TESTING THE CAREGIVER STRESS MODEL WITH THE CAREGIVERS OF CHILDREN WITH LEUKEMIA

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I hereby declare that all the information in this document has been obtained and presented in accordance with academic rules and ethical conduct. I also declare that, as required by these rules and conduct, I have fully cited and referenced all material and results that are not original to this work.

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ABSTRACT

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The aim of the present study was to investigate the relationship between the stressors of the caregiving process and the health related outcomes (depression, anxiety, and general psychological health) in caregivers of children with leukemia. Caregiver Stress Model was used as the conceptual framework for the study. In order to measure the stressors of the caregivers, caregiver well-being scale was adapted to Turkish culture as the study 1 by using the caregivers of family members with various chronic illnesses. The analyses showed that Turkish version of the caregiver well-being scale had satisfactory psychometric properties for Turkish caregivers. The sample of the study 2 was composed of 100 caregivers of children with leukemia, who were treated at oncology or hematology departments of hospitals in Ankara and İzmir, Turkey. Nine mediation models were tested using problem focused coping, emotion focused coping, and social support as mediators. The models included primary stressors (caregiving tasks and basic needs) and secondary stressors (interpersonal relationships and role strain) as independent variables; and depression, anxiety, and general psychological health as dependent variables. The findings suggested that emotion focused coping and social support were significant mediators of the relationships between the stressors and the outcomes, however, problem focused coping was not a significant mediator. Different patterns of significant relationships were found between the primary stressors, secondary stressors, and the outcome variables. However, caregiving tasks was not significantly predicting of any of the outcome variables. The strengths and limitations, as well as the implications of the findings, were discussed.

Keywords: Caregiver, leukemia, stress, depression, anxiety, health

ÖZ

LÖSEMİLİ ÇOCUKLARIN BAKICILARINDA BAKICI STRES MODELİNİN TEST EDİLMESİ

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Bu çalışmanın amacı lösemili çocukların bakıcılarında, bakıcılık sürecinin getirdiği strese sebep olan faktörler ve sağlıkla ilgili durumlar (depresyon, kaygı, genel psikolojik sağlık) arasındaki ilişkiyi incelemektir. Bakıcı Stres Modeli çalışmanın kavramsal çerçevesini oluşturmaktadır. Bakıcının strese sebep olan faktörlerini ölçmek amacıyla, 1. Çalışma olarak, bakıcı iyilik ölçeği Türk kültürüne uyarlanmıştır. Uyarlama çalışması çeşitli kronik hastalıkları olan aile bireyine sahip bakıcılar ile yapılmıştır. Bulgular, bakıcı iyilik ölçeğinin Türk versiyonunun Türk bakıcılar için yeterli psikometrik özelliklere sahip olduğunu göstermiştir. İkinci çalışmanın örneklem grubunu Türkiye'de Ankara ve İzmir'deki hastanelerin onkoloji ya da hematoloji bölümlerinde tedavi gören 100 lösemili çocuğun bakıcıları oluşturmaktadır. Problem odaklı başaçıkma, duygu odaklı başaçıkma ve sosyal destek aracı değişkenler olmak üzere 9 aracılık modeli test edilmiştir. Modeller, bağımsız değişkenler olarak strese sebep olan birincil faktörleri (bakıcılık görevleri, temel ihtiyaçlar) ve ikincil faktörleri (kişiler arası ilişkiler ve rollerde zorlanma); ve bağımlı değişkenler olarak da depresyon, kaygı ve genel psikolojik sağlığı içermektedir. Sonuçlara göre, duygu odaklı başaçıkma ve sosyal destek, strese sebep olan faktörler ve sağlık sonuçları arasındaki ilişkinin anlamlı aracı değişkenleridir. Ancak, problem odaklı başaçıkma anlamlı bir aracı değişken değildir. Strese sebep olan birincil faktörler, ikincil faktörler ve sağlık sonuçları arasında farklı anlamlı ilişki örüntüleri bulunmuştur. Ancak, bakıcılık görevleri hiç bir sağlık sonucunu yordamamıştır. Çalışmanın güçlü ve zayıf yönlerinin yanısıra, çıkarımlar da tartışılmıştır.

Anahtar kelimeler: Bakıcı, lösemi, stres, depresyon, kaygı, sağlık

To My Family

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"Success is measured not so much by the position one has reached in life, as by the obstacles one has overcome while trying to succeed." Booker T. Washington

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CHAPTER I

INTRODUCTION

According to the biopsychosocial model of Engel (1977), health and illness are affected by the interaction of biological, psychological, and social factors (cited in Nicassio and Smith, 1995). The model supplies a conceptual framework that has hierarchical subunits beginning from the cells and tissues, which cause the physical illness, to the community and the culture. There is interdependence between the systems, which means that in order to understand one part; the other parts must also be considered. The model was strengthened by the studies of chronic illnesses like dementia, AIDS, cancer, and mental illnesses (e.g. Neufeld & Harrison, 2003; Brannan & Heflinger, 2001).

Familial and social factors are one aspect of the illness system. On the part of the patient, changes occur in the social roles, relationships, daily life, and routines. Changes in the social and family relationships and daily life may affect not only the person himself/herself but also the environment. As it is stated in the model, the relationship is bidirectional. That is, the family is also affected by the circumstances that are created by the illness of the family member.

1.1. *Caregiver Health*

The impact of being caregiver had been studied by researchers for years and as a result of these studies being a caregiver is considered as a risk factor that makes the person vulnerable to some physical problems (e.g. Schultz & Beach, 1999 cited in Gopalan & Brannon, 2006), psychological problems (e.g. Cannuscio et al., 2002, cited in Gopalan & Brannon, 2006) and disruptions in social life (e.g. Harrison & Neufeld, 1997). It was found that caregivers reported less global health and take more medications for physical problems than non-caregivers. Their physiological reactions and hormone levels were also different from non-caregivers (Vitaliano, Young, & Zhang, 2004). In a study comparing caregivers and non-caregivers, it was found that caregivers experience more negative affect and sleep problems, and they are less satisfied with social support they receive (Brummett et al., 2006). Pinquart and Sörelsen (2007) reviewed the effects of caregiving on physical health for caregivers of elderly in a meta-analysis and concluded that the effects of stressors about caregiving are seen less on physical health than psychological health. Moreover, physical health was found to be affected more by feeling depressed than the objective levels of caregiving stressors. They also found that older caregivers and male caregivers are more prone to a worse physical health. In a study comparing women caregivers with non-caregivers, the caregiver group was found to have a worse overall well-being, social life, and marital satisfaction than non-caregiving women (Hoyert & Seltzer, 1992). Thus, the caregivers experience both psychological and physical health problems due to their caregiving obligations. Psychological and social problems experienced by caregivers will be further discussed in the following sections.

According to the social context perspective of illness, the patient with a chronic condition is evaluated in his/her primary social context, which is the family. It was found that disease management's success depends on the integration of individual, social, and community factors (Weihs, Fisher, & Baird, 2002). For example, Williamson, Walters, and Shaffer (2002) found that chronically ill children, whose mothers were more depressed, similar to their mothers, experience more depression. Thus, it was shown that health care studies should address not only the patient but also their caregivers, because the ill person lives in a system whose parts influence each other.

1.2. *Family Caregiver Studies*

In general, the caregiver studies can be divided into 4 by using different viewpoints: Deficit, resource, clinical course, and impact perspectives. The deficit perspective evaluates the family with an ill family member as a source of potential problems, which affects the family members in a negative way. The resource perspective declares that the family is a source of coping with the chronic illness because it provides the ill member both support and care. According to the clinical course perspective, different phases of treatment have different demands from the family and through the process; there may be rearrangements in the daily life, emotional climate in the house, and interpersonal relations. The impact perspective, on the contrary, studies the effects of the illness on the family rather than studying how the family affects the course of the illness (Steinglass, 2000).

Using one of or combinations of the perspectives mentioned above, caregiver studies examined variety of outcome variables. Some of the most frequently studied outcome variables are depression, anxiety, posttraumatic stress symptoms, marital satisfaction, quality of life, and physical health. (e.g. Given et al., 2004; Norberg, Lindblad, & Boman, 2006; Manne, Duhamel, & Redd, 2000; Dekel, Solomon, & Bleich, 2005; Earle & Eiser, 2007; and Vitaliano, Young, & Zhang, 2004).

Another subject of interest in caregiver research is what the caregivers experience throughout the caregiving process. Families, which form the informal caregiver group, were investigated longitudinally by researchers beginning from the diagnosis of the illness till the completion of the treatment or possible loss of the family member. According to Stress Coping Outcome Theory of Folkman (1984), diagnosis is an acute traumatic stressor and the treatment phase is a chronic stressor. Families may show posttraumatic stress symptoms at the diagnosis phase of the illness. After the diagnosis phase, the level of the stress decreases and stabilizes (Ow, 2003). According to one view, the level of stress is consistent at different time points. From the diagnosis through the treatment, the needs and the tasks of caregiving are decreased, however, the level of distress is independent of time, and similar stress levels are obtained when assessed at baseline, 12 month, and 18 month (Svavarsdottir, 2005). Another view asserts that the level of stress is prone to change in time. It was found that mothers' initial depressive symptoms decreased 6 months after diagnosis except for the group who has moderate to severe levels of depression. In this group, the level of depression was similar to the first administration of the measures (Manne, Miller, Meyers, Wollner, Steinherz, & Redd, 1996). Another study, conducted with the parents of children with cancer, measured distress levels at diagnosis, 6 months, 12 months, and 5 years later (Wijnberg -Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). The results showed that the level of psychological distress declined over time in a five-year period. However, the distress level was still higher than the control group, which means that some of the parents still experience distress after 5 years. Moreover, it was suggested that 6-month follow up measurements were the strongest predictor of later adjustment.

1.3. *Leukemia*

There are 1200-1500 new childhood cancer diagnoses below the age of 16 in Turkey per year (Lösev, n.d.). Among the all other types of illnesses, leukemia is on the 9th order with 1.5 % in the list of 20 causes of death (Hıfzısıhha Mektebi Müdürlüğü, 2000). While in the United Kingdom, 25% of all childhood cancer cases is leukemia (Cancer Research UK, 2004, cited in Earle & Eiser, 2007) the percentage of the illness for Turkey is 30% (Kaçuv, n.d.).

Generally, the treatment for leukemia begins with chemotherapy and continues with consolidation and maintenance therapies. Sometimes bone morrow transplantation is applied. The treatment lasts for about 2-3 years. The next 2-3 years is important for the early diagnosis of relapse. Therefore, the monthly controls continue after the completion of the treatment and the frequency of control examinations declines over time (Woznick & Goodheart, 2002).

The diagnosis is considered as a family crisis for all of the family members. While some parents are able to adapt to the new situation, the others are not. In other words, there is an individual variation. Extensive research has been made on the factors that make the adjustment more difficult or help for better adjustment (Hoeksta-Weebers et al., 2000) and many models were proposed trying to explain the adaptation process. According to the Family Systems Approach (McCubbin &

Patterson, 1983) there is an interaction between the family's existing resources and the crisis situation. After this process, an adaptation process begins in order to form a new balance. Hare, Skinner, and Kliewer (1989) tried to explain bone marrow transplantation process, a treatment option for some leukemia patients, with family systems approach. The bone marrow transplantation process is evaluated as a new stressor for the family, who already had stressors and responsibilities beforehand. Likewise, they had social and material strengths before the appearance of the new stressor. By combining the existing stressors and strengths, each family perceives the new situation differently and then, the family experiences an adjustment phase. The adaptation phase begins in which the family systems change and achieve a new balance point. The demands like financial problems, problems with the existing roles and responsibilities, existing and new resources, and the perception of the new situation influence the coping process. A successful outcome includes strengthening the existing coping strategies and adding new ones to the previous ones.

1.4. *Negative Factors*

There are several studies investigating the factors that make the adjustment difficult and end up with worse physical and psychological health. Some of these factors making the adjustment more difficult (e.g. some demographic variables like age, gender and SES; child characteristics; interpersonal/social factors; caregiving tasks; social roles; illness characteristics) will be mentioned in the following paragraphs.

1.4.1. *Demographic Variables*

The most important demographic predictor of the caregiver stress is age. It was found that as the age gets younger, the level of stress increases (Matthews, Baker, & Spillers, 2003). Gender is an important factor predicting distress of the caregivers, too. There are two issues explaining why gender is important. Firstly, women are expected to be more prone to experiencing stress (Yeh, 2002). And secondly, it is culturally expected that the women take the caregiving role (e.g. Gopalan & Brannon, 2006). This notion was supported by several studies. For example, compared to fathers, mothers of children with cancer were found to experience more depression and lower mental health (Essen, Sjöden, & Mattsson, 2004). There are also differences in the attribution styles during the adaptation process between males and females. Affiliation related attributions, that is, relationships and social network were the predictors of psychological outcomes for mothers of children with cancer, whereas achievement related attributions were predictors of psychological outcomes for fathers only (Frank, Brown, Blount, & Bunke, 2001).

A third factor impacting on caregiver stress is socioeconomic status (SES). It was found that less family income predicts more parenting stress in the caregivers of sickle cell disease (Barakat, Patterson, Tarazy, & Ely, 2007). A study, conducted with low SES group in a developing country, examined the predictors of emotional responses of the families. The most important concern of the families was provision of the necessary time and expenses (Rocha-Garcia et al., 2003). Similarly, another study revealed that the management of the economic problems increases the emotional stress. Besides, it interrupts with the process of coping with the chronic condition (Holmes & Deb, 2003).

In conclusion, the studies conducted with caregivers of various illness types revealed that the demographic variables, such as age, gender and SES play an important role in predicting caregiver stress.

1.4.2. *The Ill Child /Child Characteristics*

Child related characteristics play an important role for the caregivers. Child's age is one of the most important child related factors in the following ways. First, the developmental demands change with age that may in turn affect the tasks. Caregivers of younger children are responsible for the care of their children, whereas, as the child's age increases he/she becomes responsible of his/her own self-care. When the child becomes ill and requires care, the number of tasks increases for the caregivers of younger children. However, for the mothers of older children, the tasks are less in number. Regardless of the number of tasks, this influences the caregivers in a way that the caregivers of adolescents experience more distress, because tasks are seen as a routine part of the child care in the case of preschool ages (Barakat, Patterson, Tarazy, & Ely, 2007).

Second, child's age influences the reactions to the treatment requirements and the perception of the illness. Children at different ages react differently during the treatment. According to the results of a qualitative study; as the age of the child increases, owing to the increased awareness, difficulties for the caregiver arise. Mothers reported that the children at preschool period can cope well, whereas the children between the ages 5 and 9 experience more problems about school, the illness, and their future life. Children between the ages of 10 and 14 were the most problematic age group according to mothers' reports. They expressed their concerns about the illness and have problems in their social life (Earle & Eiser, 2007). Another study, comparing caregivers of two age groups, namely; preschool and adolescence, revealed that illness related caregiving stress was significantly more with the parents of adolescents than the parents of preschoolers (Barakat, Patterson, Tarazy, & Ely, 2007).

Another child related factor is at behavioral domain. It is found that general childrearing practices and the behavioral problems of the ill child predict the problems with the caregiving tasks regardless of child's age, prior treatment problems, and the functional impairment (Manne et al., 1999). Another study revealed that behavioral problems of the child predict mother's mental health (Sales, Greeno, Shear, & Anderson, 2004). Moreover, a pathway was found between children's emotional problems and mothers' mental health in which mothers' caregiving strain act as a mediator (Sales, Greeno, Shear, & Anderson, 2004).

1.4.3. *Interpersonal/Social Factors*

The chronic illness impacts on the social life of the whole family. There are changes in the interpersonal relationships that influence both the patient and the caregiver. Because of the time and the energy dedicated to treatment and caregiving, they need to rearrange their daily lives and social activities. Decrease in contact with others, planned activities; and decreased time for social activities are predictors of distress in cancer caregivers (Matthews, Baker, & Spillers, 2003).

Another dimension of interpersonal relations is non-supportive environment. Non-supportive relationship is an important factor contributing to the health related outcomes. It is defined as the negative contents of interactions rather than lack of relationships (Neufeld & Harrison, 2003). In other words, it is more than the absence of social support. It has a detrimental effect on the health of the caregiver (Harrison, Neufeld, & Kushner, 1995). It includes conflicts, unhelpful speech and behaviors, and ineffective help attempts. This concept was first used for the caregivers of elderly with dementia or Alzheimer's disease, and then adapted to the caregivers of children with chronic conditions (Patterson, Garwick, Bennett, & Blum, 1997). They emphasized that having a network does not necessarily mean getting social support. Sometimes, hurtful attitudes and behaviors may act as an additional source of stress. According to parents, there are three areas of non-supportive attitudes: Communication, comparison of the child with other children, and the avoidance of talking about the problem. Generally, the comments or attitudes include what is perceived rather than what is said.

Another consequence of the non-supportive environment is that it holds back the caregiver talking about the cancer caregiving experience. This concept is conceptualized as perceived social constraints by Pennebaker (Pennebaker, 1989 cited in Manne, Duhamel, & Redd, 2000). Pennebaker defined the perceived social constraint as the perceived unsupportive responses that affect people's disclosure in a negative way. It was found that perceived social constraint was related to greater post-traumatic stress symptoms in mothers of children who completed cancer treatment successfully (Manne, Duhamel, & Redd, 2000).

1.4.4. *Tasks of Caregiving*

Caregiving tasks and difficulties in fulfilling them is another source of stress. It was found that the most time and energy consuming task performed by both the mothers and fathers is the provision of emotional support to the child and supporting other children (Svavarsdottir, 2005). In a study, trying to explain the predictors of depression in caregivers of cancer patients, demands of care and the employment status of the caregiver were found as the strongest predictors of depression (Given et al., 2004).

1.4.5. *Social Roles*

Caregiving adds a new role to the social roles of the caregiver. There are two perspectives in terms of the effects of having multiple roles on the psychological well-being. According to the depletion perspective, the energy and resources of the person are limited. Thus, the person is able to fulfill a limited number of tasks. Therefore, the addition of new tasks results in stress. On the contrary, the enrichment model (Hobfoll, 1988, 1989 cited in Bainbridge, Cregan, & Kulik, 2006) suggested that energy and resources are flexible and new roles give the person the chance of personal growth and satisfaction. Having the roles of both an employee and a caregiver is a positive factor in a way that the person is able to balance the loss of energy and resource resulting from caregiving with gaining energy and resources with additional roles (Bainbridge, Cregan, & Kulik, 2006). In the study of Bainbridge, Cregan, and Kulik (2006), the interaction of disability type and working hours had an impact on caregiver stress, whereas work hours had no main effect contrary to both depletion and enrichment perspectives. Therefore, competing roles created either a positive or a negative impact on the person depending on what the role is and what it requires (Kim, Baker, Spillers, & Wellisch, 2006). That is, if the person does not have an additional parenting role and perceives being employed as a way of renewing the resources, it creates a beneficial effect. However, if the person has both the role of parenting other children and the role of being employed, it creates a strain. Consequently, the effects of having multiple roles are more meaningful when the interactions with other factors are taken into account.

1.4.6. *Illness Characteristics*

The illness characteristics are also important in predicting psychological well-being of the caregivers. Some of the illness characteristics are being an acute or chronic illness, being a life-threatening illness, requirement of hospitalization, type of the medication, and medical needs of the patient.

In a study comparing the mothers of children with cancer who were diagnosed in the last 6 months and the mothers of children with acute illnesses, it was found that the former group experienced more depression than the latter one (Barrera, D’agostino, Gibson, Gilbert, Weksberg, & Malkin, 2004). Mothers of children diagnosed with cancer did also report using emotion focused coping strategies more than the mothers of children with acute illnesses, which can possibly be explained by the uncertainty and life-threatening nature of the cancer.

Another study compared the caregivers of children with two different chronic illnesses: parents of children with cancer and parents of children with type 1 diabetes mellitus (Fuemmeler, Mullins, Pelt, Carpentier, & Parkhurst, 2005).

Diabetes was chosen because it has potential complications, is not perceived as life-threatening, and requires continuous care. It was found that 32% of parents of children with cancer met the DSM-IV criteria for post-traumatic stress disorder, while this rate was 10% for the parents of children with diabetes.

The attribution of the family with a member with cancer has also effects on the psychological well-being of both the family and the patient. Meaning of cancer experience was found to be a predictor of fear of recurrence of cancer (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007). According to this study, both caregivers and patients who attribute more positive meanings to the cancer experience had significantly less fear of cancer reoccurrence.

A longitudinal qualitative study, which was conducted with mothers of children with leukemia, revealed that continuation of a normal life is difficult both for the child and the mother. Because of the treatment, the infection risk, and potential behavior problems of the child; school attendance and social life is hard to achieve for the child. The economic burden, problems at work, and restriction of social life makes a normal life difficult to achieve for the mothers, too. A rearrangement process gives better results rather than trying to continue the daily life before the diagnosis and treatment (Earle, Clarke, Eiser, & Sheppard, 2006). Thus, the illness characteristics are important for a successful adaptation process for the caregivers.

