonra katılımcılarla hastane ziyaretleri ya da yatışları sırasında yaklaşık 30 dakika süren görüşmeler yapılmıştır. Görüşmeye ısınma amaçlı demografik bilgileri almaya yönelik sorularla başlanmıştır. Görüşmeler devam ederken algılanan kontrol için hazırlanmış olan sorunun anlaşılabilmesi nedeniyle bu soru elenmiş ve 11 soru ile devam edilmiştir. Kayıt edilmiş olan görüşmelerin dökümleri yapılmış ve bu dökümler incelenerek tema ve alt-temalar belirlenmiştir.

Bulgular

Tema 1: Duygular

Katılımcılar tarafından aktarılan duygular genellikle olumsuzdur. Üzüntü, kaygı, suçluluk ve duygu bastırma olarak 4 alt-tema belirlenmiştir. Üzüntü, özellikle tanı döneminde hissedildiği belirtilen bir duygudur. Çocuğun kaybı anlamına gelmese de, normal hayattan ve planlardan bir kayıp yaşandığı için üzüntü duygusu yaygın olarak hissedilmektedir. Kaygı, durumunun getirdiği diğer bir duygudur ve hastalığın beklenmeyen bir durum olması ve geleceğinin belirsizliği nedeniyle hissedilmektedir. Suçluluk ise ihmal edildiği düşünülen diğer sağlıklı çocuklarla ilgili olarak ve hasta çocuğun yanında geçirilmeyen zamanlar için hissedilmektedir. Duygu bastırma ya katılımcılar tarafından direkt rapor edilmiş ya da duygulardan bahsetmekte zorluklarla araştırmacı tarafından çıkarımlarla belirlenmiştir.

Tema 2: Değişim

Değişim teması altında çocukta değişim, birbirine bağlılık, psikososyal değişim ve olumlu değişimden söz edilmiştir. Çocuğun durumu hakkında doğrudan bir soru bulunmamasına rağmen çocuğun değişimi, özellikle davranış sorunları aktarılmıştır. Birbirine bağlılık durumu bakımveren-hasta çocuk ilişkisinin aşırı düzeyde birbiri ile bağlı olma durumunu

anlatmak için kullanılmıştır. Psikososyal deęişim kişilerin günlük hayatları ve sosyal çevreleri ile ilişkilerinin deęişimini ifade etmektedir ve bu deęişim olumsuz yöndedir. Olumlu deęişim ise iyimserlik, gelişim, olumlu yönlerin keşfi ve aile bağlarının güçlenmesi gibi atıfları kapsamaktadır.

Tema 3: Baş etme

Baş etme teması kaçınma, din, kabul, karşılaştırma, odak noktası, umut, bilgi arayışı ve desteęi içermektedir. Katılımcılar hastalık üzerinde düşünmeme, yakınları ile telefonda konuşmama ve “kanser” kelimesini telaffuz etme gibi yollarla durumdan kaçındıklarını aktarmışlardır. Din alt-teması ise hastalığın sebebine ve tedavisine yönelik atıflarda etkili olmuştur. Ayrıca dua gibi dini yolları baş etme aracı olarak kullandıkları bilgileri edinilmiştir. Bazı katılımcılar kabul ve alışmadan bahsetmişler, bazıları ise kendi çocuklarının durumunu dięer çocuklarla karşılaştırarak durumlarının daha iyi olduęu sonucuna ulaştıklarını aktarmışlardır. Odak noktası olarak hasta çocuęu belirlemek karşılıklı baęlılık alt-teması ile ilişkilendirilmiştir. Ayrıca, pek çok katılımcının sıklıkla umuttan bahsetmesi dikkat çekmiştir. Tdavi ekibine güven, hastalık hakkında bilgi edinme çabası ve sosyal destek belirlenen dięer alt-temalardır.