1.5. *Positive Factors*

There are factors that make the adjustment easier and decrease the negative effects of the caregiving. The crisis itself can be viewed as an opportunity for the family to get together and strengthen the relationships (Chao et al., 2003). Some positive factors, such as coping and social support are also thought to be factors that make the caregivers' adjustment easier and buffer for the negative effects of the caregiving.

1.5.1. *Coping*

Coping is studied by several researchers in the caregiving literature as a predictor or a mediator of distress and burden (e.g. Folkman & Lazarus, 1984; Pruchno & Resch, 1989 cited in Patrick & Hayden, 1999). It was found that problem focused coping is negatively related to caregiver burden (Patrick & Hayden, 1999). Similarly, problem solving ability of the caregiver of a physically disabled family member was found to be a predictor of better adjustment and less depression (Elliot & Shewchuk, 2003). It was revealed that usage of more emotion focused coping is related to higher levels of post traumatic stress symptoms and general psychological distress in the parents of children with cancer and diabetes (Fuemmeler, Mullins, Pelt, Carpentier, & Parkhurst, 2005).

When coping styles were investigated longitudinally, it was found that problem focused coping is most effective at the initial phase, which requires searching and learning more about the illness and treatment (Hoekstra-Weebers, Jaspers, Klip, & Kamps, 2000). The same study did also reveal that there may be changes in the coping styles as the treatment progresses; and the chosen coping style influences distress at that particular time. That is, previous coping styles did not have an effect on the current level of distress.

In a meta-analysis, it was stated that there were different results about the effects of coping on the psychological well-being of caregivers of children who had cancer. Some studies found no relationship between coping strategies and psychological outcomes (e.g. Barbarin & Chesler, 1984; Baskin, Forehand, & Saylor, 1985, cited in Grootenhuis & Last, 1997). On the other hand some studies (Wittrock, Larson, & Sandgren, 1994, cited in Grootenhuis & Last, 1997) found that disengaged coping styles and emotion focused coping were related to more depression and anxiety symptoms. Thus, studies examining the effect of coping styles on he psychological well-being of the caregivers are conflicting with each other.

1.5.2. *Social Support*

Social support is a very important factor in the stress literature and this is valid for the caregivers of children with chronic illnesses, too. There are three views about how social support affects psychological outcomes. According to the first view, social support directly affects the psychological outcome regardless of the level of stress (e.g. Kessler & Essex, 1982, cited in Quittner, Glueckauf & Jackson, 1990). In other words, social support has a main effect on the psychological outcome variables. The second view is the buffer model that claims that social support has an interaction effect with stressors. People with high levels of stress and who has social support experience less negative outcomes. This is parallel to the stress buffer hypothesis (Cohen & Willis, 1985). According to this model, people with strong social support tend to have better health than those with weak social support, but only with respect to exposure to stressors. The third view assumes a mediating effect of social support. Social support is between the stressors and the outcomes in the pathway (Quittner, Glueckauf & Jackson, 1990).

Norberg and colleagues (2006) found that seeking social support as a coping strategy predicts lower levels of anxiety and perceived support strengthens the relationship between coping and anxiety. The significance level is stronger for mothers than fathers, which validates the gender difference mentioned before. Another study which was conducted with mothers of deaf children revealed that the mothers of deaf children reported less social support than the control group whose children are not deaf. It was also found that the relationship between the distress symptoms and maternal adjustment was mediated by social support (Quittner, Glueckauf, & Jackson, 1990).

Families need support in different areas like informational, social, and practical areas (Lazarus & Folkman, 1984 cited in Mitchell, Clarke, & Sloper, 2006) and get support from different agents. The most important support agents are partner, family, friends, the medical team and people experiencing similar conditions. Partner support was reported as both a source of emotional support, which helps the caregivers of children with leukemia in coping and a source of practical support. Practical support is a result of new role arrangement in the house. The responsibilities of spouses are shared after the diagnosis of leukemia. Family and friend support, especially in practical areas at the diagnosis and beginning of the treatment, is an important factor in helping the caregivers (McGrath, 2001). The relationship of both the ill child and the family with the medical team is another important source of support. However, social support from the health care team is lost when the hospitalization ends. Thus, there are changes in the social support provided by the medical team (Bloom, 2000). Another important source of support comes from people who are in the same condition, that is, the caregivers who met at hospitals during the treatment. They can form a network and follow the treatment phases of each other, although relapse of another child can be a challenging situation for the others (McGrath, 2001).

When the social support is investigated longitudinally from the diagnosis to the end of the treatment, it can be said that social support from extended family, friends, and neighbors are independent of the treatment stage. In other words, it is equally needed at any stage of the treatment (Bloom, 2000). However, the degree of support provided may change in time. McGrath (2001) suggested that the level of support offers decline over time.

1.6. *Caregiver Stress Models*

Stress is a result of a complex process that includes the interaction of internal and environmental factors. Trying to explain the question of why some caregivers can adjust well, while some others cannot, researchers developed models including both internal and environmental factors (Raina et al., 2004). Two of these models are Family Systems Approach developed by McCubbin and Patterson (1983), which was mentioned before, and Caregiver Stress Model (Pearlin, Mullan, Semple, & Skaff, 1990). Family systems approach (McCubbin & Patterson, 1983) tries to explain the interaction of the stressors and resources as a process, that is, it includes the period from pre-diagnosis to post-treatment. The second model which will be mentioned in the following section is the caregiver stress model (Pearlin et al., 1990), which also includes the stressors and strengths as an interaction process.

1.6.1. Caregiver Stress Model

Caregiver stress model (Pearlin et al., 1990) is one of the models that includes an integration of positive and negative factors that influence caregivers who have a family member with a chronic illness (see Figure 1). According to the caregiver stress model (Pearlin et al., 1990), caregiving is a process composed of many conditions and the outcome is the result of the interaction of these conditions. There are four main domains in the model: The background and context of stress, the stressors, stress mediators, and the outcomes. The background characteristics are age, education level, SES, and caregiving history (relationship to the patient, length of caregiving, use of programs etc.).

According to the model, there are two types of stressors. Primary stressors are the caregiving tasks, functioning of the patient, problematic behaviors of the patient, and the daily needs. The problematic behaviors and difficulties in satisfying the needs are more effective in creating stress than the caregiving tasks and the daily needs. This was verified for the caregivers of elderly in Pearlin and colleagues' study (1990). Primary stressors do also include the overload felt by the caregiver (fatigue, restlessness etc.) and the relational deprivation (absence of or decrement in the caregiver- patient relationship), that are subjective. The secondary stressors, however, are role strains and intrapsychic strains. Role strains include hardships in tasks that need to be completed by the caregiver apart from the caregiving like the job, economic problems, and social life. Intrapsychic strains, on the other hand, are the problems about the self concept. It includes self-esteem and mastery as the global domain; and loss of self, role captivity, competence, and gain as the situational domain. As the caregiving demands and role strains increase, the self concept is

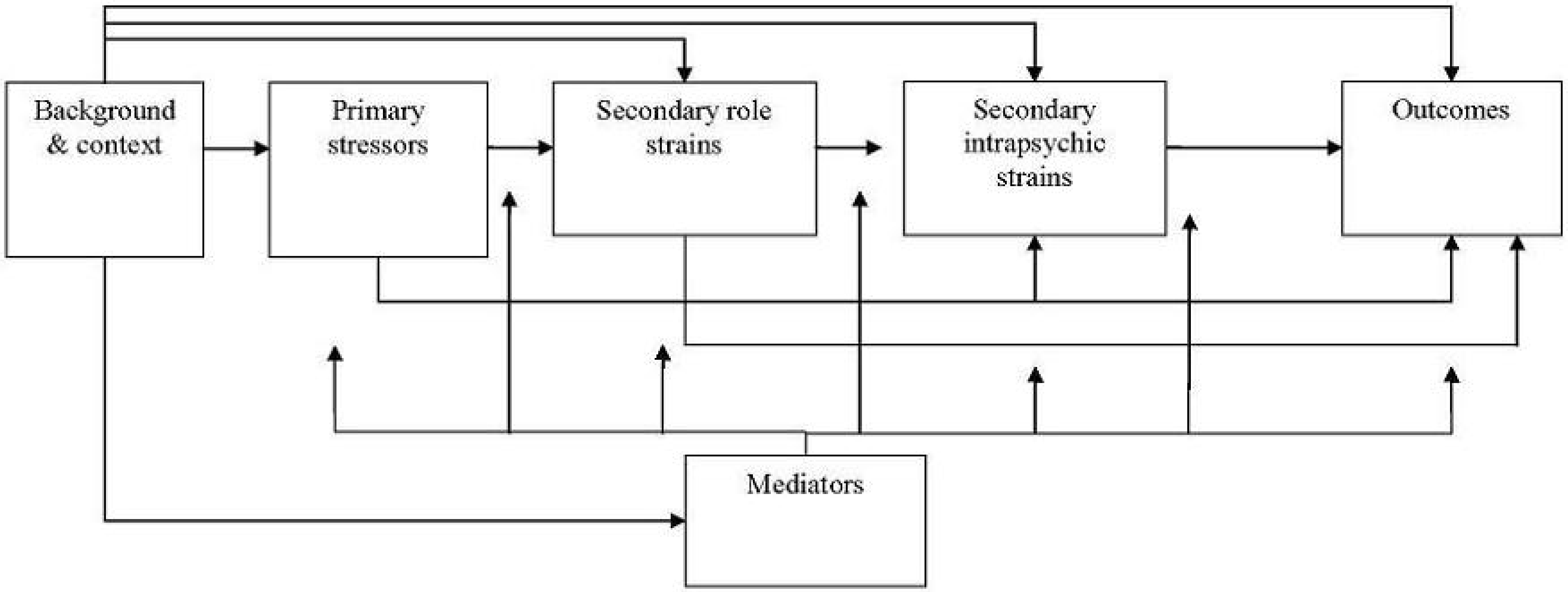


Figure 1. Caregiver Stress Model

Source: Pearlin et al., 1990.

affected negatively. As a result, the person becomes more vulnerable to stress. That is, intrapsychic strains arise from primary and secondary stressors and they influence both the primary and secondary stressors in turn. Thus, there is bi-directional relationship between intrapsychic strains, and primary and secondary stressors.

The mediators of the caregiver stress model (Pearlin, et al., 1990) are coping and social support that were validated by many studies some of which were mentioned above (e.g. Nelson et al., 2003; Norberg et al., 2006). The mediators have an effect on the relationship between the stressors and the outcome. Coping affects the relationship in three possible ways: by managing the situation that creates stress; by evaluating the meaning of the stress; and by handling the stress symptoms. Social support, another mediator in the caregiver stress model (Pearlin et al., 1990), has a buffering effect on stress. Particularly, it helps the secondary stressors to diminish or not to appear at all.

According to the model, the outcomes include the physical and psychological well-being of the caregiver. While the psychological health outcomes include depression, anxiety, cognitive disruptions, and irritability; physical health outcomes include limitations in physical actions and injuries. The most important part of the model is that it evaluates the stress as an interacting process, rather than a unique situation or event. It also includes not only the possible stressors, but also the resources and strengths, which help us to understand the powerful parts of the caregivers that help them to cope.

1.6.1.1. *Studies about Caregiver Stress Model*

The caregiver stress model (Pearlin et al., 1990) was first developed for the caregivers of patients with Alzheimer's disease. Further studies have been conducted applying the model to the caregivers of people with other chronic conditions, such as AIDS (Pearlin & Mullan, 1994; Stetz & Brown, 2004), cancer (Matthews, Baker, & Spillers, 2003), and developmental disabilities (Raina et al., 2004). The aims of these studies were to understand which stressors affect the outcomes more and how the process progresses over time.

Researchers tested the model with the caregivers of people with dementia combined with the effect of institutionalization and duration of caregiving emphasizing the role captivity. Role captivity was defined as feeling an obligation to meet the needs of an unwanted role. The important part is not the difficulties of the role; but the unwanted nature of the role. It was stated that being in an unwanted caregiver role creates more distress than the tasks of the caregiving. It was also found that as the time of caregiving decreases, the role captivity is reduced (Aneshensel, Pearlin, & Schuler, 1993).

The effects of care demands and role overload are the stressors which are open to change in time. As the illness gets worse, the difficulty of caregiving tasks may increase, which results in a change in the role overload felt by the caregiver. Therefore, studies exploring the long term effects are important to understand the changes in the stressors. To illustrate, Gaugler, Davey, Pearlin, and Zarit (2000) examined longitudinal effects of care demands and role overload on depression. Behavior problems and dependency in the activities of living of the elder patients predicted more role overload. The behavior problems were found to be particularly important in predicting well-being over time.

The model is open to the influence of culture, because culture-specific meanings of caregiving may influence the stress outcomes (Gotay, 2000). The model was tested in a study conducted in a different culture than American culture (Lee, Kim, & Kim, 2006). The Korean caregivers study revealed similar results to the ones conducted in American culture. Thus, the caregiver stress model (Pearlin et al., 1990) was found to be valid for different cultures.

In a study applying the model to the caregivers of adults with different cancer types, the following results were obtained: Young, employed, and socioeconomically challenged caregivers experienced more fatigue. Besides, people using emotion focused coping reported more difficulties in care responsibilities. In addition, the duration of the caregiving was correlated with distress. That is, if the duration of caregiving is longer, then the level of the stress is higher. Resources of the caregivers were found to impact on the stress level, too. The increment in the caregiving demands was parallel with the need for social support. People, who received social support, were more positive with managing the caregiving tasks. Therefore, the mediating effect of social support mentioned above, was verified by the study (Gaugler et al., 2005).

As it was mentioned before, the caregiver stress model (Pearlin et al., 1990) was developed originally for the caregivers of Alzheimer's disease patients. In the present study, this model will be tested on the caregivers of children with leukemia in a Turkish sample. Besides changing the sample, some adjustments were made in the model. The primary stressors that were included are caregiving tasks, difficulty in fulfilling these tasks, and the basic needs of the caregiver herself/himself. The secondary stressors used in the present study were role strains and problems in interpersonal relationships. The intrapsychic strains, which are one of the secondary stressors, were not included. Role strains were defined by Pearlin and colleagues (1990) as deficiency in activities outside the caregiving job. Although problems in interpersonal relationships, namely, non-supportive relationships and illness related interpersonal problems were not included in the original model, they were included in the present study. This arrangement was necessary for the present study that has a different sample. The original model was designed for the caregivers of elderly with Alzheimer's disease, whereas the present study was conducted with the caregivers of children with leukemia. The problems in interpersonal relationships were included in the secondary stressors part, because it is not a direct consequence of having the illness. According to the model, the stressors which do not directly stem from the illness and caregiving are included in secondary stressors. In the present study, the mediators, which are social support and coping strategies, are the same with the original model. Depression, anxiety, and general psychological health are the outcome variables. The modified caregiver stress model used in the present study can be seen in Figure 2.

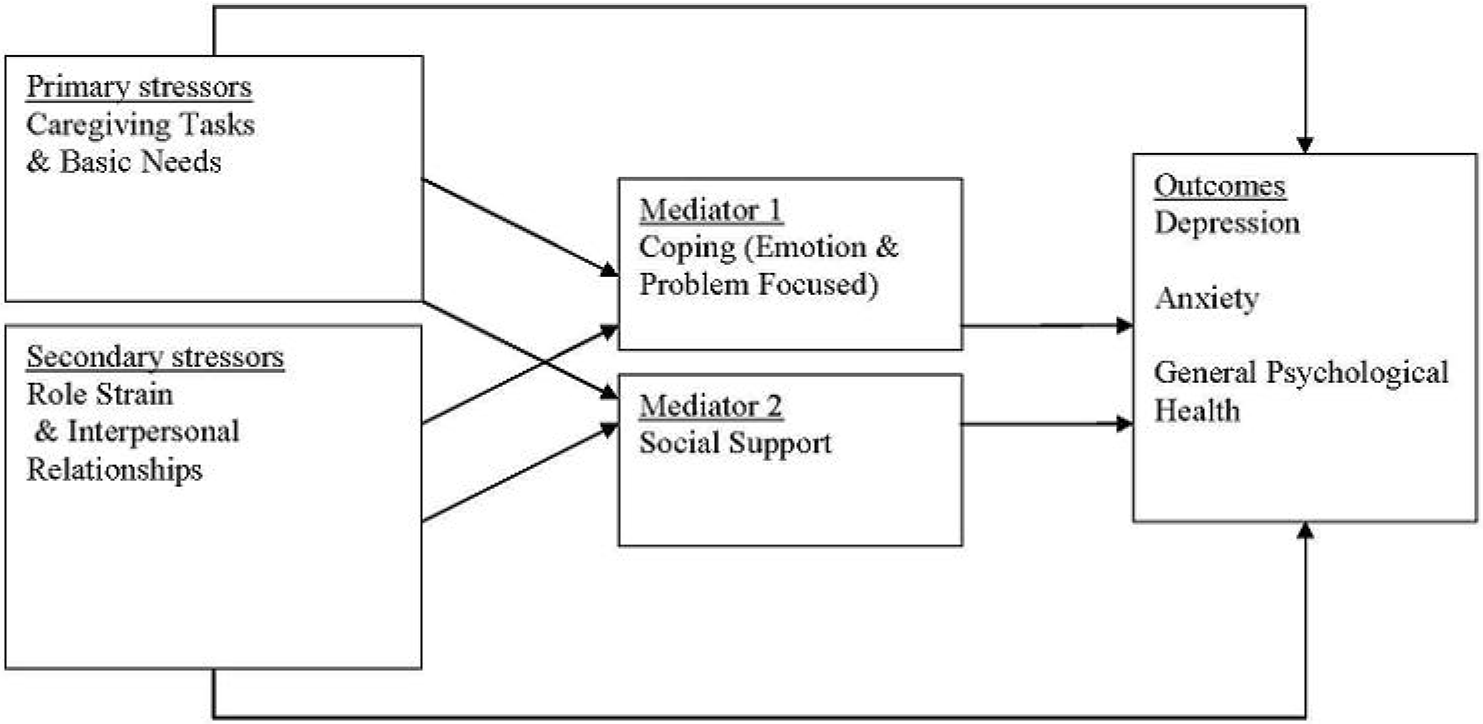


Figure 2. The path model of the present study.

1.7. *Caregiver Studies in Turkey*

There are limited numbers of studies conducted with the caregivers of cancer patients in Turkey. Okyayuz (2004) compared depression, anxiety, family functioning, and the level of emotional suppression in families of cancer patients, Behçet's disease patients, and a control group. It was found that depression, anxiety, and emotional suppression levels of the families of cancer patients were the highest among the three groups. However, in terms of family functioning, there was no difference among the groups. In another study conducted as a master's thesis (Kocaoğlan, 2003), the effect of childhood cancer on marital adjustment of parents was studied. It was found that as the number of previous hospitalizations of the ill child and the support received from the spouse increased, the marital adjustment increased, as well.

1.8. *Aims of the Present Study*

In general, this study aims at finding out the predictors of psychological health of caregivers of children with leukemia. The potential predictors are chosen in the light of the caregiver stress model including the caregiving tasks and basic needs of the caregiver, as primary stressors that are objective; role strain and problems in interpersonal relations, as secondary stressors that are subjective; coping strategies and social support, as mediators.

Specifically, the aim of the present study is to test the caregiver stress model (Pearlin et al, 1990) with the caregivers of children with leukemia in a Turkish sample. By using two mediator variables (i.e. coping and social support) and three outcome variables (i.e. depression, anxiety, and general psychological health) 9 mediation models will be tested. Based on the all of the findings mentioned above, the hypotheses are: (1.a.) as the primary stressors (caregiving tasks and basic needs) increase, depression will increase as well; (1.b.) as the primary stressors (caregiving tasks and basic needs) increase, anxiety will increase as well; (1.c.) as the primary stressors (caregiving tasks and basic needs) increase, general psychological health will decrease; (2.a.) as the secondary stressors (role strain and interpersonal relationships) increase, depression will increase, as well; (2.b.) as the secondary stressors (role strain and interpersonal relationships) increase, anxiety will increase, as well; (2.c.) as the secondary stressors (role strain and interpersonal relationships) increase, general psychological health will decrease; (3.a.1.) problem focused coping will mediate the relationship between primary and secondary stressors and depression; (3.a.2.) problem focused coping will mediate the relationship between primary and secondary stressors and anxiety; (3.a.3.) problem focused coping will mediate the relationship between primary and secondary stressors and general psychological health; (3.b.1.) emotion focused coping will mediate the relationship between primary and secondary stressors and depression; (3.b.2.) emotion focused coping will mediate the relationship between primary and secondary stressors and anxiety; (3.b.3.) emotion focused coping will mediate the relationship between primary and secondary stressors and general psychological health; (4.a.) Social support will mediate the relationship between primary and secondary stressors and depression; (4.b.) social support will mediate the relationship between primary and secondary stressors and anxiety; (4.c.) social support will mediate the relationship between primary and secondary stressors and general psychological health.

In order to test the hypotheses of the present study, before conducting the main study, a preliminary study will be conducted to adapt the Caregiver Well-Being Scale (Berg-Weger, Rubio, & Tebb, 2000) to Turkish culture.

CHAPTER II

STUDY I

The aim of study 1 is to adapt the caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000), which will be used to measure the basic needs of the caregiver, which is one of primary stressors, and role strain, which is one of secondary stressors. The Caregiver Well-being scale was developed by Tebb (1995) and further studies were conducted (Rubio, Berg-Weger, & Tebb, 1999; Berg-Weger, Rubio, & Tebb, 2000) to examine the psychometric properties of the scale. The aim of the scale was identifying caregivers' needs, deficiencies and strengths. It uses a strength-based perspective focusing on the resources, positive features, and support, so that the social workers could enhance the caregivers in a better way (Berg-Weger, Rubio, & Tebb, 2000).

2.1. *Method*

2.1.1. *Participants*

One hundred individuals participated in the Study 1. Fifty of these individuals were the caregivers of chronically ill patients (*N* = 50; 47 women, 94%;

3 men, 6%), and 50 of them were non-caregivers, who constituted the control group (*N* = 50; 47 women, 94%; 3 men, 6%). While more than half of the caregivers were mothers (*n* = 33, 66%), the rest were daughters (*n* = 12, 24%), spouses (*n* = 3, 6%), a sibling (*n* = 1, 2%) and a father (*n* = 1, 2%). The age of the caregivers ranged between 20 and 56 with the mean of 39.97 (*SD* = 8.38). Thirty percent of the sample had a lower perceived family income (*n* = 15) while 56% perceived their family income as middle (*n* = 28) and 12% upper (*n* = 6). The education level of the sample was as follows: 34% primary school (*n* = 17), 18% secondary school (*n* = 9), 28% high school (*n* = 14), 12% university (*n* = 6) and 4% graduate school (*n* = 2) graduates. The mean length of caregiving was 84.17 month (*SD* = 60.99, range = 2 - 264). The individuals in the caregiver group were taking care of the patients with different illnesses. Some of them were people with developmental (*n* = 31, 62%) or physical disabilities (*n* = 14, 28%) and some of them were people who need post-operational care (*n* = 5, 10%).

The control group represented the non-caregiver group (*N* = 50, 50%) with the age range of 23 and 59 (*M* = 39.88, *SD* = 8.94). The sample characteristics of the caregiver and non-caregiver groups were presented in Table 1.

Table 1

Demographic Characteristics of the Sample of Study 1

	Caregiver Group		Control Group	
	N	%	N	%
Relationship to the patient				
Mother	33	66	-	-
Spouse	3	6	-	-

Table 1 (Continued)

	Caregiver Group		Control Group	
	N	%	N	%
Daughter	12	24	-	-
Father	1	2	-	-
Sibling	1	2	-	-
Perceived family income				
Lower	15	30	2	4
Middle	28	56	32	64
Upper	6	12	14	28
Education				
Primary school	17	34	5	10
Secondary school	9	18	0	0
High school	14	28	16	32
University	6	12	28	56
Graduate	2	4	0	0
Occupation				
Unemployed	6	12	21	42
Employed	38	76	19	38
Marital status				
Single	2	4	1	2
Married	45	90	48	96
Widowed	1	2	0	0
Divorced	2	4	1	2

2.1.2. *Measures*

The questionnaire set used in study 1 included demographic information form, The Caregiver Well-Being Scale (Berg-Weger, Rubio, & Tebb, 2000), Mental, Physical and Spiritual Well-being Scale (Vella - Brodrick & Allen, 1995), and Beck Depression Inventory (Beck, Rush, Shaw, & Emery, 1979).

2.1.2.1. *Demographic Information Form*

The demographic information form was composed of two parts (See Appendix A). The first part included questions about age, gender, education, occupation, marital status, and perceived family income. In the second part, there were questions about the illness and the caregiving process, such as, the relationship to the patient, duration of caregiving, and the presence of other caregivers. The non-caregiver version of the form included the first part. Only, the number of people that the person has to look after, being diagnosed with physical and psychological illnesses, and any medication prescribed were also asked both to the caregiver and the non-caregiver group to control for their confounding effects.

2.1.2.2. *The Caregiver Well-Being Scale*

This scale aims to evaluate the basic needs and daily activity needs of the caregivers (Berg-Weger, Rubio, & Tebb, 2000) (See Appendix B). It measures the level of daily functioning in the presence of the caregiver role. There are two subscales of the scale, which are 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 or personal growth. The internal consistency reliability of the subscale is .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, such as having a hobby. The internal consistency reliability of the activities of living subscale measured by Cronbach Alpha is .81. The correlation coefficient between the two subscales was found .69, indicating the convergent validity of the subscales. By examining the correlations of basic needs and activities of living subscales with caregiver strain, measured by Caregiver Strain Inventory (Robinson, 1983, cited in Berg-Weger, Rubio, & Tebb, 2000), a moderate discriminant validity was found (r = .30 and r = .29 respectively) (Berg-Weger, Rubio, & Tebb, 2000).

2.1.2.3. *Mental, Physical and Spiritual Well-Being Scale*

In order to measure general well-being of the participants, Mental, Physical and Spiritual Well-being Scale (MPS well-being scale) (Vella - Brodrick & Allen, 1995) was used (See Appendix C). MPS Well-Being Scale aims to measure well-being in 3 dimensions, namely; mental, physical, and spiritual, which represent the holistic approach of health combining mind, body, and spirit (Vella - Brodrick & Allen, 1995). The internal consistency of the subscales ranged from 0.75 to 0.85. There are 30 items (10 items for each subscale) with a 5-point Likert type scale ranging between “never” and “always”. The aim of the scale is to measure the behaviors rather than the feelings and opinions that are subjective.

The aim of using MPS well-being scale in the present study is to measure the convergent validity by looking at the relation between caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000) and MPS well-being scale (Vella - Brodrick & Allen, 1995). To illustrate, it was hypothesized that as the scores on caregiver well-being scale increases, general well-being of the caregivers will increase, as well.

2.1.2.4. *Beck Depression Inventory*

This scale was developed by Beck, Rush, Shaw, and Emery (1979), and adapted to Turkish by Hisli (Hisli, 1988 cited in Savaşır & Şahin, 1997). It includes 21 items about how the person felt last week (See appendix D). The inventory includes somatic, cognitive, motivational, and emotional symptoms. The person rates himself/herself on a 4 point scale ranging between 0 and 3. As the score on this inventory increases, the level of depressive symptoms increases.

2.1.3. *Procedure*

The original version of the scale was translated to Turkish by 3 independent translators. The items that represent the original ones best were chosen and then translated back to English by a bilingual individual. The back-translated version was compared with the original items.

Caregivers of the people who had chronic illnesses were asked to fill in the questionnaires. People who wanted to participate, after reading the informed consent, were included in the study. It took the participants nearly 20 minutes to fill out the questionnaires. For the re-test reliability, 15 people were reached 1 month after the first administration. The comparison group that included the individuals who were not caregivers were selected randomly and included in condition. Their demographic characteristics were similar to those of the caregiver group in terms of their age and marital status.

2.1.4. *Data Analysis*

The data was analyzed by using Statistical Package for Social Sciences (SPSS) (Green, Salkind, & Akey, 1997). Principal components factor analysis was conducted for the two subscales of caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000) in order to investigate the factor structure. Reliability of the scale was assessed by using Cronbach alpha values. Pearson product correlations were run for test - re-test reliability and construct validity. In order to compare the caregiver group with the non-caregiver group, independent samples t-test was used.

2.2. *Results*

The psychometric properties of basic needs and activities of living subscales of the caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000) were evaluated separately.

2.2.1. *Basic Needs Subscale*

An initial principal components factor analysis with a direct oblimin rotation was performed on 22 items of basic needs subscale for a sample of 150 caregivers. Direct oblimin rotation was found appropriate because the component correlation matrix revealed that the factors were not orthogonal. Five factors were extracted in the initial solution according to Kaiser criterion; with eigenvalues over 1. The eigenvalues ranged between 9.30 and 1.09. By looking at the eigenvalues, the proportion of variance accounted, and the scree plot in the main factor analysis, it was forced to 3 factors. The obtained factors accounted for 57.02 % of the total variation. Item loadings, communalities, eigenvalues, and proportions of variance explained by the factor analysis of basic needs subscale are displayed in Table 2.

The first factor, named as *self esteem and esteem for others*, consisted of 9 items with a cut off point .44. It accounted for 42.28 % of the total variance. The second factor was composed of 9 items which included the items about *expression of feelings and attendance to physical needs*. The second factor explained 8.34% of the total variance. The third factor, which represented *security* with 4 items, accounted for 6.40% of the total variance. The items 17 and 20 had crossloads and they were included in the factors which were theoretically more appropriate.

Table 2

The Item Loadings of Basic Needs Subscale

No	Item	Factor I (Self esteem and esteem for others)	Factor II (Expression of feelings and attendance to physical needs)	Factor III (Security)
14.	Feeling appreciated by others	**.84**	.00	-.19
15.	Feeling good about family	**.82**	.31	.15
13.	Feeling worthwhile	**.81**	-.13	-.28
16.	Feeling good about yourself	**.67**	-.11	.00
21.	Having people who think highly of you	**.53**	-.007	.37
12.	Learning new skills	**.52**	-.25	-.17
18.	Having close friendships	**.49**	.00	.23
22.	Having meaning in your life	**.49**	-.22	.43
5.	Having time for recreation	**.44**	-.21	.23
8.	Expressing anger	-.10	**.82**	-.13
3.	Getting enough sleep	-.11	**-.78**	.14
10.	Expressing sadness	.00	**-.73**	.00
2.	Eating a well-balanced diet	.00	**-.73**	.16
7.	Expressing love	.24	**-.70**	-.20
9.	Expressing laughter and joy	.27	**-.65**	.00
4.	Attending to your medical and dental needs	.00	**-.57**	.27
6.	Feeling loved	.37	**-.56**	-.11
11.	Enjoying sexual intimacy	.36	**-.37**	.00
19.	Having a home	-.10	.00	**.70**

Table 2 (Continued)

No Item	Factor I	Factor II	Factor III
1. Having enough money	.26	-.17	**.57**
17. Feeling secure about the future	.45	-.17	**.43**
20. Making plans about the future	.28	-.34	**.33**
Eigenvalue	9.30	1.84	1.41
Explained Variance (%)	42.28	8.34	6.40
Alpha Coefficient	.88	.89	.73

The internal consistency reliability coefficient as estimated by Cronbach's alpha for the basic needs subscale was .93. The results of the reliability analysis are presented in Table 3. The test – re-test reliability of the basic needs subscale was found as $r = .79$, $p < .001$ with an application of the scale to 15 participants after a 1 month interval. The construct validity was measured by examining correlation coefficients between depression ($r = -.71$, $p < .01$) for divergent validity and general well-being scores ($r = .55$, $p < .01$) for convergent validity and it can be concluded that the basic needs subscale has both divergent validity and convergent validity. That is, the more the caregivers satisfy their basic needs, the less likely they suffer from depression; and the more likely they have higher well-being.

Table 3

Reliabilities of Basic Needs Subscale

Item	Mean	SD	α if item deleted	Item-total r
Item 1	3.00	1.16	.9284	.5907
Item 2	3.16	1.37	.9264	.6942

Table 3 (Continued)

Item	Mean	SD	α if item deleted	Item-total r
Item 3	3.07	1.27	.9287	.5692
Item 4	2.47	1.26	.9281	.6028
Item 5	2.16	0.98	.9284	.6062
Item 6	2.27	1.28	.9268	.6803
Item 7	3.44	1.35	.9271	.6578
Item 8	3.42	1.31	.9302	.4884
Item 9	3.16	1.34	.9255	.7460
Item 10	3.27	1.15	.9294	.5236
Item 11	2.16	1.21	.9279	.6150
Item 12	2.16	1.15	.9295	.5220
Item 13	2.89	1.18	.9280	.6141
Item 14	3.15	1.20	.9277	.6291
Item 15	3.92	1.14	.9304	.4633
Item 16	3.33	1.18	.9272	.6601
Item 17	2.96	1.34	.9267	.6829
Item 18	3.21	1.38	.9297	.5208
Item 19	4.14	1.38	.9350	.2317
Item 20	3.00	1.34	.9275	.6390
Item 21	3.31	1.29	.9274	.6441
Item 22	3.43	1.34	.9251	.7645
Total scale	68.09	17.72		

Note. The internal consistency coefficient of the scale as measured by Cronbach's alpha is .93.

2.2.2. Activities of Living Subscale

An initial principal components factor analysis with a direct oblimin rotation was performed on 23 items of activities of living subscale for a sample of 150 caregivers because the component correlation matrix showed high correlations between the items (ranged between r = .24 and r = .85). The initial solution included 6 factors according to Kaiser criterion; with eigenvalues over 1. The eigenvalues ranged between 7.46 and 1.05. By looking at eigenvalues, the proportion of variance accounted, and the scree plot in the main factor analysis, it was forced to 4 factors with direct oblimin rotation. The total variance accounted for is 59.97%. Item loadings, communalities, eigenvalues and proportions of variance explained of the factor analysis of the activities of living subscale are displayed in Table 4.

The first factor, named as *time for self and leisure activities*, consisted of 13 items. It accounted for 33.55 % of the total variance. The second factor, *household maintenance*, included 5 items explaining 11.82 % of the total variance. The third factor included 2 items about *support* and it accounted for 8.63 % of the total variance. The final and fourth factor, which represented *self care*, had 2 items explaining 5.97 % of the total variance.

Table 4

The Item Loadings of the Activities of Living Subscale

No	Item	Factor I (time for self and leisure activities)	Factor II (household maintenance)	Factor III (support)	Factor IV (self care)
14.	Taking time for reflective thinking	**.78**	.01	.10	-.31
16.	Noticing the wonderment of things around you	**.77**	.00	.00	.22
11.	Enjoying a hobby	**.77**	-.14	.00	.19
12.	Starting a new interest or hobby	**.76**	.00	.00	.00
13.	Attending social events	**.75**	.00	.00	-.13
23.	Taking time to have fun with family or friends	**.72**	.00	.00	.12
21.	Maintaining employment or career	**.69**	.00	-.30	-.12
10.	Exercising	**.67**	.00	.00	.00
19.	Laughing	**.66**	.00	.10	.32
20.	Treating or rewarding yourself	**.58**	-.17	.13	.45
15.	Having time for inspirational or spiritual interests	**.53**	.00	.13	-.17
9.	Relaxing	**.47**	.15	.00	.37
7.	Purchasing clothing	**.46**	.38	.25	.00
3.	Getting the house clean	.00	**.87**	-.16	.00
2.	Preparing meals	.00	**.84**	-.18	.11
5.	Getting home maintenance done	.00	**.70**	.00	.24

Table 4 (Continued)

No Item	Factor I	Factor II	Factor III	Factor IV
6. Having adequate transportation	.00	**.67**	.22	.00
1. Buying food	.16	**.53**	.29	-.32
17. Asking for support from your friends or family	.00	.00	**.91**	.00
18. Getting support from your friends or family	.00	.00	**.88**	.00
8. Washing and caring for clothing	.00	.28	.11	**.71**
22. Taking time for personal hygiene and appearance	.29	.21	.00	**.45**
Excluded item				
Getting yard work done	.00	.00	. .00	.37
Eigenvalue	7.38	2.60	1.90	1.31
Explained Variance (%)	33.55	11.82	8.63	5.97
Alpha Coefficient	.91	.79	.83	.63

Cronbach's alpha coefficient for the activities of living subscale was .89 (See Table 5 for the results of the reliability analysis). One item was eliminated from the activities of living subscale (getting yard work done), because it reduced the internal consistency coefficient possibly due to it's inappropriateness for the most of Turkish families. The test - re-test reliability for the activities of living subscale was found to be as $r = .86, p < .001$. Similar to the basic needs subscale, activities of living subscale seems to have both convergent and divergent validities: The correlation of the activities of living subscale with depression ($r = -.69, p < .01$) and general well-being ($r = .54, p < .01$) were significant, indicating that the higher the caregivers' performance on activities of living, the lower their depression, and the higher their well-being. Moreover, convergent validities of the subscales were further confirmed by the strong correlation between the basic needs and activities of living subscales ($r = .86, p < .001$), indicating that as the level of satisfaction of the basic needs increased, the performance on activities of living increased, as well.

Table 5

Reliabilities of Activities of Living Scale

Item	Mean	SD	α if item deleted	Item-total r
Item 1	4.00	0.99	.8875	.3869
Item 2	4.22	1.12	.8875	.3900
Item 3	4.14	1.16	.8880	.3773
Item 5	4.01	1.26	.8878	.3938
Item 6	3.58	1.42	.8907	.3243
Item 7	2.71	0.98	.8820	.6269
Item 8	3.99	1.03	.8871	.4052
Item 9	2.17	1.14	.8821	.5938
Item 10	1.58	0.90	.8832	.5890
Item 11	2.06	1.18	.8811	.6263
Item 12	1.54	0.86	.8820	.6622
Item 13	1.88	1.04	.8815	.6332
Item 14	2.40	1.15	.8831	.5593
Item 15	2.18	1.05	.8880	.3691
Item 16	2.59	1.32	.8789	.6857
Item 17	3.17	1.31	.8927	.2332
Item 18	3.06	1.21	.8903	.2973

Table 5 (Continued)

Item	Mean	SD	α if item deleted	Item-total r
Item 19	2.43	1.20	.8792	.6924
Item 20	2.14	1.13	.8828	.5698
Item 21	2.52	1.61	.8892	.4022
Item 22	3.42	1.21	.8843	.5123
Item 23	2.31	1.24	.8796	.6720
Total scale	62.15	14.17		

Note. The internal consistency coefficient of the scale as measured by Cronbach's alpha is .89.

The results of the present study are congruent with the original version of the scale. Basic needs subscale had 4 factors in the principal component factor analysis of Rubio, Berg-Weber, and Tebb's study (1999). In the present study there are 3 factors according to the results of the factor analysis. The factors expression of feelings and attendance to physical needs converged and included in the same factor. Similarly, for the activities of living subscale there were 5 factors. However, in the present study, the results showed that time for self and leisure activities took part under the same factor.

2.2.3. *Group Comparisons*

Further analysis, using independent samples t-test, was run to compare the caregivers with the non-caregivers on both subscales of caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000) (see Table 6). There was a significant difference between the caregiver group and the non-caregiver group in terms of basic needs subscale (*t*(98) = -5.20, *p* < .001) and activities of living subscale (*t*(98) = -7.02, *p* < .001). The caregivers got significantly lower scores on basic needs subscale (*M* = 73.66, *SD* = 18.85) than the non-caregivers (*M* = 90.80, *SD* = 13.68). Similarly, for the activities of living subscale the scores of caregivers (*M* = 69.31, *SD* = 14.25) were significantly lower than the non-caregivers (*M* = 87.72, *SD* = 11.86). Thus, both of the subscales significantly differentiated the caregivers from the non-caregivers, indicating acceptable criterion validity.

Table 6

Descriptive Statistics and T-Test Results for Caregivers and Non-caregivers

	Caregivers		Non-caregivers		*t* (98)	*p*
	M	*SD*	*M*	*SD*		
Basic needs	73.66	18.85	90.80	13.68	-5.20	.001
Activities of living	69.31	14.25	87.72	11.86	-7.02	.001

The aim of study 1 was to adapt the caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000) to Turkish culture. After the translations were completed, caregivers of various illnesses that require continuous care participated in the study by filling out the questionnaire sets including the Caregiver Well-Being Scale (Berg-Weger, Rubio, & Tebb, 2000), Mental, Physical and Spiritual Well-being Scale (Vella - Brodrick & Allen, 1995), and Beck Depression Inventory (Beck, Rush, Shaw, & Emery, 1979). The results of the Study 1 indicated that the caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000) seems to be a reliable and valid measure that can be used in Study 2.

CHAPTER III

STUDY 2

3.1. *Method*

3.1.1. *Participants*

Study 2 was conducted with the caregivers of leukemia who were being followed at one of the following hospitals: Ankara Sami Ulus Pediatric Hematology Service and Oncology Polyclinics, Hacettepe University İhsan Doğramacı Children's Hospital Pediatric Hematology Polyclinics, İzmir Ege University Pediatric Hematology Service, and 9 Eylül University Pediatric Hematology Service and Polyclinics. The age of the participants ranged between 18 and 51 with a mean of 33.1 (*SD* = 5.90). Mothers made up of 90% of the sample (*n* = 90), while the remaining were fathers (*n* = 3, 3%), sisters (*n* = 3, 3%) and aunts (*n* = 4, 4%). Perceived family income per month was categorized into 3 as lower, middle, and upper. People who defined themselves as lower income group constituted 36% of the sample (*n* = 36). The remaining 59% were middle (*n* = 59) and 5% were the upper income individuals (*n* = 5). Education levels of the participants were as follows: 34% primary school (*n* = 34), 18% middle school (*n* = 18), 27% high school (*n* = 27), 20% university (*n* = 20), and 1% graduate school (*n* = 1). Seventy six percent of the sample did not have a job currently (*n* = 76). The percentage of the participants who did not get help for care giving was 70% (*n* = 70), whereas 30% received help from either a helper or grandmother (*n* = 30). People, who had another child to look after, made up of 58% of the sample (*n* = 58). And finally, the time passed after the first symptoms of leukemia ranged between 1-81 months with a mean of 14 months.