Tartışma

Duygular genellikle olumsuz duyguları kapsamaktadır. Ayrıca, duyguların tek başlarına deęil birbirleri ile ilişkili olarak ve aynı anda hissedilebileceęi göz önünde bulundurulmalıdır (Oatley & Duncan, 1992). Hastalığın yapısı gereęi uzun süreli hastane yatışları kayıp olarak düşünülerek üzüntüyü, belirsiz bir gelecek ise kaygıyı beraberinde getirmektedir. Ayrıca, çocuęa ve tedaviye kendini adama süreci, göz ardı edilen dięer çocuklar ve kendi algılanan hatalar nedeni ile suçluluk duygusunu düşündürmektedir. Duyguların ifade edilmesi, bazı katılımcılar tarafından zayıflık olarak algılandığı ve aile bireylerine sıkıntı verdięi düşüncesi ile hoş karşılanmadığı için bastırma yolunun tercih edilmesi anlamını taşımaktadır. Ancak, duyguların uygun şekilde ifade edilmesinin psikolojik saęlık açısından daha olumlu olduęu bilinmektedir (Denollet ve ark., 1996, Jensen, 1987). Duygular konusunda belirlenen alt-temalar dışında bahsedilmeyen bir duygu dikkat çekmiştir. Hastalıkla ilintili olarak hissedilmesinin normal olduęu önerilen

(Woznick & Goodheart, 2002) *öfke*, katılımcılar tarafından aktarılmamıştır. Bu durumun duyguları bastırma eğiliminin bir sonucu olabileceği düşünülmektedir. Değişim, hastalık ve tedavi sürecinin beklenen ve doğal bir sonucudur. Günlük hayatta, ilişkilerde ve hayata bakışta hastalığın etkileri görülmektedir. Bu durum literatürde bulunan diğer çalışmalar ile de desteklenmektedir (örn. Fletcher, 2010). Baş etme konusu Lazarus ve Folkman'ın (1984) sunduğu teorik çerçevede incelendiğinde, katılımcıların çoğunlukla duygu odaklı baş etme yollarını tercih ettikleri sonucuna varılmıştır. Kaçınma, din, yalnızca çocuğa odaklanıp kendi ihtiyaç ve duygularını bastırma gibi yollar, sorunu tanımlama, çözmeye çalışma gibi problem odaklı yollara oranla daha sık bahsedilmiştir.

İlk çalışmada olduğu gibi bu çalışmada da müdahale programı için önemli çıkarımlar bulunmaktadır. Bunlardan en önemlisi duyguların normalleştirilmesi ve ifade edilmesinin teşvik edilmesidir. Ayrıca odak noktalarının çocukları olduğu bilgisine dayanarak anne-çocuk ilişkisinin müdahale programında kapsanması gerektiği düşünülmüştür.

Diğer niteliksel çalışmalarda olduğu gibi bu çalışmada da genellenebilirliğin kısıtlılığı ve öznellik gibi kısıtlayıcı etmenler bulunmaktadır. Ayrıca kontrol edilebilirlik hakkındaki soru, görüşmelerden önce anlaşılabilirlik açısından denetlenmesine rağmen sorunlu algılanmıştır. Böylece durum üzerinde algıladıkları kontrol konusu bu çalışmada açığa çıkarılamamıştır. Gelecek çalışmalarda din, travma sonrası gelişim gibi konuların incelenmesi önerilmektedir.

3. Çalışma: Kanserli Çocukların Bakımverenler için Geliştirilen Bir Grup Psiko-Eğitim Müdahale Programının Etkililiği

Amaç ve Hipotezler

Çalışmanın amacı kanserli çocukların bakımverenlerinin uyum sürecini kolaylaştırıcı bir program geliştirmek, uygulamak ve etkinliğini test etmektir. Program geliştirmede, ilk iki çalışmanın, önceki çalışmaların (örn. Demirtepe-Saygılı & Bozo, 2011c) ve literatür bulgularının yanı sıra Transaksiyonel Baş Etme Teorisi (Lazarus & Folkman, 1984) kullanılmıştır. Programın amaçları normalleştirme, duygu ve deneyimleri paylaşma, stres ve baş etme konularında bilgi verme, baş etmeyi daha bilinçli kullanabilme ve kendine