To be included in the study, firstly, the person should be the primary caregiver. This was asked as "who spends the most time for the caregiving of the child". Secondly, the age of the child should be under 18. Finally, children should have been diagnosed at least 1 month before. Therefore, the primary caregivers whose child was below 18, who got the diagnosis of leukemia at least 1 month ago, and who gave consent to participate in the study were included in the study. The caregivers whose children were having chemotherapy as inpatients (*n* = 30, 30%) and who brought their child for daily treatment or control to the polyclinic (*n* = 70, 70%) were included in the study. The age of the children ranged between 9 months and 17 years (*M* = 6.89; *SD* = 3.17). The ratio of children who were having chemotherapy was 91% (*n* = 91). The remaining 9% included children at the phase of consolidation (*n* = 2) and monthly control (*n* = 7) (See Table 7 for the demographic characteristics of the sample).

Table 7

Demographic Characteristics of the Sample of Study 2

	M	SD	%
Caregiver's age	33.1	5.90	
Marital status			
Single			6
Married			90
Widowed			2

Table 7 (Continued)

	M	SD	%
Divorced			2
Relationship to the patient			
Mother			90
Father			3
Sister			3
Aunt			4
Perceived family income			
Low			36
Middle			59
High			5
Education			
Primary school			34
Secondary school			18
High school			27
University			20
Graduate school			1
Occupation			
Housewife/unemployed			76
Employee			20
Self-employed			4
Child's age	6.89	3.17	
Stage of the treatment			
Chemotherapy			91

Table 7 (Continued)

	M	SD	%
Maintenance therapy			2
Other (control)			7
Time of appearance of symptoms	14.45	11.98	

3.1.2. *Measures*

The questionnaire set used in study 2 included demographics and caregiving history form, Caregiving Tasks Index, The Caregiver Well-Being Scale (Berg-Weger, Rubio, & Tebb, 2000), Interpersonal Relationships of Caregivers Index, The Ways of Coping Inventory (Folkman & Lazarus, 1980), Multidimensional Scale of Perceived Social Support (MSPPS) (Zimet, Dahlem, Zimet, & Farley, 1988), Beck Depression Inventory (Beck, Rush, Shaw, & Emery, 1979), Beck Anxiety Inventory (Beck, Epstein, Brown, & Steer, 1988)and Symptom Checklist (SCL-90) (Derogatis, 1977).

3.1.2.1. *Demographics and Caregiving History Form*

The demographic information form, which was prepared for the caregivers of children with leukemia, included general demographic questions about age, gender, education, occupation, marital status, and perceived family income (See Appendix E). Besides, it contained questions about the illness and the caregiving process, such as the relationship to the patient, duration of caregiving, the phase of the illness, number of people living at home, number of caregivers, number of children except for the ill child, having physical and psychological illness or not, and membership to an illness related organization or support group.

3.1.2.2. *Caregiving Tasks Index*

In order to test the primary stressors of the caregivers, an index for caregiving tasks (e.g. giving medicine, staying at hospital) and daily needs (e.g. feeding, dressing up) was prepared. The index was composed of two parts: the frequency of engaging in the behaviors and the frequency of experiencing difficulties in fulfilling the tasks (See Appendix F). The frequency part is a 5-point Likert type scale ranging between “never” and “always”. The caregiving tasks were defined according to the elderly in the original model of Pearlin and colleagues (1990) and they may not reflect the child care giving tasks. Therefore, they were rearranged in a way that represents the tasks that need to be fulfilled by the caregivers of children with chronic illnesses.

The caregiving task score was calculated in the following way: For each task, the frequency of engaging in the behavior was multiplied by the difficulty in fulfilling that behavior. Then, the scores were added together to get a total score of caregiving task. Higher scores on this index indicate experiencing more problems in caregiving tasks.

3.1.2.3. *The Caregiver Well-Being Scale*

Turkish adaptation of the scale, which was done in study 1, was used in the present study (See Appendix B). Information about the reliability and the validity of the scale were presented in the results section of the study 1. The basic needs subscale was used to measure needs of the caregiver as one of the primary stressors, and the activities of living subscale was used to assess the role strains, which is one of the secondary stressors.

Basic needs subscale includes the daily needs of the caregiver himself/herself. Higher scores on this subscale means the caregiver is able to satisfy his/her basic needs adequately.

Role strains were defined by Pearlin and colleagues (1990) as deficiency in activities outside the caregiving job. The activities of living subscale includes the non-caregiving activities of the caregiver. In this sense, having high scores on the subscale means that the activities outside caregiving are done by the caregiver and the role strains of the caregiver are low.

3.1.2.4. *Interpersonal Relationships of Caregivers Index*

The index was developed to evaluate the interpersonal relationships, that is, the secondary stressors of the model especially for leukemia caregivers. It is composed of two subscales, namely non-supportive relationships and leukemia related distress. It includes 10 statements on which the participants rate themselves on a 5-point Likert type scale (See appendix G). The alpha coefficient was found .76 for the full scale; .67 for non-supportive relationships, and .73 for the leukemia related distress. The statements for the non-supportive relationships subscale were formed according to Patterson and colleagues' study (1997) and Neufeld and Harrison's qualitative study (2003). The categories of non-support were converted to sentences. Higher scores on this subscale indicate experiencing non-support in the relationships.

Leukemia related distress items were formed by using the websites of support networks of leukemia in Turkey (e.g. Lösev, Kaçuv). By reviewing these websites, the most distracting situations that the caregivers face were identified and based on these situations the items of leukemia related distress were constructed. Similar to the non-support subscale, higher scores on this scale point higher levels of distress.

3.1.2.5. *The Ways of Coping Inventory*

It was developed by Folkman and Lazarus (1980) and adapted to Turkish by Siva (1991) with the Cronbach alpha coefficient .90 (Siva, 1991, cited in Gençöz, Gençöz, & Bozo 2006). The Turkish version of the scale includes 74 items (See appendix H). In the Gençöz, Gençöz, and Bozo study (2006), hierachical dimensions of coping styles were examined and three factors were identified, namely, problem focused, emotion focused, and indirect coping. The Cronbach alpha coefficients were found .90 for problem focused coping subscale, .88 for emotion focused coping subscale and .84 for indirect coping subscale.

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

This scale consists of 12 items that aimed at assessing perceived social support (See Appendix I). 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 ranging 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.

3.1.2.7. *Beck Depression Inventory (BDI)*

It was developed by Beck, Rush, Shaw, and Emery (1979), and adapted to Turkish by Hisli (1988). It includes 21 items about how the person felt last week (See Appendix D). The inventory includes somatic, cognitive, motivational, and emotional symptoms. The person rates himself/herself on a 4 point scale between 0 and 3. As the score increases, the level of depressive symptoms increases (Savaşır & Şahin, 1997).

3.1.2.8. *Beck Anxiety Inventory (BAI)*

It measures the frequency of the anxiety symptoms that the person experiences on a 4-point scale. It was developed by Beck, Epstein, Brown, and Steer (1988), and adapted to Turkish by Ulusoy, Şahin, and Erkmen (1996) (See Appendix J). The Cronbach Alpha for the Turkish version is .93. It is composed of two subscales, which are subjective anxiety and somatic symptoms. The inventory includes 21 items about the anxiety symptoms felt since last week. Higher scores on this scale indicate more anxiety (cited in Savaşır & Şahin, 1997).

3.1.2.9. *Symptom Checklist (SCL-90)*

For evaluating the general psychological health, Symptom Checklist (SCL-90) developed by Derogatis (1977), was used (See Appendix K). The short version (Brief Symptom Inventory) with 53 items was adapted to Turkish by Şahin and Durak (1994). The reliability coefficients of the 9 subscales range between .71 and .85 in the original scale. The reliability coefficient of the Turkish version of the subscales range between .55 and .86 (Şahin & Durak, 1994 cited in Savaşır & Şahin, 1997). The scale includes statements about physical and psychological symptoms. Higher scores on this checklist indicate experiencing higher levels of psychological symptoms.

3.1.3. *Procedure*

The necessary permissions were received from Ankara Provincial Directorate of Health and the head of the pediatric oncology or hematology departments of the hospitals. The study was conducted in the departments that let the researcher to administer the questionnaire sets to the caregivers. The participants were contacted at their patients' hospital stays at the inpatient clinics, and treatment or examination appointments in outpatient polyclinics. The researcher introduced herself, told the aims of the study and asked questions about what the diagnosis was, when the diagnosis was made, and whether the person is the primary caregiver. The participants who gave consent were included in the study. The caregivers filled in the questionnaires in an empty room in the inpatient clinics and in the waiting rooms of polyclinics. Some of the participants needed the questions being read to them because of having problems in reading. The researcher read the questions and marked the answers for them in that case. If they prefered to fill the questionnaires by themselves, the researcher waited and handed over the forms. Once they accepted to participate in the study, it took the caregivers approximately 45- 55 minutes to fill in the questionnaires. There was no time limit. That is, the participants took breaks because their children or doctors could call them any time.

3.1.4. *Data Analysis*

To test the mediation model, which was derived from the original model of Pearlin and colleagues (1990), path analysis was run. Statistical analysis was done by using SPSS (Statistical Package for Social Sciences) (Green, Salkind, & Akey, 1997). In order to test all of the hypotheses of the main study, 9 mediation models were tested, i.e. 18 path analyses were run.

3.2. *Results*

3.2.1. *Preliminary Analyses*

In order to find out the predictive values of demographic variables (caregiver age, the number of people living in the house, and the duration of caregiving) on the outcome variables (depression, anxiety, and general psychological health), separate regression analyses were conducted (see Table 8). Similarly, to see the variation of outcome variables (depression, anxiety, and general psychological health) based on the caregivers' level of education, perceived income, and the child's age, one way ANOVAs were performed.

Regression analyses run with the demographic variables revealed that younger caregivers experienced more depression ($\beta = -.32$, $p < .001$), more anxiety ($\beta = -.25$, $p < .01$) and more mental health symptoms ($\beta = -.43$, $p < .001$).

The number of people living in the house predicted the outcome variables, as well. As the number of people living in the house increased, depression, ($\beta = .46$, $p < .001$), anxiety ($\beta = .41$, $p < .01$), and psychological health symptoms ($\beta = .32$, $p < .001$) of the caregivers increased, too.

The effect of the duration of caregiving had no significant effect on any of the outcome variables (for depression; $\beta = .02$, $p = .83$, for anxiety; $\beta = .07$, $p = .52$, for general psychological health; $\beta = .12$, $p = .22$).

Table 8

Regression Analyses Predicting Outcome Variables (Depression, Anxiety, General Psychological Health) from the Demographic Variables (Caregiver Age, the Number of People Living in the House, the Duration of Caregiving)

Variable	Mean	SD	B	SE B	F change	β
Depression						
Caregiver Age	33.10	5.90	-.49	.15	11.04	-.32***
Number of people living in the house	4.30	1.26	3.30	.70	26.79	.46***
Duration of caregiving	14.45	11.98	.17	.08	.05	.02
Anxiety						
Caregiver Age	33.10	5.90	-.44	.17	6.78	-.25**

Table 8 (Continued)

Variable	Mean	SD	B	SE B	F change	β
Number of people living in the house	4.30	1.26	3.30	.75	19.44	.41**
Duration of caregiving	14.45	11.98	.05	.09	.42	.07
General Psychological Health						
Caregiver Age	33.10	5.90	.32	.26	22.38	.12***
Number of people living in the house	4.30	1.26	7.87	2.35	11.24	.32***
Duration of caregiving	14.45	11.98	.32	.26	1.54	.12

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

To examine the effects of education level, three one way ANOVA's were performed on the dependent variables separately (See Table 9). The effect of education level on depression was found significant ($F(3, 96) = 31.15, p < .001$). Post hoc analyses using Tukey HSD test revealed that primary school graduates had significantly higher depression scores ($m = 23.47$) than the high school graduates ($m = 12.51$) and university graduates ($m = 7.33$). Secondary school graduates did also have significantly higher depression scores ($m = 20.00$) than high school graduates ($m = 12.51$) and university graduates ($m = 7.33$). The difference between high school graduates ($m = 12.51$) and university graduates ($m = 7.33$) in terms of depression scores was significant, too, indicating that high school graduates had higher depression scores than university graduates.

Similarly, education level significantly affected the caregivers' anxiety level (*F*(3, 96) = 16.66, *p* < .001). According to Tukey HSD test, primary school graduates reported significantly more anxiety (*m* = 22.94) than the high school graduates (*m* = 13.70) and university graduates (*m* = 7.00). The difference between secondary school graduates (*m* = 17.67) and university graduates (*m* = 7.00) was significant, too. That is, secondary school graduates had significantly higher depression scores than university graduates. Moreover, high school graduates (*m* = 13.70) had significantly higher anxiety scores than university graduates (*m* = 7.00).

As in the case of depression and anxiety, the effect of education level on general psychological health was significant, too (*F*(3, 96) = 10.24, *p* < .001). Post hoc analyses using Tukey HSD test revealed that university graduates had significantly less psychological health symptoms (*m* = 16.19) than primary school graduates (*m* = 57.09), secondary school graduates (*m* = 50.44), and high school graduates (*m* = 46.00). The differences between the other groups were not significant.

Table 9

Descriptive Statistics, Analysis of Variance, and Tukey HSD Tests for the Scales and Education Level

	Primary		Secondary		High School		University		One-way ANOVA		
	m	*sd*	*m*	*sd*	*m*	*sd*	*m*	*sd*	df	F(3,96)	p
BDI	23.47_a	5.33	20.00_a	9.98	12.51_b	7.00	7.33_c	3.68	3, 96	31.15	.001
BAI	22.94_a	7.74	17.66_{ab}	11.96	13.70_b	8.86	7.00_c	4.01	3, 96	16.66	.001
SCL	57.09_a	24.24	50.44_a	33.05	46.00_a	35.51	16.19_b	6.68	3, 96	10.24	.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 variation of outcome variables (depression, anxiety, and general psychological health) based on the categorization of the perceived family income was examined by performing a one way ANOVA (See Table 10). The results showed that the effect of perceived family income on depression was significant ($F(2, 97) = 27.58, p < .001$). When the differences between the lower, middle, and upper income groups were examined with Tukey HSD test, it was found that lower income group had significantly more depression ($m = 23.64$) than the middle ($m = 12.88$) and the upper income groups ($m = 7.80$). The difference between people having middle and upper income levels was not significant.

Similar results were obtained for anxiety. The effects of perceived family income on anxiety were significant ($F(2, 97) = 22.41, p < .001$). Further post hoc analysis with Tukey HSD test revealed that lower income group had significantly higher scores on anxiety ($m = 23.53$) than middle income ($m = 12.51$) and upper income groups ($m = 6.00$). The difference between people having middle and upper income levels was not significant as in the case of depression.

Similar to depression and anxiety, the effect of perceived family income on general psychological health was significant ($F(2, 97) = 14.99, p < .001$). According to Tukey HSD test, lower income group had significantly more psychological symptoms ($m = 63.01$) than middle income ($m = 35.69$) and upper income groups ($m = 11.60$). There was not a significant difference between people having middle and upper income levels.

Table 10

Descriptive Statistics, Analysis of Variance, and Tukey HSD Tests for the Scales and Perceived Family Income

	Lower		Middle		Upper		One-way ANOVA		
	m	*sd*	*m*	*sd*	*m*	*sd*	*df*	*F*(2,97)	*p*
BDI	23.64_a	6.95	12.88_b	7.83	7.80_b	1.09	2	27.58	.001
BAI	23.53_a	9.08	12.51_b	8.42	6.00_b	3.39	2	22.41	.001
SCL	63.01_a	27.49	35.69_b	28.09	11.60_b	2.07	2	14.99	.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.

Depending on their age, children were categorized into three as preschool children ($n = 46$, *range* = 0 – 6), primary school children ($n = 47$, *range* = 7 – 11) and adolescents ($n = 7$, *range* = 12 – 17); and one way ANOVA was conducted to investigate the effect of age of the children on the outcome variables (depression, anxiety, and general psychological health). The results of the analysis showed no significant effects for depression ($F(2, 97) = 1.65, p = .20$), anxiety ($F(2, 97) = .52, p = .60$), and general psychological health ($F(2, 97) = .36, p = .70$).

3.2.2. *Group Comparisons*

Group comparisons on depression, anxiety, and general psychological health were performed by using independent samples t-test. Being a caregiver in an inpatient or outpatient clinic, having other children to be looked after by the leukemia caregiver or not, getting help from another person for caregiving or not and having an occupation at the moment or not, were used as the independent variables that may have an effect on the outcome variables (depression, anxiety, and general psychological health).

There was a significant difference between the inpatient and outpatient caregiver group in depression ($t(98) = -6.94$, $p < .001$) and anxiety ($t(98) = -3.06$, $p< .01$) but not in general psychological health ($t(98) = -1.82$, $p= .07$) . The caregivers of the outpatient group got significantly lower scores on depression (*m* = 13.09, *sd* = 7.36) than the inpatient caregivers (*m* = 24.46, *sd* = 7.85). Similarly, for anxiety scores of outpatient caregivers (*m* = 14.18, *sd* = 10.20) were significantly lower than the inpatient caregivers (*m* = 20.73, *sd* = 8.76) (See Table 11).

Table 11

Descriptive Statistics and T-Test Results for Inpatient and Outpatient Groups

		n	*m*	*sd*	*t* (98)	*p*
BDI	Outpatient	70	13.09	7.36	-6.94	.001
	Inpatient	30	24.46	7.85	-6.94	.001
BAI	Outpatient	70	14.18	10.20	-3.06	.01
	Inpatient	30	20.73	8.76	-3.06	.01
SCL	Outpatient	70	40.67	33.48	-1.82	.07
	Inpatient	30	52.82	22.06	-1.82	.07

When the effects of having other children was examined, it was found that there was a significant difference between the caregivers with and without other children in terms of depression (*t*(98) = -3.39, *p* < .001) and anxiety (*t*(98) = -2.93, *p* < .01) but not in general psychological health (*t*(98) = -1.52, *p* = .13) . The caregivers who had other children got significantly higher scores on depression (*m* = 19.00, *sd* = 9.83) than the caregivers who has only the ill child (*m* = 13.04, *sd* = 6.75). Similarly, the anxiety scores of caregivers with other children (*m* = 18.60, *sd* = 10.37) were significantly higher than the anxiety scores of caregivers with only child (*m* = 12.76, *sd* = 9.02) (See Table 12).

Table 12

Descriptive Statistics and T-Test Results of Participants Having Other Children or Not

		n	*m*	*sd*	*t* (98)	*p*
BDI	Having other children	58	19.00	9.83	-3.39	.001
	Having only the ill child	42	13.04	6.75	-3.39	.001
BAI	Having other children	58	18.60	10.37	-2.93	.01
	Having only the ill child	42	12.76	9.02	-2.93	.01
SCL	Having other children	58	38.83	29.82	-1.52	.13
	Having only the ill child	42	38.83	31.32	-1.52	.13

Getting help from another person for caregiving or not did not differentiate the people who has a helper for the caregiving and from the people who has not on any of the outcome variables (for depression (*t*(98) = .06, *p* = .95), for anxiety (*t*(98)

= 1.15, *p* = .25), and for general psychological health (*t*(98) = 1.13, *p* = .26).

As Table 13 illustrates, the differences between caregivers who had a job and who did not have a job were significant on all of the outcome variables. For depression (*t*(98) = 5.15, *p* < .001), caregivers who had an occupation at the moment were lower (*m* = 9.04, *sd* = 5.89) than caregivers without a current occupation (*m* = 18.85, *sd* = 8.71). Similarly, for anxiety scores (*t*(98) = 4.91, *p* < .001), caregivers who had an occupation at the moment were lower (*m* = 8.12, *sd* = 5.24) than caregivers without a current occupation (*m* = 18.68, *sd* = 10.09). The results of the t-tests were significant for general psychological health, too (*t*(98) = 5.31, *p* < .001). Caregivers who had an occupation at the moment had significantly less general psychological symptoms (*m* = 18.46, *sd* = 8.91) than the caregivers who did not (*m* = 52.48, *sd* = 30.90)

Table 13

Descriptive Statistics and T-Test Results of Participants Having an Occupation or Not

		n	*m*	*sd*	*t* (98)	*p*
BDI	Occupation	24	9.04	5.89	5.15	.001
	No occupation	76	18.85	8.71	5.15	.001
BAI	Occupation	24	8.12	5.24	4.91	.001
	No occupation	76	18.68	10.09	4.91	.001
SCL	Occupation	24	18.46	8.91	5.31	.001
	No occupation	76	52.48	30.90	5.31	.001

3.2.3. *Correlations*

Zero order correlation coefficients among the measures were examined in order to investigate the relationships among the primary stressors, secondary stressors, potential mediators and the outcome variables (See Table 14). The variables were found to have significant correlations with each other except for the caregiving tasks. Caregiving tasks, which are one of the primary stressors, had no relationship with the outcome variables. The outcome variables were highly correlated with each other. The correlation coefficient between depression and anxiety was $r =. 80$, $p < .001$, correlation coefficient between depression and general psychological health was $r =. 64$, $p < .001$ and the correlation coefficient between anxiety and was general psychological health is $r = .79$, $p < .001$.

Table 14

Correlation Coefficients among Measures

	1	2	3	4	5	6	7	8	9	10
1. Caregiving tasks	1.00									
2. Basic needs	-.04	1.00								
3. Role strain	-.17	.86***	1.00							
4. Interpersonal relations	.31**	-.37***	-.31***	1.00						
5. Social support	.15	.79***	.69***	-.39***	1.00					
6. Problem focused coping	.17	.63***	.54***	-.22*	.69***	1.00				
7. Emotion focused coping	.11	-.47***	-.49***	.32**	-.39***	-.21*	1.00			
8. Depression	.14	-.67***	-.65***	.51***	-.62***	-.38***	.65***	1.00		
9. Anxiety	-.07	-.60***	-.49***	.37***	-.57***	-.32**	.64***	.80***	1.00	
10. General psychological health	-.10	-.61***	-.47***	.39***	-.53***	-.24*	.51***	.64***	.79***	1.00

Note. For all correlations, $N = 100$ * $p < .05$; ** $p < .01$; *** $p < .001$

3.2.4. *Predictors of Depression*

A hierarchical regression analysis was computed to predict depression with the primary stressors (caregiving tasks and basic needs), the secondary stressors (role strain and interpersonal relationships) and the mediators (problem focused coping, emotion focused coping, and social support) when the demographic variables (age, education level, having an occupation or not, and perceived family income) were controlled (See Table 15). In the first step, the demographic variables explained 55% of the variance in depression ($R^2 = .55$, $F(4, 95) = 28.69$, $p < .001$). Age ($\beta = -.22$, $p < .01$), education level ($\beta = -.54$, $p < .001$), and perceived family income ($\beta = -.23$, $p < .05$) were found to be negatively associated with depression. The stressors and mediators increased the explained variance from 55% to 70% ($R^2 = .70$, $F(7, 88) = 6.28$, $p < .001$). The only significant predictor of depression was emotion focused coping ($\beta = .29$, $p < .001$) when the demographic variables were controlled. Thus, as the use of emotion focused coping increases the level of depression increases, as well.

Table 15

Summary of Hierarchical Regression Analysis for Variables Predicting Depression

	Model 1			Model 2		
Variable	*B*	*β*	*p*	*B*	*β*	*p*
Age	-.34	-.22**	.01	-.26	-.17*	.05
Education level	-4.19	-.54***	.001	-1.11	-.14	.25
Occupation	1.50	.07	.46	1.97	.09	.27

Table 15 (Continued)

Variable	*B*	*β*	*p*	*B*	*β*	*p*
Perceived family income	-3.69	-.23*	.02	-1.84	-.11	.25
Caregiving tasks				.00	.01	.85
Basic needs				-.05	-.09	.53
Role strain				-.12	-.17	.20
Interpersonal relationships				.18	.14	.08
Problem focused coping				.04	.05	.56
Emotion focused coping				.22	.29***	.001
Social support				-.09	-.17	.16
R		.74			.83	
R^2		.55			.70	
Adjusted R^2		.53			.66	
ΔR^2		.55			.15	
F change		28.69			6.28	

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

3.2.5. *Predictors of Anxiety*

A hierarchical regression analysis was computed to predict anxiety with the primary stressors (caregiving tasks and basic needs), the secondary stressors (role strain and interpersonal relationships) and the mediators (problem focused coping, emotion focused coping, and social support) when the demographic variables (age, education level, having an occupation or not, and perceived family income) were controlled (See Table 16). The demographic variables, when entered in step 1, explained 41% of the variance in anxiety ($R^2 = .41$, $F(4, 95) = 16.52$, $p < .001$). Education level ($\beta = -.30$, $p < .05$) and perceived family income ($\beta = -.31$, $p < .01$) were the significant predictors of anxiety. The stressors and mediators increased the explained variance from 41% to 62% ($R^2 = .62$, $F(7, 88) = 6.78$, $p < .001$). Basic needs ($\beta = -.41$, $p < .05$) and emotion focused coping ($\beta = .44$, $p < .001$) were the significant predictors of anxiety when the demographic variables were controlled. Thus, as the basic needs of the caregiver met, anxiety level declines. Moreover, as the use of emotion focused coping increases anxiety level increases, as well.

Table 16

Summary of Hierarchical Regression Analysis for Variables Predicting Anxiety

	Model 1			Model 2		
Variable	*B*	*β*	*p*	*B*	*β*	*p*
Age	-.28	-.16	.05	-.30	-.17*	.05
Education level	-2.64	-.30*	.05	.11	.01	.93
Occupation	-1.16	-.05	.65	-1.66	-.07	.46
Perceived family income	-5.55	-.31**	.01	-.53	-.03	.79
Caregiving tasks				-.04	-.13	.11
Basic needs				-.25	-.41*	.05
Role strain				.18	.22	.14

Table 16 (Continued)

Variable	*B*	*β*	*p*	*B*	*β*	*p*
Interpersonal relationships				.02	.02	.86
Problem focused coping				.05	.07	.53
Emotion focused coping				.39	.44***	.001
Social support				-.12	-.20	.15
R		.64			.78	
R^2		.41			.62	
Adjusted R^2		.38			.57	
ΔR^2		.41			.21	
F change		16.52			6.78	

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

3.2.6. *Predictors of General Psychological Health*

A hierarchical regression analysis was computed to predict general psychological health with the primary stressors (caregiving tasks and basic needs), the secondary stressors (role strain and interpersonal relationships) and the mediators (problem focused coping, emotion focused coping, and social support) when the demographic variables (age, education level, having an occupation or not, and perceived family income) were controlled (See Table 17). In the first step, the demographic variables explained 42% of the variance in general psychological health (R^2 = .42, *F*(4, 95) = 17.23, $p < .001$). Age (β = -.35, $p < .001$) and perceived family income (β = -.37, $p< .001$) significantly predict general psychological health. The stressors and mediators increased the explained variance from 42% to 69% (R^2 = .69, *F*(7, 88) = 10.80, $p < .001$). Caregiving tasks (β = -.20, $p< .01$), basic needs (β = -.62, $p< .001$) and emotion focused coping (β = .33, $p < .001$) were the significant predictors of general psychological health, controlling the demographic variables. Thus, as the caregiving tasks and the level of satisfaction of the basic needs declines, psychological symptoms increase. Furthermore, as the use of emotion focused coping increases general psychological symptoms increase, as well.

Table 17

Summary of Hierarchical Regression Analysis for Variables Predicting General Psychological Health

	Model 1			Model 2		
Variable	*B*	*β*	*p*	*B*	*β*	*p*
Age	-1.82	-.35***	.001	-1.95	-.37***	.001
Education level	.61	.02	.86	8.47	.32*	.01
Occupation	-15.08	-.21	.05	-17.79	-.25**	.01
Perceived family income	-20.60	-.37***	.001	-.12	.00	.98
Caregiving tasks				-.21	-.20**	.01
Basic needs				-1.15	-.62***	.001
Role strain				.60	.25	.07
Interpersonal relationships				.09	.02	.80

Table 17 (Continued)

Variable	*B*	*β*	*p*	*B*	*β*	*p*
Problem focused coping				.20	.09	.34
Emotion focused coping				.87	.33***	.001
Social support				-.40	-.22	.08
R		.65			.83	
R^2		.42			.69	
Adjusted R^2		.40			.65	
ΔR^2		.42			.27	
F change		17.23			10.80	

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

3.2.7. *Model Testing*

In order to test the main hypotheses of the study, 9 mediation models were tested. Using problem focused coping, emotion focused coping, and social support as mediators, the models included primary stressors (caregiving tasks and basic needs) and secondary stressors (interpersonal relationships and role strain) as independent variables; and depression, anxiety, and general mental health as the dependent variables. According to Baron & Kenny (1986) the conditions necessary for the mediation relation to exist are (1) variations in the independent variables account for variations in the mediator, (2) variations in the mediator account for variations in the dependent variables, and (3) when the effects in the first two conditions are controlled, the previously significant relation between independent and dependent variables are lessened or disappears fully. Accordingly, three regression analyses were computed for each model by using standard multiple regression analysis. For the models that satisfy these conditions, Sobel test was conducted to test the significance of the indirect effect.

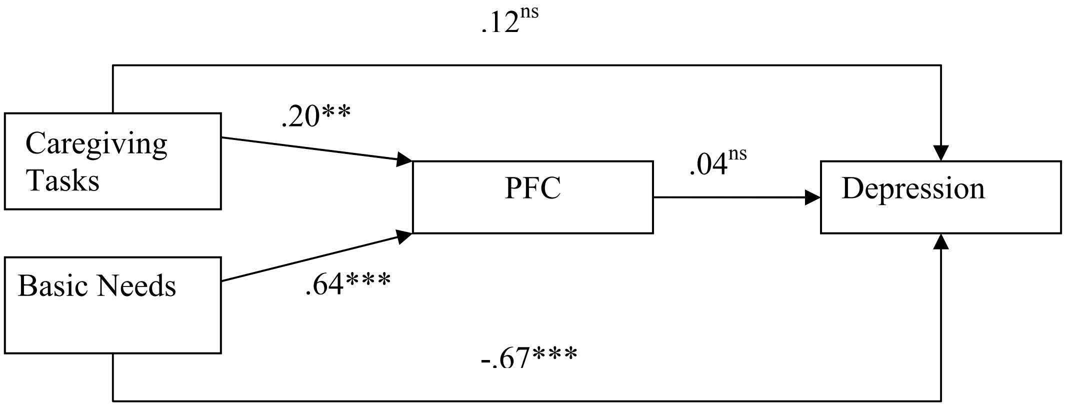
3.2.7.1. *Mediation Models for Depression*

Six mediation models were proposed for depression being the dependent variable. The independent variables were primary stressors (caregiving tasks and basic needs) and secondary stressors (role strain and interpersonal relationships). The mediators were problem focused coping, emotion focused coping, and social support.

3.2.7.1.1. *Problem Focused Coping as Mediator*

Caregiving tasks (primary stressor) predicted problem focused coping significantly ($\beta = .20, p < .01$). However, it was not a significant predictor of depression ($\beta = .12, p = .12$). Therefore, problem focused coping did not mediate the relationship between caregiving tasks and depression (See Figure 3).

Problem focused coping did not mediate the relationship between basic needs (primary stressor) and depression, as well (See Figure 3). Although basic needs was a significant predictor of depression ($\beta = - .67, p < .001$) and of problem focused coping ($\beta = .64, p < .001$), problem focused coping was a not significant predictor of depression while controlling for basic needs ($\beta = .04, p = .65$).

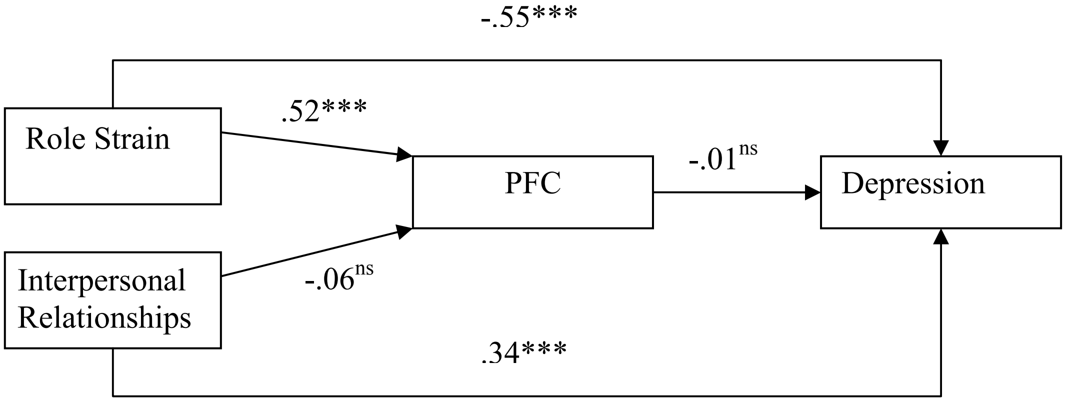


Note. * $p < .05$; ** $p <.01$; *** $p <.001$

Figure 3. The Relationship between the Primary Stressors and Depression Having Problem Focused Coping as the Mediator.

Similarly, the path for the secondary stressors (role strain and interpersonal relationships) with problem focused coping as the mediator was not significant (See Figure 4). Although role strain predicted problem focused coping ($\beta = .52, p < .001$) and depression ($\beta = - .55, p < .001$), problem focused coping was not a significant predictor of depression ($\beta = -.01, p = .88$). Therefore, problem focused coping did not mediate the relationship between role strain (secondary stressor) and depression.

Interpersonal relationships predicted depression ($\beta = .34, p < .001$) significantly. However, it did not predict problem focused coping significantly ($\beta = -.06, p = .47$). Thus, problem focused coping did not mediate the relationship between interpersonal relationships (secondary stressor) and depression (See Figure 4).



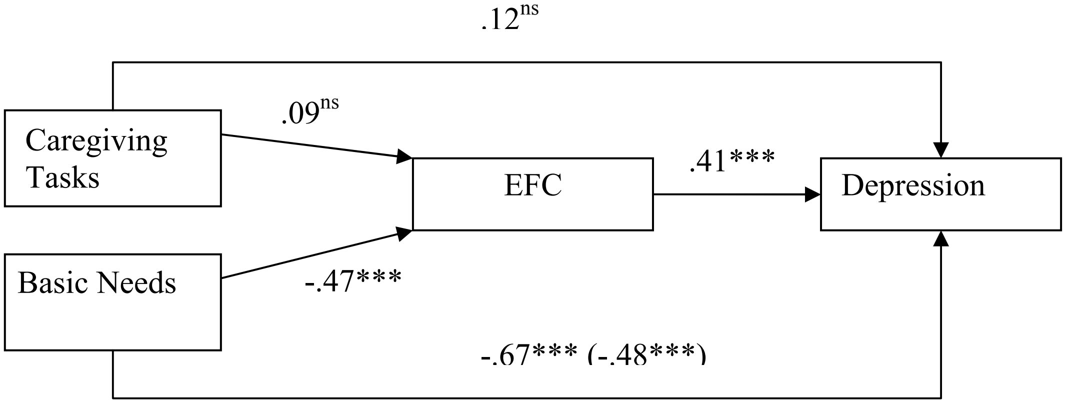
Note. * $p < .05$; ** $p < .01$; *** $p < .001$

Figure 4. The Relationship between the Secondary Stressors and Depression Having Problem Focused Coping as the Mediator.

3.2.7.1.2. *Emotion Focused Coping as Mediator*

The relationship between caregiving tasks (primary stressor) and depression was not mediated by emotion focused coping because the conditions of mediation were not fulfilled. That is, caregiving tasks predicted neither depression ($\beta = .12$, $p = .12$) nor emotion focused coping ($\beta = .09$, $p = .29$) (See Figure 5).

The relationship between basic needs (primary stressor) and depression was mediated by emotion focused coping. As Figure 5 illustrates, the standardized regression coefficient between basic needs and depression decreased substantially when controlling for emotion focused coping (from $\beta = -.67$, $p < .001$ to $\beta = -.48$, $p < .001$). The other conditions of mediation were also met: Basic needs was a significant predictor of depression ($\beta = -.67$, $p < .001$) and of emotion focused coping ($\beta = -.47$, $p < .001$), and emotion focused coping was a significant predictor of depression while controlling for basic needs ($\beta = .41, p < .001$). The mediating role of emotion focused coping between basic needs and depression was confirmed by Sobel test (Sobel $z = 3.82, p < .001$). Thus, emotion focused coping mediated the relationship between basic needs and depression.



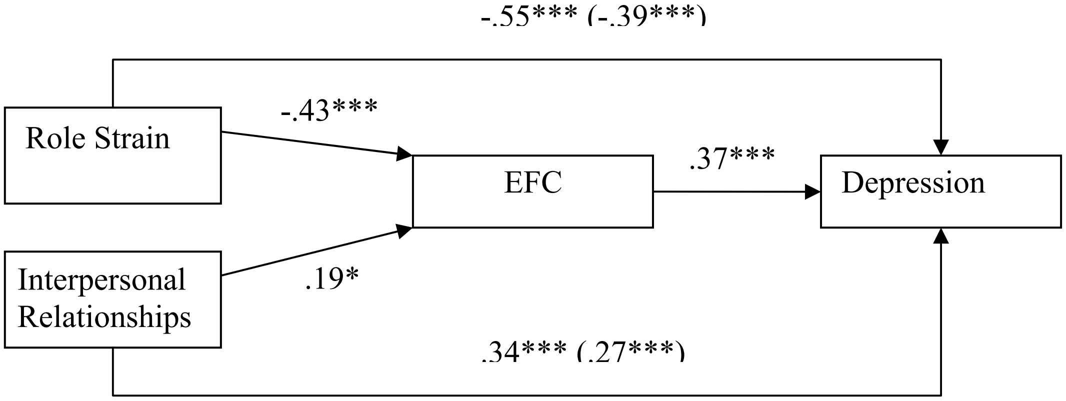
Note. * $p < .05$; ** $p < .01$; *** $p < .001$

Figure 5. The Relationship between the Primary Stressors and Depression Having Emotion Focused Coping as the Mediator.

Emotion focused coping mediated the relationship between depression and role strain (secondary stressor) (See Figure 6). The standardized regression coefficient between role strain and depression decreased substantially when controlling for emotion focused coping (from $\beta = -.55, p < .001$ to $\beta = -.39, p < .001$). The other conditions of mediation were also met: Role strain was a significant predictor of depression ($\beta = -.55, p < .001$) and of emotion focused coping ($\beta = -.43, p < .001$). Emotion focused coping was a significant predictor of depression while controlling for role strain and interpersonal relationships ($\beta = .37, p < .001$).

The mediating role of emotion focused coping between role strain and depression was confirmed by Sobel test (Sobel *z* = -3.46, *p* < .001). Hence, emotion focused coping mediated the relationship between role strain and depression.

Similar to role strain, the standardized regression coefficient between interpersonal relationships (secondary stressor) and depression decreased significantly when controlling for emotion focused coping (from β = .34, *p* < .001 to β = .27, *p* < .001). Interpersonal relationships was also a significant predictor of depression (β = .34, *p* < .001) and of emotion focused coping (β = .19, *p* < .05), and emotion focused coping was a significant predictor of depression while controlling for role strain and interpersonal relationships (β = .37, *p* < .001). However, the mediator role of emotion focused coping between interpersonal relationships and depression was not confirmed by Sobel test (Sobel *z* = 1.94, *p* = .05). Therefore, emotion focused coping did not mediate the relationship between interpersonal relationships and depression (See Figure 6).



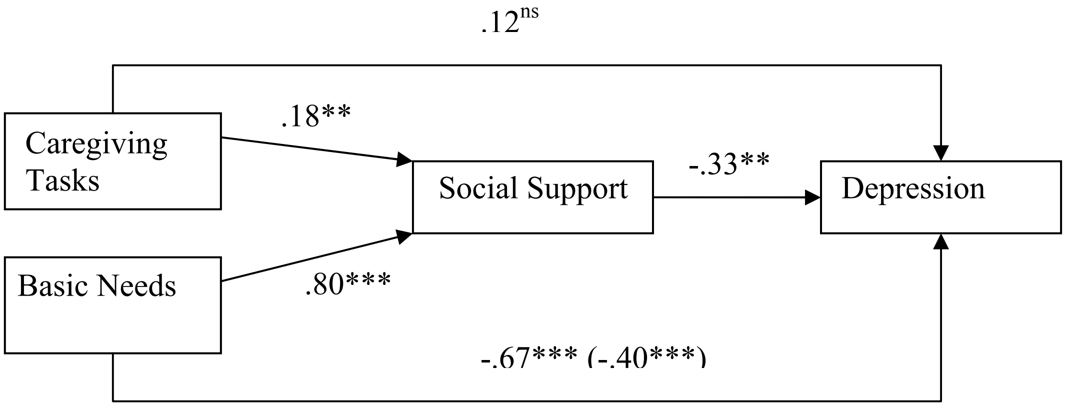
Note. * *p* < .05; ** *p* <.01; *** *p* <.001

Figure 6. The Relationship between the Secondary Stressors and Depression Having Emotion Focused Coping as the Mediator.

3.2.7.1.3. *Social Support as Mediator*

The relationship between caregiving tasks (primary stressor) and depression was not mediated by social support because the conditions of mediation were not fulfilled. That is, although caregiving tasks predicted social support ($\beta = .18, p < .01$), it did not predict depression ($\beta = .12, p = .12$) (See Figure 7). Thus, social support did not mediate the relationship between caregiving tasks and depression.

The relationship between basic needs (primary stressor) and depression was mediated by social support. As shown in Figure 7, the standardized regression coefficient between basic needs and depression decreased from $\beta = -.67, p < .001$ to $\beta = -.40, p < .001$ when controlling for social support. The other conditions of mediation were also met: Basic needs was a significant predictor of depression ($\beta = -.67, p < .001$) and of social support ($\beta = .80, p < .001$), and social support was a significant predictor of depression while controlling for basic needs ($\beta = -.33, p < .01$). The mediating role of emotion focused coping between basic needs and depression was confirmed by Sobel test (Sobel $z = -2.64, p < .01$). Thus, social support mediated the relationship between basic needs and depression.