bakabilmeyi sağlamaktır. Ayrıca, baş etmeyi destekleme amacıyla nefes egzersizi uygulaması da programa eklenmiştir. Program ilk planlandığında 6 haftalık, uygulamalı ve detaylı olmasına rağmen katılım sorunları nedeniyle kısaltılmış önce ard arda 2 gün daha sonra da bir öğleden sonra uygulanmış ve daha genel konuları ve amaca yönelik önerileri içerir hale getirilmiştir. Programın son hali için 4-8 kişi arasında değişen katılımcı sayısına sahip 4 grup seansı düzenlenerek toplam 21 kişiye ulaşılmıştır. Bunlardan 16 kişi ön-test ve son-testleri tamamlamış ve katılımcı grubunu oluşturmuştur.

Yöntem

Katılımcılar

Çocukları çeşitli kanser tanıları almış ve en az 3 haftadır pediatrik onkoloji bölümünde yatarak tedavi gören 16 bakımveren çalışmaya katılmıştır. Yaş ortalaması 31.26'dır. hastalık süresi 1 ve 17 ay arasında değişmiştir ($M = 7.06$).

Veri Toplama Araçları

Pozitif ve Negatif Duygu Skalası: Watson, Clark ve Tellegen (1988) tarafından geliştirilen ölçek Türkçe'ye Gençöz (2000) tarafından uyarlanmıştır. Pozitif ve negatif duygular olmak üzere iki altölçekten oluşmaktadır ve iç tutarlılık katsayıları her iki altölçek için de .58 olarak bulunmuştur. Yönerge, ön-test uygulamasında "son 2 hafta içinde", son-test uygulamasında ise "şu anda" her bir duyguyu ne derecede hissettikleri şeklinde düzenlenmiştir.

Müdahale Programı: "Aile Destek Grubu" adı verilen bir grup müdahale programı hazırlanmış ve aslına uygunluğu sağlamak amacı ile uygulayıcı el kitabı hazırlanmıştır.

İşlem

Katılımcılarla hastanenin yataklı bölümünde doktor aracılığı ile tanışılmış ve programdan bahsedilmiştir. Katılmak için gönüllü olanlara ön-test ölçümleri uygulanmış, seansa davet edilmiş ve seansa katılanlara sonrasında son-test uygulaması yapılmıştır.

Bulgular

İlk çalışmada kullanılan test bataryası grup katılımcılarına ön-test olarak uygulanmış, bu sayede grup katılımcıları ile diğerleri arasında herhangi bir değişken için anlamlı bir fark olup olmadığı kontrol edilmiştir. Buna göre, hiçbir değişken için iki grup arasında anlamlı bir fark bulunmamıştır. Yapılan Wilcoxon işaretli sıralamalar testi ile, pozitif ve negatif duygularda ön-test–son-test arası anlamlı farklar elde edilmiştir. Buna göre, katılımcılar son test ölçümlerinde anlamlı derecede daha yüksek düzeyde pozitif duygu ve daha düşük düzeyde negatif duygu rapor etmişlerdir. Özellikle hangi maddelerde farklar bulunduğu bakılmak üzere PANAS’ın her bir maddesi için t-testi yapılmış, pozitif duygulardan “ilgili”, “güçlü”, “hevesli”, “ilhamlı” ve “aktif” maddelerinin son-testlerde ön-testlere oranla daha yüksek rapor edildiği, negatif duygularda anlamlı derecede daha düşük olduğu belirlenen maddelerin ise “sıkıntılı” ve “mutsuz” olduğu bulunmuştur.