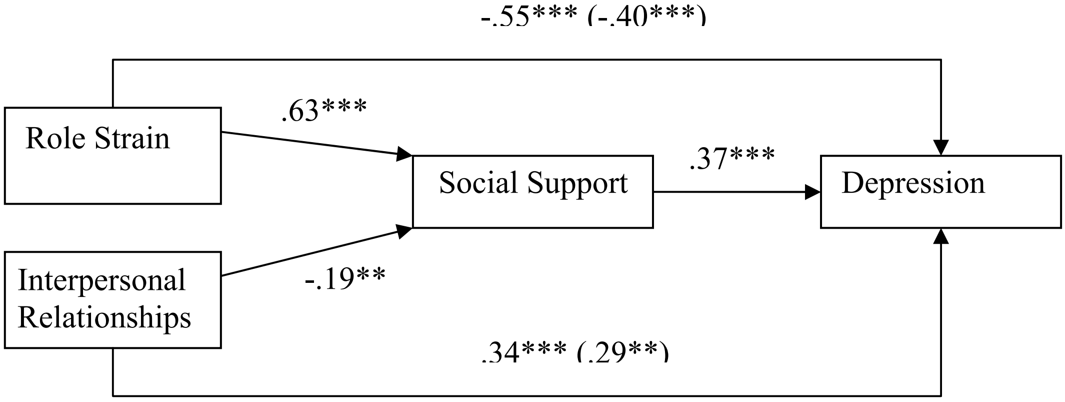


Note. * $p < .05$; ** $p <.01$; *** $p <.001$

Figure 7. The Relationship between the Primary Stressors and Depression Having Social Support as the Mediator.

For the secondary stressors, social support mediated the relationship between depression and role strain (secondary stressor). As shown in Figure 8, the standardized regression coefficient between role strain and depression decreased substantially when controlling for social support (from $\beta = - .55$, $p < .001$ to $\beta = - .40$, $p < .001$). The other conditions of mediation were also met: Role strain was a significant predictor of depression ($\beta = - .55$, $p < .001$) and of social support ($\beta = .63$, $p < .001$). Social support was a significant predictor of depression while controlling for role strain and interpersonal relationships ($\beta = .37$, $p < .001$). The mediating role of social support between role strain and depression was verified by Sobel test (Sobel $z = -2.34$, $p < .05$). Thus, social support mediated the relationship between role strain and depression.

Similarly, the standardized regression coefficient between interpersonal relationships and depression decreased significantly when controlling for social support (from *β* = .34, *p* < .001 to *β* = .29, *p* < .001). Interpersonal relationships was also a significant predictor of depression (*β* = .34, *p* < .001) and of social support (*β* = -.19, *p* < .01) and social support was a significant predictor of depression while controlling for role strain and interpersonal relationships (*β* = .37, *p* < .001). The Sobel test did not reveal a significant result for the mediated relationship for interpersonal relationships (Sobel *z* = 1.78, *p* = .07). Therefore, social support did not mediate the relationship between interpersonal relationships and depression (See Figure 8).



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

Figure 8. The Relationship between the Secondary Stressors and Depression Having Social Support as the Mediator.

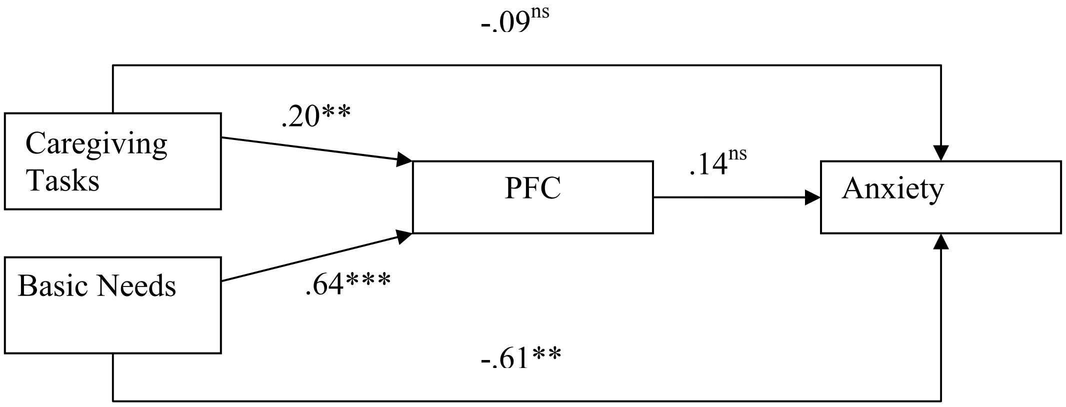
3.2.7.2. *Mediation Models for Anxiety*

Six mediation models were proposed for anxiety being the dependent variable. The independent variables were primary stressors (caregiving tasks and basic needs) and secondary stressors (role strain and interpersonal relationships). The mediators were problem focused coping, emotion focused coping, and social support.

3.2.7.2.1. *Problem Focused Coping as Mediator*

Caregiving tasks (primary stressor) predicted problem focused coping significantly ($\beta = .20$, $p < .01$). However, it was not a significant predictor of anxiety ($\beta = -.09$, $p = .26$). As the conditions of mediation were not met, problem focused coping did not mediate the relationship between caregiving tasks and anxiety (See Figure 9).

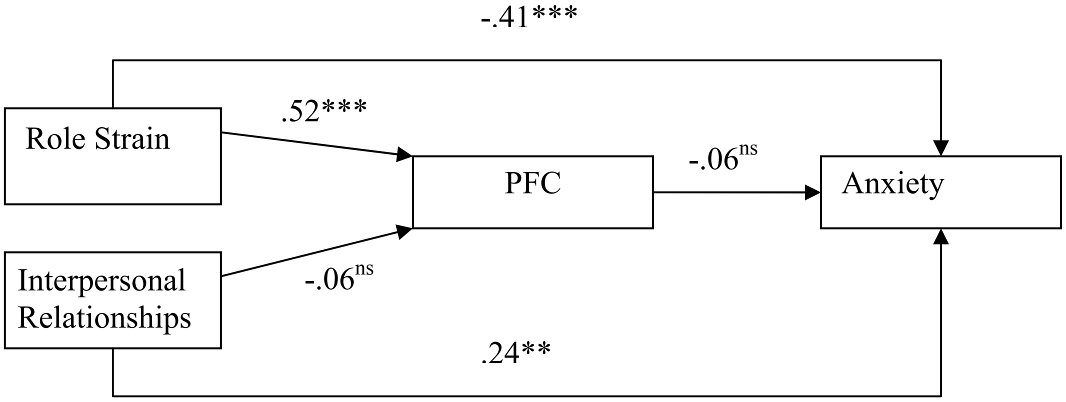
Problem focused coping did not mediate the relationship between basic needs (primary stressor) and anxiety, as well (See Figure 9). Although basic needs was a significant predictor of anxiety ($\beta = -.61$, $p < .01$) and of problem focused coping ($\beta = .64$, $p < .001$), problem focused coping was a not significant predictor of anxiety while controlling for basic needs ($\beta = .14$, $p = .19$). Thus, the analysis suggested that problem focused coping did not mediate the relationship between basic needs and caregiving tasks with anxiety.



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

Figure 9. The Relationship between the Primary Stressors and Anxiety Having Problem Focused Coping as the Mediator.

As in the case of primary stressors, problem focused coping did not mediate the relationship between secondary stressors (role strain and interpersonal relationships) and anxiety, because problem focused coping did not predict anxiety ($\beta = - .06, p = .55$). However, the effect of role strain on problem focused coping ($\beta = .52, p < .001$) and anxiety ($\beta = - .41, p < .001$) and the effect of interpersonal relationships on anxiety ($\beta = .24, p < .001$) were significant (See Figure 10).



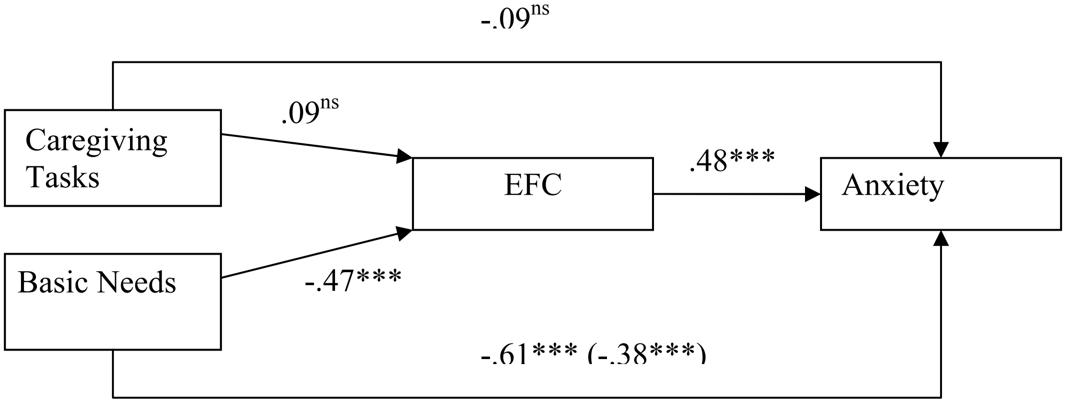
Note. * $p < .05$; ** $p < .01$; *** $p < .001$

Figure 10. The Relationship between the Secondary Stressors and Anxiety Having Problem Focused Coping as the Mediator.

3.2.7.2.2. *Emotion Focused Coping as Mediator*

The relationship between caregiving tasks (primary stressor) and anxiety was not mediated by emotion focused coping because the conditions of mediation were not met. That is, caregiving tasks did not predict anxiety ($\beta = -.09, p = .26$) and emotion focused coping ($\beta = .09, p = .29$) (See Figure 11).

The relationship between basic needs (primary stressor) and anxiety was mediated by emotion focused coping. As Figure 11 illustrates, the standardized regression coefficient between basic needs and anxiety decreased substantially when controlling for emotion focused coping (from $\beta = -.61, p < .001$ to $\beta = -.38, p < .001$). The other conditions of mediation were also met: Basic needs was a significant predictor of anxiety ($\beta = -.61, p < .001$) and of emotion focused coping ($\beta = -.47, p < .001$), and emotion focused coping was a significant predictor of anxiety while controlling for basic needs (*β* = .48, *p* < .001). The mediating role of emotion focused coping between basic needs and anxiety was confirmed by Sobel test (Sobel *z* = -3.98, *p*< .001). Therefore, emotion focused coping mediated the relationship between basic needs and anxiety.

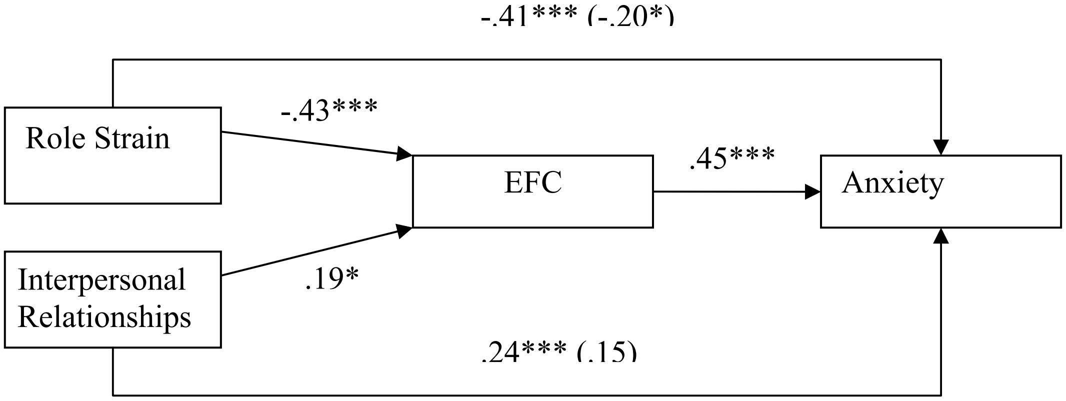


Note. * *p* < .05; ** *p* <.01; *** *p* <.001

Figure 11. The Relationship between the Primary Stressors and Anxiety Having Emotion Focused Coping as the Mediator.

Emotion focused coping mediated the relationship between anxiety and role strain (secondary stressor) (See Figure 12). The standardized regression coefficient between role strain and anxiety declined substantially when emotion focused coping was controlled (from *β* = - .41, *p* < .001 to *β* = - .20, *p* < .001). The other conditions of mediation were also met: Role strain was a significant predictor of anxiety (*β* = - .41, *p* < .001) and of emotion focused coping (*β* = - .43, *p* < .001). Emotion focused coping was a significant predictor of anxiety while controlling for role strain and interpersonal relationships (*β* = .37, *p* < .001). The mediating role of emotion focused coping between role strain and anxiety was confirmed by Sobel test (Sobel *z* = -3.64, *p* < .001).

Emotion focused coping mediated the relationship between anxiety and interpersonal relationships (secondary stressor), too (See Figure 12). The standardized regression coefficient between interpersonal relationships and anxiety decreased and was no longer significant when controlling for emotion focused coping (from $\beta = .24$, $p < .01$ to $\beta = .15$, $p = .06$). This mediated relationship between interpersonal relationships and anxiety that became insignificant was a full mediation according to Baron and Kenny (1986). Interpersonal relationships was also a significant predictor of anxiety ($\beta = .24$, $p < .01$) and of emotion focused coping ($\beta = .19$, $p < .05$) and emotion focused coping was a significant predictor of anxiety while controlling for role strain and interpersonal relationships ($\beta = .37$, $p < .001$). Sobel test displayed significant results for mediating role of emotion focused coping between interpersonal relationships and anxiety (Sobel $z = 1.97$, $p < .05$). Thus, emotion focused coping mediated the relationship between anxiety and both role strain and interpersonal relationships (secondary stressors).



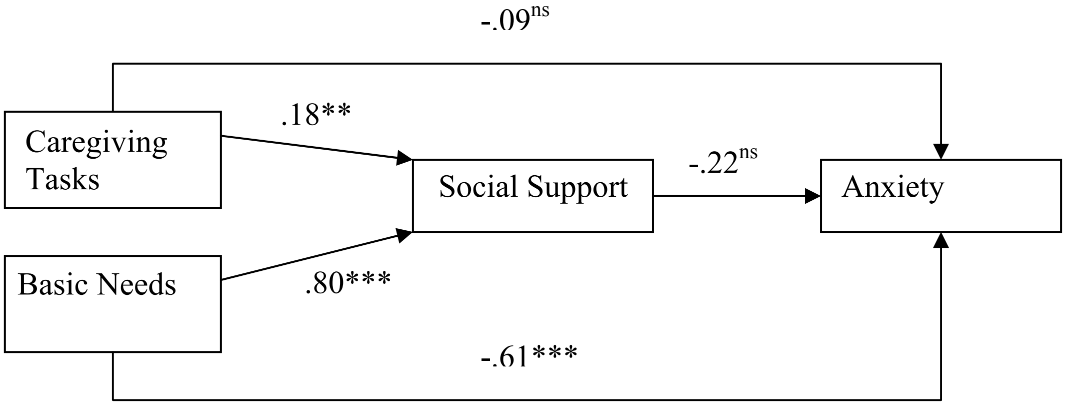
Note. * $p < .05$; ** $p <.01$; *** $p <.001$

Figure 12. The Relationship between the Secondary Stressors and Anxiety Having Emotion Focused Coping as the Mediator.

3.2.7.2.3. *Social Support as Mediator*

The relationship between caregiving tasks (primary stressor) and anxiety was not mediated by social support because the conditions of mediation were not fulfilled. That is, although caregiving tasks predicted social support (β = .18, p < .01), it did not predict anxiety (β = -.09, p = .26) (See Figure 13). Moreover, social support was not a significant predictor of anxiety (β = -.22, p = .11). Thus, social support did not mediate the relationship between caregiving tasks and anxiety.

The relationship between basic needs and anxiety was not mediated by social support, too (See Figure 13). Only the following conditions of mediation were met: Basic needs was a significant predictor of anxiety (β = - .61, p < .001) and of social support (β = .80, p < .001). Therefore, social support did not mediate the relationship between primary stressors (caregiving tasks and basic needs) and anxiety.

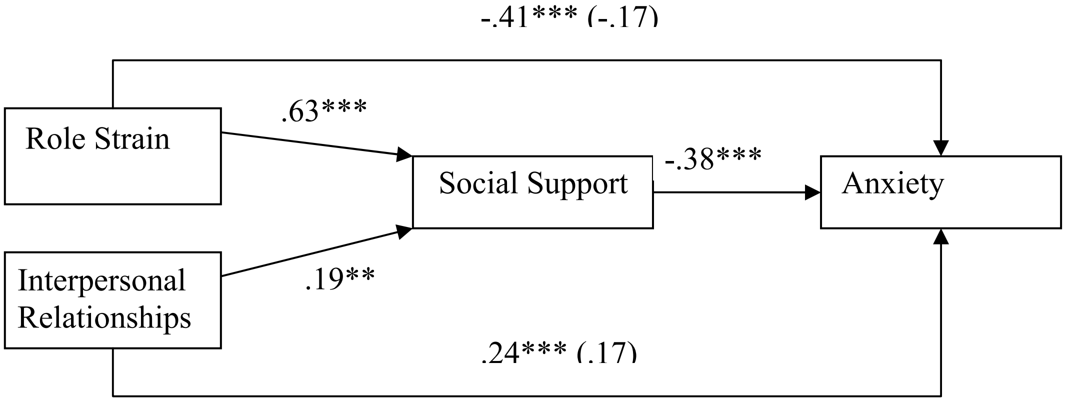


Note. * p < .05; ** p <.01; *** p <.001

Figure 13. The Relationship between the Primary Stressors and Anxiety Having Social Support as the Mediator.

The relationship between anxiety and the secondary stressors (both role strain and interpersonal relationships) was mediated by social support (See Figure 14). The standardized regression coefficient between role strain and anxiety decreased considerably and became insignificant, indicating a full mediation, when social support was controlled (from $\beta = -.41$, $p < .001$ to $\beta = -.17$, $p = .13$). The other conditions of mediation were also met: Role strain was a significant predictor of anxiety ($\beta = -.41$, $p < .001$) and of social support ($\beta = .63$, $p < .001$). Social support was a significant predictor of anxiety while controlling for role strain and interpersonal relationships ($\beta = -.38$, $p < .001$). The mediating role of social support between role strain and anxiety was confirmed by Sobel test (Sobel $z = -3.07$, $p < .01$).

The standardized regression coefficient between interpersonal relationships and anxiety also decreased and was no longer significant when controlling for social support (from $\beta = .24$, $p < .01$ to $\beta = .17$, $p = .06$) which was another full mediation (See Figure 14). Interpersonal relationships was a significant predictor of anxiety ($\beta = .24$, $p < .01$) and of social support ($\beta = .19$, $p < .01$) and social support was a significant predictor of anxiety while controlling for role strain and interpersonal relationships ($\beta = -.38$, $p < .001$). The mediating role of social support between interpersonal relationships and anxiety was confirmed by Sobel test (Sobel $z = 2.05$, $p < .05$). Thus, social support mediated the relationship between the secondary stressors (role strain and interpersonal relationships) and anxiety.



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

Figure 14. The Relationship between the Secondary Stressors and Anxiety Having Social Support as the Mediator.

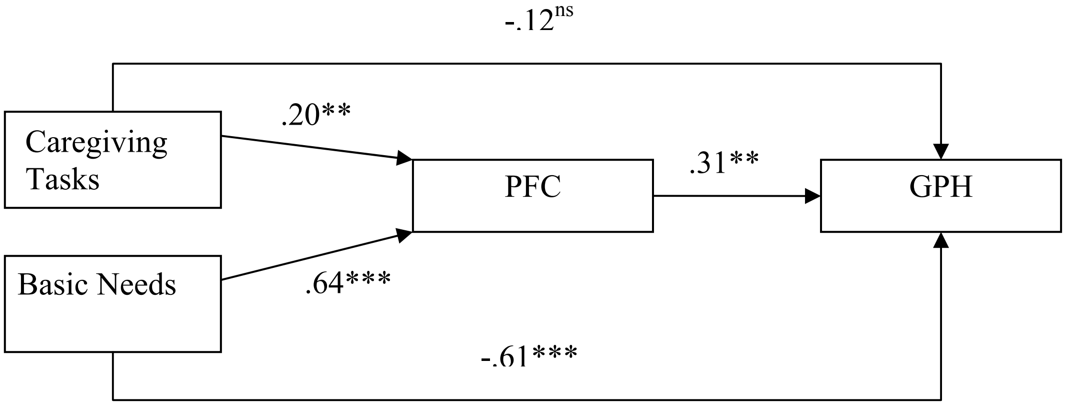
3.2.7.3. *Mediation Models for General Psychological Health*

Six mediation models were proposed for general psychological health as the dependent variable. The independent variables were primary stressors (caregiving tasks and basic needs) and secondary stressors (role strain and interpersonal relationships). The mediators were problem focused coping, emotion focused coping, and social support.

3.2.7.3.1. *Problem Focused Coping as Mediator*

Caregiving tasks (primary stressor) predicted problem focused coping significantly ($\beta = .20, p < .01$). However, it did not predict general psychological health (shown as GPH in the figure) ($\beta = -.12, p = .12$). Since the conditions of mediation were not met, problem focused coping did not mediate the relationship between caregiving tasks and general psychological health (See Figure 15).

Problem focused coping did not mediate the relationship between basic needs (primary stressor) and general psychological health, as well (See Figure 15). Basic needs was a significant predictor of general psychological health ($\beta = -.61, p < .001$) and of problem focused coping ($\beta = .64, p < .001$) and problem focused coping was a significant predictor of general psychological health while controlling for basic needs ($\beta = .31, p < .01$). However, the following condition of mediation was not met: When the basic needs and problem focused coping were entered in the equation as the final step, the standardized regression coefficient between basic needs and general psychological health increased when controlling for emotion focused coping (from $\beta = -.61, p < .001$ to $\beta = -.81, p < .001$). Thus, the analysis suggested that problem focused coping did not mediate the relationship between basic needs and general psychological health.

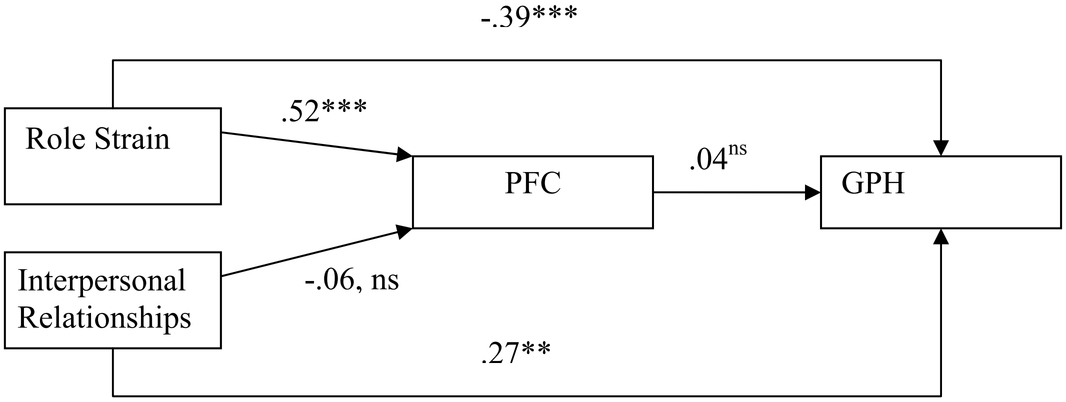


Note. * $p < .05$; ** $p < .01$; *** $p < .001$

Figure 15. The Relationship between the Primary Stressors and General Psychological Health Having Problem Focused Coping as the Mediator.

Similarly, problem focused coping did not mediate the relationship between role strain and general psychological health (See Figure 16). Although role strain predicted problem focused coping ($\beta = .52, p < .001$) and general psychological health ($\beta = -.39, p < .001$) and interpersonal relationships predicted general psychological health ($\beta = .27, p < .01$) significantly, problem focused coping did not predict general psychological health when role strain was controlled ($\beta = .04, p = .68$).

The relationship between interpersonal relationships and general psychological health was not mediated by problem focused coping, too (See Figure 16). Interpersonal relationships predicted significantly general psychological health ($\beta = .27, p < .001$). However, it did not predict problem focused coping significantly ($\beta = -.06, p = .47$) and problem focused coping did not predict general psychological health ($\beta = .04, p = .68$) when interpersonal relationships was controlled. Thus, the relationship between the secondary stressors (role strain and interpersonal relationships) and general psychological health was not mediated by problem focused coping.



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

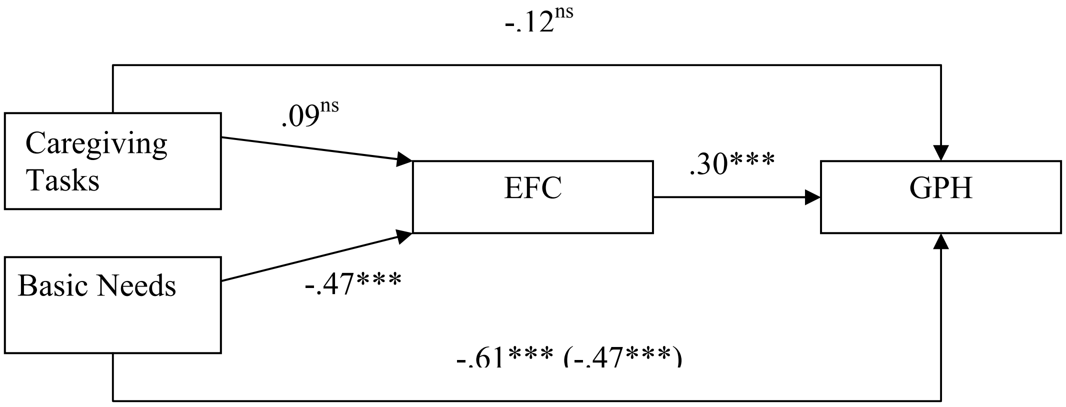
Figure 16. The Relationship between the Secondary Stressors and General Psychological Health Having Problem Focused Coping as the Mediator.

3.2.7.3.2. *Emotion Focused Coping as Mediator*

Emotion focused coping did not mediate the relationship between caregiver tasks (primary stressor) and general psychological health, as shown in Figure 17. The following conditions of mediation were not met: Caregiving tasks (primary stressor) neither predicted emotion focused coping significantly ($\beta = .09, p = .29$) nor general psychological health ($\beta = -.12, p = .12$). Since the conditions of mediation were not met, emotion focused coping did not mediate the relationship between caregiving tasks and general psychological health.

Emotion focused coping mediated the relationship between basic needs (primary stressor) and general psychological health (See Figure 17). The standardized regression coefficient between basic needs and general psychological health decreased substantially when controlling for emotion focused coping (from β

= - .61, $p < .001$ to $\beta = -.47$, $p < .001$). The other conditions of mediation were met, as well: Basic needs was a significant predictor of general psychological health ($\beta = -.61$, $p < .001$) and of emotion focused coping ($\beta = -.47$, $p < .001$), and emotion focused coping was a significant predictor of general psychological health while controlling for basic needs ($\beta = .30$, $p < .001$). Sobel test results verified the mediating role of emotion focused coping between basic needs and general psychological health (Sobel $z = -2.94$, $p < .001$). Thus, emotion focused coping mediated the relationship between basic needs and general psychological health.

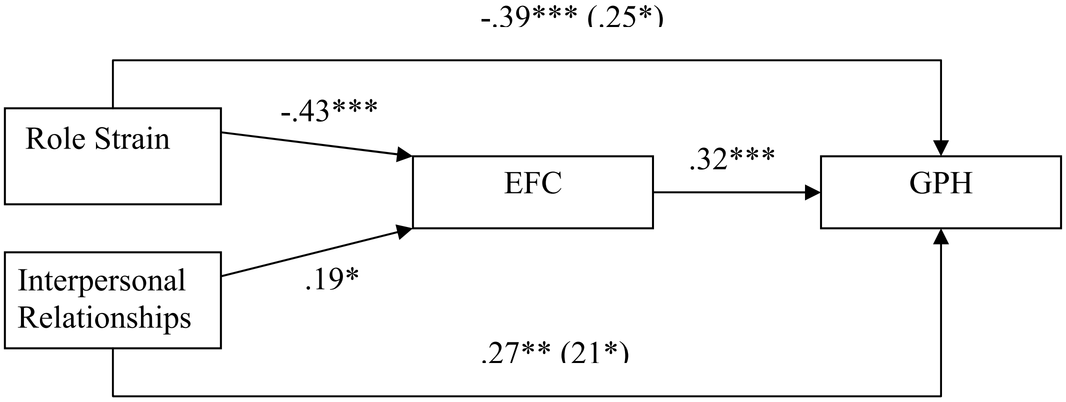


Note. * $p < .05$; ** $p < .01$; *** $p < .001$

Figure 17. The Relationship between the Primary Stressors and General Psychological Health Having Emotion Focused Coping as the Mediator.

The relationship of general psychological health with role strain (secondary stressor) was mediated by emotion focused coping (See Figure 18). The standardized regression coefficient between role strain and general psychological health decreased considerably when emotion focused coping was controlled (from $\beta = -.39$, $p < .001$ to $\beta = -.25$, $p < .01$). The other conditions of mediation were also met: Role strain was a significant predictor of general psychological health (*β* = - .39, *p* < .001) and of emotion focused coping (*β* = - .43, *p* < .001). Emotion focused coping was a significant predictor of general psychological health while controlling for role strain and interpersonal relationships (*β* = .32, *p* < .001). Sobel test confirmed that the mediating role of emotion focused coping between role strain and general psychological health (Sobel *z* = -2.73, *p* < .01). Thus, emotion focused coping mediated the relationship between role strain and general psychological health.

Emotion focused coping did not mediate the relationship between interpersonal relationships and general psychological health (See Figure 18). The standardized regression coefficient between interpersonal relationships and general psychological health decreased (from *β* = .27, *p* < .01 to *β* = .21, *p* < .05). Interpersonal relationships was also a significant predictor of anxiety (*β* = .27, *p* < .001) and of emotion focused coping (*β* = .19, *p* < .05) and emotion focused coping was a significant predictor of general psychological health while controlling for role strain and interpersonal relationships (*β* = .32, *p* < .001). However, for interpersonal relationships and general psychological health, the mediation could not be confirmed (Sobel *z* = 1.78, *p* = .07). Therefore, emotion focused coping did not mediate the relationship between interpersonal relationships and general psychological health.



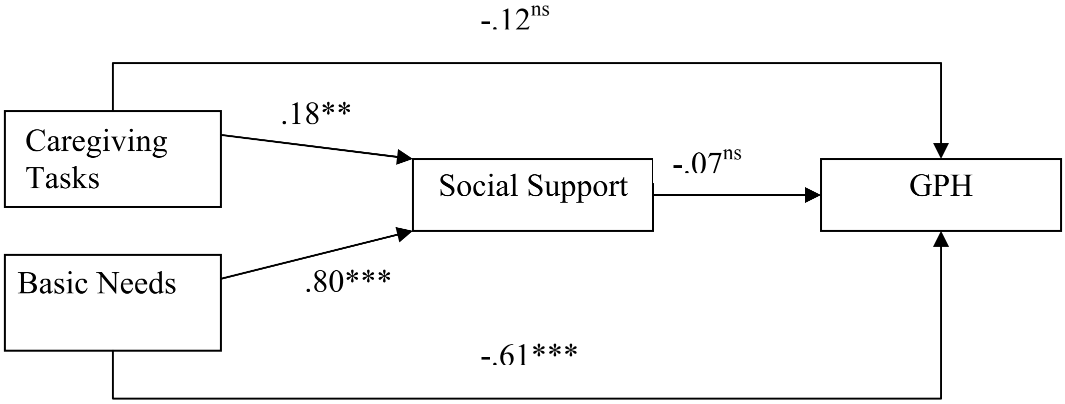
Note. * $p < .05$; ** $p <.01$; *** $p <.001$

Figure 18. The Relationship between the Secondary Stressors and General Psychological Health Having Emotion Focused Coping as the Mediator.

3.2.7.3.3. *Social Support as Mediator*

The relationship between caregiving tasks (primary stressor) and general psychological health was not mediated by social support (See Figure 19). Caregiving tasks predicted social support ($\beta = .18, p < .01$), however, it did not predict general psychological health ($\beta = -.12, p = .12$). Besides, social support did not predict general psychological health significantly ($\beta = -.07, p = .59$).Thus, social support did not mediate the relationship between caregiving tasks and general psychological health.

Similarly, social support did not mediate the relationship between basic needs and general psychological health (See Figure 19). Although basic needs was a significant predictor of general psychological health ($\beta = - .61, p < .001$) and of social support ($\beta = .80, p < .001$), social support was a not significant predictor of general psychological health while controlling for basic needs ($\beta = -.07, p = .59$). Thus, social support did not mediate the relationship between the primary stressors (both caregiving tasks and basic needs) and general psychological health.



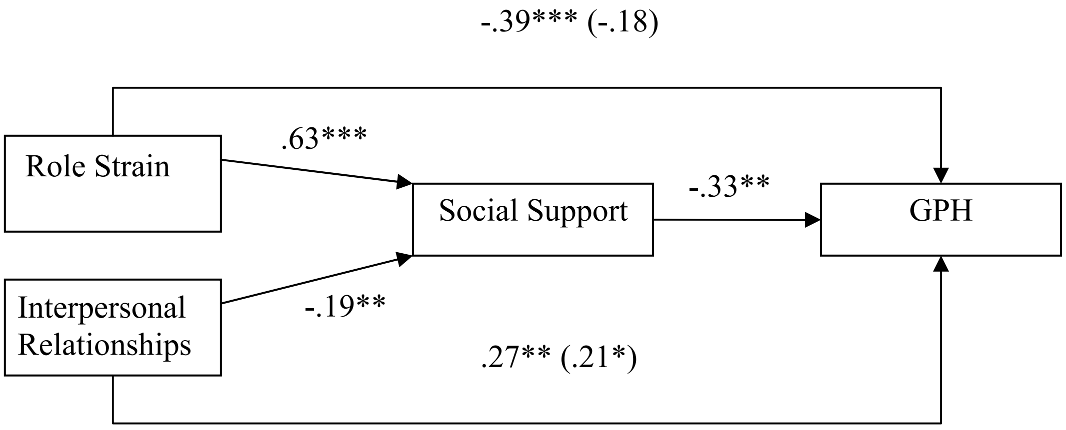
Note. * $p < .05$; ** $p < .01$; *** $p < .001$

Figure 19. The Relationship between the Primary Stressors and General Psychological Health Having Social Support as the Mediator.

Social support mediated the relationship between general psychological health and role strain (secondary stressor), as shown in Figure 20. The standardized regression coefficient between role strain and general psychological health was no longer significant when social support was controlled (from $\beta = -.39, p < .001$ to $\beta = -.18, p = .12$). The other conditions of mediation were also met: Role strain was a significant predictor of general psychological health ($\beta = -.39, p < .001$) and of social support ($\beta = .63, p < .001$). Social support was a significant predictor of general psychological health while controlling for role strain and interpersonal relationships ($\beta = -.33, p < .01$). Sobel test confirmed the mediating role of social support between role strain and general psychological health (Sobel $z = -2.61, p <$

.01). Therefore, social support mediated the relationship between general psychological health and role strain

The relationship between general psychological health and interpersonal relationships (secondary stressor) was not mediated by social support, as shown in Figure 20 The standardized regression coefficient between interpersonal relationships and general psychological health decreased when social support was controlled (from $\beta = .27$, $p < .01$ to $\beta = .21$, $p < .05$). Interpersonal relationships was also a significant predictor of general psychological health ($\beta = .27$, $p < .01$) and of social support ($\beta = -.19$, $p < .01$) and social support was a significant predictor of general psychological health while controlling for role strain and interpersonal relationships ($\beta = -.33$, $p < .01$). However, for interpersonal relationships and general psychological health the mediation could not be confirmed (Sobel $z = 1.89$, $p = .05$).



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

Figure 20. The Relationship between the Secondary Stressors and General Psychological Health Having Social Support as the Mediator.

The summary for the mediation models tested with the primary stressors (basic needs and caregiving tasks), secondary stressors (role strain and interpersonal relationships), and the psychological outcomes (depression, anxiety and general psychological health) having problem focused coping, emotion focused coping and social support as the mediators are presented in Table 18.

Table 18

The Results of the Path Analyses

IV	Mediator	DV	Mediation	Sobel
Basic Needs	PFC	Depression	No	
Basic Needs	EFC	Depression	**Yes**	Significant
Basic Needs	SS	Depression	**Yes**	Significant
Caregiving Tasks	PFC	Depression	No	
Caregiving Tasks	EFC	Depression	No	
Caregiving Tasks	SS	Depression	No	
Role Strain	PFC	Depression	No	
Role Strain	EFC	Depression	**Yes**	Significant
Role Strain	SS	Depression	**Yes**	Significant
Interpersonal Relationships	PFC	Depression	No	
Interpersonal Relationships	EFC	Depression	**Yes**	Not Significant
Interpersonal Relationships	SS	Depression	**Yes**	Not Significant
Basic Needs	PFC	Anxiety	No	
Basic Needs	EFC	Anxiety	**Yes**	Significant
Basic Needs	SS	Anxiety	No	
Caregiving Tasks	PFC	Anxiety	No	

Table 18 (Continued)

IV	Mediator	DV	Mediation	Sobel
Caregiving Tasks	EFC	Anxiety	No	
Caregiving Tasks	SS	Anxiety	No	
Role Strain	PFC	Anxiety	No	
Role Strain	EFC	Anxiety	**Yes**	Significant
Role Strain	SS	Anxiety	**Yes**	Significant
Interpersonal Relationships	PFC	Anxiety	No	
Interpersonal Relationships	EFC	Anxiety	**Yes**	Significant
Interpersonal Relationships	SS	Anxiety	**Yes**	Significant
Basic Needs	PFC	GPH	No	
Basic Needs	EFC	GPH	**Yes**	Significant
Basic Needs	SS	GPH	No	
Caregiving Tasks	PFC	GPH	No	
Caregiving Tasks	EFC	GPH	No	
Caregiving Tasks	SS	GPH	No	
Role Strain	PFC	GPH	No	
Role Strain	EFC	GPH	**Yes**	Significant
Role Strain	SS	GPH	**Yes**	Significant
Interpersonal Relationships	PFC	GPH	No	
Interpersonal Relationships	EFC	GPH	**Yes**	Not Significant
Interpersonal Relationships	SS	GPH	**Yes**	Not Significant

CHAPTER IV

DISCUSSION

Caregiver studies addressed various contextual and background factors, stressors, several mediator variables (e.g. social support), and outcomes; and some models were proposed to understand multiple mechanisms of caregiver stress including some of the stressors and outcomes, examples of which were mentioned in Chapter I. The present study was one of those studies trying to include the most important variables for the caregiver's health outcomes, which in turn will affect the health of the patient, the family and the caregiver himself/herself. The aim of the present study was to explore the predictors and mediators of psychological outcomes of the caregivers of children with leukemia. The Caregiver Stress Model (Pearlin et al., 1990) was used as a conceptual framework of the present research, the hypotheses of which were mentioned in Chapter I (p. 25).

4.1. *Results of the Study*

The findings of the study will be discussed in the light of the literature. The psychometric properties of the scales, the effects of demographic variables on the outcome variables, predictors of the outcome variables, and the mediation models are presented in this section.

4.1.1. *Psychometric Properties of the Scales*

Although the caregiver stress model of Pearlin and colleagues (1990) was selected as a framework of the present study, the measurement devices were different. In the development of the original model (Pearlin et al., 1990), questions were developed for each variable by the researchers. However, some valid objective measures were used in the present study. The only similarity is that both studies used self-report measures.

To assess the primary and secondary stressors, some objective measures were needed. Therefore, the caregiver well-being scale, which was developed by Berg-Weger, Rubio, and Tebb (2000), was found appropriate because the operational definitions and example items of daily needs (one of primary stressors) and role strain (one of secondary stressors) were compatible with the definitions and items of the basic needs subscale and activities of living subscale. The adaptation of the scale was conducted as study 1 with a caregiver sample of various illnesses that require continuous care.

The analysis of the basic needs subscale and activities of living subscale of the caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000) showed that both scales were psychometrically reliable and valid for Turkish caregivers. Similar results were obtained by Tebb (1995) and Berg-Weger, Rubio, and Tebb (2000) with regard the internal consistency coefficients and validity measures. The comparisons with a non-caregiver group allowed us to draw some conclusions, which were also confirmed by studies in the literature (e.g. Hoyert & Seltzer, 1992). It was found in the present study that the means of the caregiver group were significantly lower than the non-caregiver group for both the basic needs and the activities of living subscales. Therefore, the study supported that being a caregiver is a risk factor for psychosocial problems for people caregiving a chronically ill family member. The findings also supported Tebb's (1995) study that the caregiver well-being scale (Berg-Weger, Rubio, & Tebb, 2000) is able to distinguish caregivers from non-caregivers.

In study 2, some modifications in the secondary stressors were seen necessary because the nature of the illness, and the care-receivers who were different from the original model. Some illness related modifications were prepared for the caregivers of leukemia. In addition to role strain, interpersonal relationships was added to the secondary stressors. Therefore, an interpersonal relationships index for leukemia caregivers was designed in order to assess the problems in the interpersonal relationships. It included statements about non-supportive relationships and leukemia related distress. The index had acceptable internal consistency coefficient; thus, it was used as a reliable measure in study 2.

4.1.2. *The Effects of Demographic Variables*

The effects of some demographic variables (i.e. caregiver age, the number of people living in the house, and the duration of caregiving) were investigated. Congruent with the literature (e.g. Matthews, Baker, & Spillers, 2003), it was found that the age of the caregiver predicts the level of distress. The younger the age, the higher the level of depression and anxiety, and the worse the general psychological health.

The number of people living in the house was another predictor of the outcome variables (depression, anxiety and general psychological health). Caregivers living with more people experienced more depression, anxiety, and general psychological symptoms. A possible explanation of these findings may be that more people may mean more workload and more expenses, which adds to role strain and economic problems. Another possible explanation is that the family members may tend to stay away from the illness instead of being close and providing support because of the characteristics of the illness like being life threatening. Thus, living with more people resulted in more negative psychological outcomes.