Tartışma

Drotar’ın (2006) önerdiği gibi, psiko-eğitim, paylaşım ve nefes egzersizinden oluşan çok yönlü bir müdahale programı hazırlanmış, uygulanmış ve etkililiği test edilmiştir. Katılımcı bulma ve devamlılık sağlamada yaşanan sorunlar nedeniyle ilk planlanan programda bir takım değişiklikler ve kısaltmalar yapılmak zorunda kalınmış, yaşanan sorunların sebepleri ile ilgili de akıl yürütülmüştür. Zorlukların sebeplerinin Türkiye’de genel olarak psikolojik sağlık ve psikoloğun rolü konusunda bilgi eksikliği bulunması olabileceği gib, özellikle bakımverenler için böyle bir programın kendileri için nasıl bir yardım sağlayabileceği hakkında bir bilgisizlik de olabileceği düşünülmüştür. Ayrıca, tamamlanabilen denemelerde, tamamlanamayanlardan farklı olarak doktor yönlendirmesi yapılmıştır. Bu durumun da katılımı artıran bir etmen olduğu düşünülmektedir.

Sonuçlar değerlendirildiğinde katılımcıların ön-test ölçümleri ile diğer bakımverenler arasında herhangi bir değişken için anlamlı fark bulunmaması iki şekilde yorumlanmıştır. Bunlardan ilki katılımcıların diğer bakımverenleri temsil eden bir grup olmasıdır. Diğer ise katılım isteğini yordayıcı olası bir değişkenin bu çalışmada içerilmemiş olduğudur. Ayrıca, kaçınmayı bir baş etme yolu olarak kullanan bakımverenlerin katılmama eğiliminde olduğu da düşünülebilir. Ön-test–son-test ölçümleri arasında beklenen yönde

bir fark bulunması hipotezlerin doğrulanmasına işaret etmektedir. Özellikle pozitif duygulardan anlamlı olarak artmış olduğu bulunan duyguların kişilerin baş etme konusunda bir hazırlık ve motivasyon artışına sahip oldukları şeklinde yorumlanabileceği düşünülmüştür. Stresli durumlarda sahip olunan pozitif duyguların baş etmede kullanılan kaynakları destekleyen bir durum olduğu bulunmuştur (Lazarus, Kanner & Folkman, 1980). Beklenen yönde bulunan bu anlamlı fark, olası karıştırıcı değişkenlerin etkisinin de olabileceği düşüncesi ile birlikte değerlendirilmelidir. Örneğin, seanslar sırasında katılımcıların erken çıkması, geç gelmesi ya da çağrılıp çıkması durumu ile karşılaşmıştır. Bu durumda tümüne katılım kontrol edilemeyen bir değişkendir. Sonuçlar üzerinde etkisi olabilecek bir diğer değişken tüm seanslarda aynı uygulayıcının rol almış olmasıdır. Bu durumda uygulayıcının kişisel özellikleri, ilgi göstermesi, yakınlığı gibi etmenler de olumlu sonuçlarda etkili olabilir (örn. Corso ve ark., 2012). Olası değişkenlerin etkilerinin yanı sıra, müdahale programında bulunan 3 bölümden (paylaşım, psiko-eğitim ve nefes egzersizleri) her birinin etkinliği için de literatür desteği bulunmaktadır (örn. Van Daele ve ark., 2012). Bu nedenle sonuçlar yorumlanırken tüm bu açıklamalar dikkate alınmalıdır.

Bu çalışma, benzer programlar hakkında bilginin ve kendi sorunları hakkında farkındalığın etkilerini ortaya koymuştur. Ayrıca, psikoloğun tedavi ekibinin bir parçası olması gerekliliğini de açığa çıkarmıştır. Biyopsikososyal modele göre (Engel, 1977) tedavi için biyolojik, psikolojik ve sosyal yönlerin tamamını içermek büyük önem taşımaktadır.

Çalışmada izleme ölçümlerinin bulunmaması önemli bir kısıtlılıktır. Duygu değişiminin kısa süreli etkili olabileceği ve çevresel koşullardan etkilenebileceği unutulmamalıdır (Zautra, Potter & Reich, 1997).

4. Genel Tartışma

Bu çalışmanın genel amacı kanserli çocukların bakımverenlerinin baş etme süreçlerini kapsamlı bir şekilde incelemektir. Bu amaca yönelik üç çalışma yapılarak farklı açılardan durum incelenmiş ve baş etme sürecini kolaylaştıracak bir müdahale programı geliştirilmiştir. Çalışmanın araştırmaya ve uygulamaya yönelik çıkarımlarına geçmeden

önce tüm çalışmalar için geçerli olan bazı noktalara dikkat çekilecektir. Bunlardan ilki, katılımcuların çoğunun kadın oluşudur. Genellikle ailede bakımveren rolünü kadınların üstlenmeleri sebebi ile benzer çalışmaların örneklemelerini genellikle kadınlar oluşturmaktadır (Pinquart & Sorensen, 2006). Diğer önemli nokta kültür konusudur. Çalışmanın bulguları kişilerin kültürel çerçeveleri içinde değerlendirilmelidir. Bunun sebebi, kültürün baş etme stratejilerini (Wong, Wong, & Scott, 2006), rolleri ve benlik algısını (Markus & Kitayama, 1991), duyguların ifade edilmesini (Davis ve ark., 2012) ve sosyal çevreyi (Kağıtçıbaşı, 2010) etkiliyor olmasıdır. Son olarak, katılımcılar ile ilgili edinilen genel izlenime göre bu sürecin onlar için bir kendini adama süreci olduğu, diğer her şeyin arka planda kaldığı, hayatlarındaki en büyük önceliğin çocuklarının iyileşmesi olduğu ve bundan umutlu olduklarıdır.

Yapılacak olan bakımveren araştırmaları için bakımverenin iyilik halinin çocuğun iyiliğini etkilediği (Wolfe-Christensen ve ark., 2010) göz önünde bulundurulmalıdır. Koruyucu ve risk faktörleri belirleme amaçlı ve müdahale programı geliştirme amaçlı çalışmaların devamının gerekli olduğu düşünülmektedir. Müdahale programı geliştirme amaçlı çalışmalar az sayıdadır, bu sayının artması için teorik çerçeveyi hastane ortamı gibi çevresel koşullarla birleştirebilmek, hedef grubun ihtiyaç ve önceliklerine uyum sağlayabilmek ve kültürel çevre koşullarını göz ardı etmemek önemlidir. Bu çalışmada detaylı bir şekilde aktarılan sorunlara (katılımcı kaybı gibi) benzer sorunlara hazırlıklı olunmalı, beklenmeyen sorunların da çıkabileceği unutulmamalıdır. Bunların yanı sıra bu çalışmalarda aralarında görev paylaşımının olduğu bir ekibe ve maddi kaynaklara sahip olmanın önemli olduğunun altı çizilmelidir.

Araştırmalara yönelik çıkarımların yanı sıra uygulama alanında da bir takım çıkarımlar yapılmıştır. Uygulamalarda yalnızca çocuğa odaklanmak, yalnızca bakımverene odaklanmak ve bir bütün olarak bakımveren-hasta çocuk sistemine odaklanmak önemlidir. Uygulamalarda her birinin hem ayrı ayrı ihtiyaçları, hem de aralarındaki ilişki üzerinde durulmalıdır. Tedavi ekibinde aktif olarak görev yapan bir psikoloğun bulunması önemlidir. Atılabilecek bazı adımlar şunlardır: Bakımverme süreci hakkında bilgilendirme, kişinin risk ve koruyucu faktörler açısından bireysel değerlendirilmesi, ortak sorunlara yönelik grup müdahale programları uygulama, bireysel ihtiyaçlar için bireysel müdahaleler ya da yönlendirmeler ve son olarak tedavi sonrası izleme.