Level of education was another demographic predictor of caregiver stress. The primary school graduates had the highest scores on depression, anxiety, and general psychological symptoms and as the level of education increased the level of depression, anxiety and general psychological symptoms decreased, indicating that education provided people with a more positive psychological well-being. Similar to level of education, SES was also a significant predictor of psychological outcome variables in caregivers. Although state insurance pays for the medical expenses, the treatment process of leukemia is costly. Moreover, 70% of the participants did not have a current job, which meant a decrement in family income. As a result, the loss of family income was identified as the most important predictor of caregiver quality of life (Yun et al., 2005). SES was considered as a protective factor not only for caregivers, but also for non-caregivers. Pinquart and Sörensen (2007) concluded that SES had effects on physical health of non-caregivers, too. Both groups took the advantage of high SES. Thus, family income was an important factor influencing the physical and psychological health outcomes.

It was hypothesized that the age of the child with a chronic illness would predict the psychological outcomes of the caregivers. The studies found that as the age of the child increases, the level of caregiver distress increases, as well (Barakat, Patterson, Tarazy, & Ely, 2007). On the contrary, the present study did not reveal any significant differences between the caregivers of different age groups. The reason of this difference could be the insufficient number of participants who were caregivers of adolescents, which resulted in an unbalanced group sizes.

Leukemia is one of the disorders that require hospitalization in the first phase. There may be some differences between caregiving at the hospital setting and home setting. Hence, some differences in the level of distress might be expected. Ow (2003) compared the caregiver burden of mothers of children with cancer at the beginning of hospitalization and post-hospitalization, and found that the level of stress at the former measure was higher than the latter one. Moreover, a study, comparing health related quality of life of mothers of children with leukemia at hospital care, home care, and regular care revealed that hospital care group had the worst scores of health related quality of life (Yamazaki et al., 2005), the findings of which were verified by the present study. Caregivers of outpatient group had lower scores on depression, anxiety, and general psychological symptoms than the caregivers of inpatient group. Thus, caregiving during hospitalization results in more negative psychological health outcomes. A possible explanation is that during hospitalization, the initial reactions to the diagnosis could still be active. However, after post-hospitalization, the initial reactions decline and the level of stress becomes stable (Ow, 2003), as explained earlier (p. 4). Moreover, hospitalization may require extra time and expenses compared to home setting. During hospitalization, it might be more difficult to continue the daily activities, which might have influenced the basic needs and thereby resulted in more negative outcomes.

The caregiving process is dynamic; including fluctuations in health of both the care-receiver and the caregiver (Nijboer et al., 1998). In that sense, the events and changes during the process may be more important than the length of the caregiving process. The findings of the present study showed that the duration of caregiving did not predict any of the psychological outcome variables. This finding also supports the notion that objective illness variables are not associated with psychological outcomes (Hoekstra-Weebers, Jaspers, Klip, & Kamps, 2000; Nijboer et al., 1998). Thus, subjective appraisal of the illness is more important than the objective criteria.

The caregivers, who were mostly mothers, have to spend their time and energy with their ill child. Having other children to be looked after is a risk factor for the caregivers. It was found that having an additional parenting role increases the level of distress experienced by the caregiver (Kim et al., 2006). The present study did also find that there was a difference between the caregivers with and without other children. In terms of depression and anxiety, significant differences were found. The caregivers who have child(ren) other than the ill child had higher scores on depression and anxiety than the caregivers who were looking after only the ill child. However, there was not a significant difference on general psychological symptoms between the groups.

A potential intervening factor is having assistants in caregiving (Nelson, 1997 cited in Kim et al., 2006). Contrary to the predictions, in the current study getting help from another person for caregiving was not a significant predictor of psychological outcome variables. This can be explained by the assumption that although the tasks were shared, the care giving responsibility might not be shared. That is, having the role of caregiver is only felt by the primary caregiver, and that responsibility may not be shared. Moreover, as it was mentioned, caregiving tasks did not appear as a significant predictor of psychological outcomes. Thus, changes in the number of tasks did not make a difference.

As mentioned previously, there were two views about having a job as a caregiver. The first view asserts that having a job increases distress because the energy and time of the caregiver is limited and therefore the caregiver cannot work in full capacity. On the other hand, the second view argues that having a job is a protective factor, because it adds to the resources of the caregiver (Kim et al., 2006). The findings of the present study supported the second view. It was found that caregivers with a job had significantly less depression, anxiety, and general psychological symptoms.

4.1.3. *Predictors of Depression, Anxiety, and General Psychological Health*

The effects of the independent variables, which were the primary stressors (caregiving tasks and basic needs), the secondary stressors (role strain and interpersonal relationships), and the mediators (problem focused coping, emotion focused coping, and social support) on depression were investigated, controlling for the effects of the demographic variables (age, education level, having an occupation or not and perceived family income). The analyses revealed that the only significant predictor of depression was emotion focused coping when the demographic variables were controlled. As the use of emotion focused coping increased, the level of depression increased, as well.

For anxiety, the significant predictors were basic needs and emotion focused coping, when the demographic variables were controlled. As the satisfaction with the basic needs decreased, the anxiety level increased. Similar to depression, the more the use of emotion focused coping, the higher the level of anxiety.

For general psychological health, the significant predictors were caregiving tasks, basic needs, and emotion focused coping. The decrements in the satisfaction with the basic needs resulted in an increase in general psychological symptoms. As the use of emotion focused coping increased, the level of general psychological symptoms increased, as well.

The analyses revealed three significant predictors for the psychological outcomes. First, the use of emotion focused coping resulted in more negative psychological outcomes, which was also suggested by previous studies (e.g. Fuemmeler et al., 2005; Penley, Tomaka, Wiebe, 2002). The findings suggested that the use of emotion focused coping was a risk factor for the psychological well-being of the caregivers of children with leukemia. Second, the satisfaction of the basic needs of caregivers was found as a significant predictor of anxiety and general psychological health. Similarly, it was confirmed by other studies that the level of the satisfaction of basic needs was important for the psychological well-being of the caregiver (e.g. Quittner et al., 1998, Pearlin et al., 1990).

4.1.4. *The Mediation Models*

The mediating effects of problem focused coping, emotion focused coping, and social support were investigated. Eighteen models were proposed between the primary stressors (caregiving tasks and basic needs), secondary stressors (role strain and interpersonal relations) and the outcome variables (depression, anxiety, and general psychological health). In spite of the fact that the outcome variables were highly correlated with each other, the path analyses revealed important differences for each of the outcome variables. The similarities are that caregiving tasks was not a significant predictor of any of the outcome variables, and problem focused coping did not mediate the relationships between any of the stressors and the outcome variables. Possible explanations of these results will be discussed in the following sections.

4.1.4.1. *The Summary of the Mediation Models*

The models having depression as a dependent variable showed that only basic needs from the primary stressors influenced depression through the mediation of emotion focused coping. This model proposed that the caregivers who met their basic needs less, would have more use of emotion focused coping and thereby reported more depression. Basic needs influenced depression through the mediation of social support, too. The caregivers who met their basic needs more, reported less depression via getting more social support.

From the secondary stressors, role strain, but not interpersonal relationships predicted depression through the mediation of emotion focused coping and social support. Caregivers who experienced higher role strain, in other words, who were less satisfied with their non-caregiving activities, used emotion focused coping more, resulting in an increase in depression. Similarly, caregivers who experienced high role strain, reported getting less social support, and thus, more depression.

The models having anxiety as a dependent variable revealed that the fulfillment of basic needs predicted anxiety through the mediation of emotion focused coping. Similar to depression, the effect of caregiving tasks on anxiety was not verified by the analyses.

The effects of both of the secondary stressors (role strain and interpersonal relationships) on anxiety were mediated by emotion focused coping. That is, the increment in role strain and interpersonal relationships caused an increased use of emotion focused coping, which resulted in increased anxiety. Similarly, the relationship between both the role strain and the interpersonal relationships with anxiety were mediated by social support. Increments in the role strain and interpersonal relationships caused less perceived social support, a condition which resulted in an increased anxiety. An important difference about interpersonal relationships was that the effects of interpersonal relationships only on anxiety was mediated by emotion focused coping and social support.

The models having general psychological health as the dependent variable showed that basic needs (primary stressor) affects general psychological health, indicating a relationship mediated by emotion focused coping. This model proposed that the caregivers who met their basic needs less would have more use of emotion focused coping, and thereby reported more less general psychological health.

Role strain, one of the secondary stressors, predicted general psychological health through the mediation of both emotion focused coping and social support. Caregivers who were less satisfied with their non-caregiving activities, i.e. experienced role strain more, used emotion focused coping more, which brought about a decrease in general psychological health. Similarly, caregivers who experienced more role strain, reported less social support and as a result, they reported less general psychological health. Unlike the role strain, interpersonal relationships did not have a mediated effect on general psychological health.

4.1.4.2. *The Mediators*

As mentioned previously, the studies revealed contradictory results for the effects of coping styles on psychological well-being of caregivers (Grootenhuis & Last, 1997). The present study revealed that emotion focused coping was both a predictor and a mediator of the outcome variables, resulting in worse psychological outcomes. Unlike emotion focused coping, problem focused coping did not mediate the relationship between the stressors and the outcomes.

Use of emotion focused coping was an important mediator between the stressors and the outcomes. It was a worsening factor that influenced the negative effects of the stressors. Penley, Tomaka and Wiebe (2002) concluded in their meta-analysis study that emotion focused coping had moderate levels of associations with negative health outcomes for non-clinical population. Problem focused coping was also associated with the outcomes, to a lesser degree as compared to emotion focused coping. Ben-Zur (2005) examined the relationship between coping and stress outcomes in a community sample, too and found that problem focused coping was not as a strong predictor of distress as emotion focused coping. However, when there was a stressful life event, the effects of problem focused coping was more evident in predicting stress. This difference, which becomes more evident in stressful situations, could be explained by the appraisal of control. Personal control plays an important role for coping with stress (Folkman, 1984). The perception of control depends on the appraisal of the situation. If the situation is perceived as controllable, the use of problem focused coping is more adaptive for the person. However, if the person perceives the situation as uncontrollable, the use of emotion focused coping is more commonly used (Folkman, 1984). In the case of childhood leukemia, the parents might have seen the illness as uncontrollable and might have felt no control over the situation. In this case, they might not use problem focused coping as an adaptive coping mechanism, instead, they might have used emotion focused coping. Thus, the reason why emotion focused coping was a significant mediator rather than problem focused coping may be that leukemia is seen as uncontrollable by the caregivers, resulting in the use of emotion focused coping instead of problem focused coping.

Social support emerged as an effective mediator, decreasing the negative effects of the stressors, as confirmed by the literature (e.g. Hoekstra-Weebers, et al., 2000; McGrath, 2001). Social support was a stronger mediator of the relationship between the secondary stressors and the outcome variables compared to the relationship between primary stressors and the outcome variables. A possible explanation to this difference stems from different nature of the primary and secondary stressors. Primary stressors included basic needs and tasks, whereas secondary stressors included non-basic activities and problems of social life. It is natural that problems in social life get better with perception of more social support and result in less negative outcomes.

4.1.4.3. *The Stressors*

The caregiving tasks, an important part of the caregiver stress model (Pearlin et al., 1990), were studied by the researchers and it was suggested that the type of tasks was more important than number of tasks or time spent for caregiving. That is, if the tasks are confining in terms of difficulty or time consuming, they create more burden (Given et al., 1990 cited in Nijboer et al., 1998). Thus, the perception of the caregiver is more important than the actual burden of the tasks. The present study found no effect of caregiving tasks on psychological outcomes. This could be explained by the fact that the care-receiver is the child. Caregiving tasks of a child and an elderly might be perceived differently by the caregiver. As it was mentioned before, caregiver stress model (Pearlin et al., 1990) was originally developed for the caregivers of Alzheimer's disease patients. The demented person, who was independent and was able to manage his/her self-care, becomes dependent on his/her children due to his/her disease. In other words, the person who was giving care, is now receiving care from his/her child(ren). In the case of the caregivers of children with leukemia, however, the parents may think that they are parents and, regardless of the disease, they already have to take care of their children. Thus, there is not any change in roles. In other words, being a caregiver of their children or their parents may be interpreted differently by the adult caregivers. Therefore, they might not have evaluated the caregiving task as a part of caregiving a patient, but as caregiving their child. In other words, it might not created extra burden for them. This could be the reason of why the caregiving tasks was an insignificant predictor of depression, anxiety, and general psychological health.

The present study supported the findings in the literature that the unsatisfaction with the basic needs resulted in more negative psychological outcomes. It was found that the caregivers reported more disruptions than non-caregivers in daily routine tasks, such as sleep and meals. The disruptions resulted in less marital satisfaction of the caregivers; however, there was not a significant difference on depression scores between caregivers and non-caregivers (Bristol et al., 1988, cited in Quittner et al., 1998). Thus, the satisfaction of the basic needs becomes more difficult to achieve in the case of caregivers, resulting in more distress.

Role strain was defined as the unsatisfaction of the daily activities and the negative effect of role strain was evident on all three of the outcome variables in the present study. Similar results were found by Quittner and colleagues (1998). They indicated that compared to a control group, parents of children with cystic fibrosis experienced more role strain and less time for recreational activities, and this resulted in more distress.

The interpersonal relationships, which had two parts (non-supportive relationships and illness related distress), included the negative interactions which spring from the presence of the illness. The findings suggested that the effects of interpersonal relationships had a deteriorative effect on the outcome variables; however, this negative effect was mediated by emotion focused coping and social support and only on anxiety.

Compared to primary stressors, secondary stressors were more effective in predicting the psychological outcomes. Secondary stressors are more subjective than the primary stressors (Pearlin et al., 1990). Soskolne, Halevy-Levins, and Cohen (2007) also tested Pearlin and colleagues' caregiver stress model and evaluated the stressors as perceived stressors. That is, they tested appraisal of the stressors, which were subjective, and found that perception was more important than the actual situation. The findings of both this study and Soskolne, Halevy-Levins, and Cohen's study (2007) are important for showing the importance of the perception of the caregivers rather than objective criteria.

In summary, the present study tried to identify possible mechanisms through which the stressors influence the psychological well-being of the caregivers of children with leukemia. The outcome variables were different but interrelated, and findings suggested different patterns for the mediation models of the outcome variables. This study provided empirical confirmation for caregiver studies having emotion focused coping and social support as mediators between the stressors and outcomes.

4.2. *Limitations of the Present Study*

One of the most important limitations of the study is the insufficient number of male participants, which hinders a gender based comparison. The reason of this problem is that the ones who brought their children to the hospital and stayed with them in the inpatient service are mostly the mothers. Even though fathers were contacted at the hospitals, they reported mothers as the primary caregiver, which was a necessary condition to be included in the study. Thus, the present study cannot reject or support the studies suggesting that there is a gender difference between males and females about the amount of caregiver stress (e.g. Essen et al., 2004).

Another important limitation is about the non-supportive relationships concept that has not been studied extensively so far. To the researcher's knowledge, there is not a scale developed for measuring the concept. However, it was included in the study in spite of the absence of a validated measurement device because non-supportive relationships might have been a potential stressor which stem from the presence of illness. Although reliability analysis revealed adequate results, drawing strict conclusions about the results of non-supportive relations measures might not be convenient. Further studies about the concept are needed for more accurate results.

Yet another limitation is that the study was conducted only with the caregivers who gave consent to fill in the questionnaires. There were people who did not want to be included in the study. Therefore, they could not be represented by the results of the study. This is a common problem of the caregiver studies (e.g. Kazak et al., 1997; Barrera et al., 2004). In Kazak and colleagues' study, (1997) post traumatic stress symptoms of caregivers of children with leukemia were measured. This limitation of the present study about willingness for participation was discussed also in their study. They suggested that avoidance could be the reason of not participating in the study; in fact, avoidance was a post traumatic stress symptom, too. Some other possible reasons for being involuntary were having a high level of distress, being illiterate and not reporting this, or not having time for filling in the questionnaires. Yet another explanation is about the setting of the study. The questionnaires were filled out at hospital settings. Especially the caregivers, who were expecting the routine test results at the outpatient clinics, might feel anxious. This might have negatively affected the caregivers and changed their mood. Thus, the results represent only the caregivers who had sufficient time, energy and willingness to participate in the study.

Still another limitation is the absence of one demographic variable which might have made a difference, namely the residence of the caregivers. The study was conducted in more developed cities, i.e. Ankara and İzmir that have more treatment opportunities. Therefore, in addition to the residents of the cities, there were patients who were referred to the hospitals from smaller cities or towns. Aitken and Hathaway (1993) (cited in Barrera et al., 2004) found that distance from the treatment center was reported as a major stressor for families. Being away from home might increase the level of distress, which is a confounding variable that the present study failed to measure. Thus, further studies must include the place of residence as a demographic variable.

4.3. *Clinical Implications*

The most important implication is about developing appropriate interventions for caregivers. If the factors that make the people more vulnerable for developing problems are identified, interventions addressing those factors can be developed. Similarly, the strong sides and successful coping strategies of the caregivers can be used as resources in the interventions. One topic to be included in the interventions, derived from the findings of the present study, is teaching coping strategies to the caregivers. Specifically, the issue of control could be distinguished between the controllable aspects and uncontrollable aspects of leukemia. After making this distinction, how to manage the controllable parts could be thought, including problem solving skills, planning, and information gathering, which are the parts of problem focused coping (Folkman & Lazarus, 1984 cited in Folkman & Moskowitz, 2000) because people use problem focused coping more when they perceive the situation as controllable (Folkman, 1984).

Caregivers or families of individuals with chronic conditions consist of an important area for intervention. Specifically for cancer, the emergence of psycho-oncology in the 1970s proved the importance of team work for successful treatment of cancer (Holland, 1992). The team includes the patient, the caregiver and the family, and the medical team. The aims of psycho-oncology studies are to understand the emotional responses of the patients and their families; and to find out the biological, social, and psychological factors that influence the prognosis of the illness. The importance of combining biological, psychological, and social factors rather than focusing only on the biology of the illness was discovered (Holland, 1992). In Turkey, it was seen, by the oncologists, that including the patient alone was not sufficient for a successful treatment (Özkan, 2007). Studies about the inclusion of the family and mental health workers to cancer treatment were started in some hospitals. It was found that referrals to psychiatry departments increased in the recent years, which was interpreted as a sign of change towards a team work in oncology departments (Soygür et al., 2005). Thus, developing interventions, which include the patient, the caregivers, and the medical staff for a successful outcome, is an important issue for researchers and clinicians working with families of cancer.

4.4. *Directions for Future Studies*

Further longitudinal studies, which begin with the diagnosis and continue throughout the treatment process, can give a better understanding of the progress of psychological well-being of the caregivers. Moreover, it will help to find out the critical points such as, bone morrow transplantation (Hare, Skinner, & Kliewer, 1989) or relapse in which stress level can increase. In this way, the time points at which professional help can be needed will be determined.

Studies comparing different types of illnesses give a better understanding of the conditions specific to the illnesses. As it was mentioned before, the illness characteristics had an effect on the caregiver stress. For this reason, studies comparing leukemia with other chronic conditions or other types of childhood cancers will help understanding illness specific characteristics. Similarly, comparing the caregivers with children at different stages of the illness such as; chemotherapy and maintenance therapies will help determining the most stressful periods of the illness. Moreover, focusing on mother caregivers only will give an opportunity to understand the mechanisms specific to the mothers and will make the results more reliably generalized to mother caregivers.

Further studies about developing interventions for specific populations such as, caregivers of leukemia are needed. Drotar, Witherspoon, Zebracki, and Peterson (2006) determined some important points that need to be identified in developing interventions. These points are the targets of the intervention; namely, children, parents or both, some risk factors to which the intervention will address, and resilience factors that will be improved by the intervention. They also emphasized the importance of having a theoretical model in shaping the intervention because the mechanism of change will be determined more accurately if it is based on a particular theory.

In the caregiver studies, focusing on the factors that increase distress for people having a chronically ill family member is not sufficient. Instead, the protective factors should be examined together with the risk factors because there is a multiple mechanism processing for the caregivers.

4.5. *Conclusion*

The findings of the study were compatible with the caregiver stress model (Pearlin et al., 1990) suggesting that the model can be appropriate for the caregivers of children as well as the caregivers of the elderly. The stressors that may affect the caregivers of children with leukemia in negative way, resulting in more psychological health problems were dissatisfaction with the basic needs, role strain and problems in interpersonal relationships; and the mediating factors were emotion focused coping and low social support. Interventions addressing those factors will help the caregivers experience less distress.

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APPENDICES

APPENDIX A: Study 1 Demographic Information Form

Bu çalışma Orta Doğu Teknik Üniversitesi Psikoloji Bölümü Öğretim Üyesi Dr. Özlem Bozo ve Klinik Psikoloji Yüksek Lisans Öğrencisi Dilek Demirtepe tarafından yürütülmektedir. Çalışmanın amacı, hasta aile bireylerine bakım veren kişilerin ihtiyaçlarını ve günlük aktivitelerini ölçmeyi amaçlayan Bakım Veren İyi-Oluş Ölçeği'nin adaptasyonunu yapmaktır. Vereceğiniz cevaplar sadece araştırma amacıyla kullanılacak ve gizli tutulacaktır.

Katılımınız için