Sonuç

Bu çalışma, kanserli çocukların bakımverenlerinde uyumu artırma gayesi ile baş etme süreçlerini farklı açılardan adım adım incelemiştir. İlk olarak bakımveren stresini yordayan etmenler Transaksiyonel Baş Etme Teorisi (Lazarus & Folkman, 1984) çerçevesinden incelenmiştir. İkinci olarak yapılan görüşmelerle niteliksel olarak bu süreçte kişilerin önemli bulduğu konular üzerinde durulmuştur. Son olarak pilot bir grup psiko-eğitim programı geliştirilmiş, uygulanmış ve pozitif ve negatif duygulardaki değişim incelenerek etkililiği test edilmiştir. Çalışmanın, bu ve benzer gruplarla çalışan araştırmacı ve uygulamacılar için önemli çıkarımları bulunmaktadır. Niceliksel ve niteliksel metodları bir arada kullanan, müdahale programları ile uyumu kolaylaştırmayı amaçlayan ve araştırmacı ve uygulamacı bakış açılarını birleştiren çok az sayıda çalışma bulunmaktadır. Bu nedenlerle bu çalışmanın sahip olduğu uygulama ve araştırma çıkarımları ile, baş etme sürecini detaylı bir şekilde incelemesi ile ve müdahale programı geliştirme, uygulama ve etkililiğini test etme örneği teşkil etmesi ile gelecekte yapılacak çalışmalara ön ayak olacağı düşünülmektedir.

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Degree	Institution	Year of Graduation
MS	Middle East Technical University, Department of Psychology	2008
BS	Middle East Technical University, Department of Psychology	2005

WORK EXPERIENCE

Year	Place	Enrollment
2013- Present	Atilim University, Department of Psychology	Instructor
2012-2013	Atilim University, Department of Psychology	Part-Time Instructor

FOREIGN LANGUAGES

Advanced English

PUBLICATIONS

- Demirtepe-Saygılı, D. & Bozo, Ö. (2011). Perceived social support as a moderator of the relationship between caregiver well-being indicators and psychological symptoms. *Journal of Health Psychology, 16*(7), 1091-1100.
- Demirtepe-Saygılı, D. & Bozo, Ö. (2011). Predicting depressive symptoms among mother caregivers of children with leukemia: A Caregiver Stress Model perspective. *Psychology & Health, 26*(5), 585-599.

Demirtepe-Saygılı, D. & Bozo, Ö. (2011). Correlates of depressive and anxiety symptoms among the caregivers of children with leukemia. *Journal of Clinical Psychology in Medical Settings*, 18, 46-54.

Demirtepe, D. & Bozo, Ö (2009). Bakıcı İyilik Ölçeği'nin uyarlama, güvenirlik ve geçerlik çalışması. *Türk Psikoloji Yazıları*, 12(23), 28-37.

Demirtepe, D. (2008). *Testing the caregiver stress model with the caregivers of children with leukemia*. Unpublished Master's thesis, Middle East Technical University.

AWARDS AND SCHOLARSHIPS

METU, Graduate School of Social Sciences 2008-2009 Academic Year Graduate Courses Performance Award

METU, The Foundation of Prof. Dr. Mustafa N. Parlar 2007-2008 Academic Year "METU The Thesis of the Year" Award

METU, Graduate School of Social Sciences 2007-2008 Academic Year "The Best Thesis" Award

The Scientific and Technological Research Council of Turkey (TÜBİTAK), National Scholarship Programme for PhD Students

TEZ FOTOKOPİSİ İZİN FORMU

ENSTİTÜ

Fen Bilimleri Enstitüsü

Sosyal Bilimler Enstitüsü

Uygulamalı Matematik Enstitüsü

Enformatik Enstitüsü

Deniz Bilimleri Enstitüsü

YAZARIN

Soyadı : Demirtepe Saygılı

Adı : Dilek

Bölümü : Psikoloji

TEZİN ADI (İngilizce) : Examination of the Coping Processes of Caregivers of Children with Cancer

TEZİN TÜRÜ : Yüksek Lisans Doktora

1. Tezimin tamamından kaynak gösterilmek şartıyla fotokopi alınabilir.
2. Tezimin içindekiler sayfası, özet, indeks sayfalarından ve/veya bir bölümünden kaynak gösterilmek şartıyla fotokopi alınabilir.
3. Tezimden bir bir (1) yıl süreyle fotokopi alınamaz.

TEZİN KÜTÜPHANEYE TESLİM TARİHİ: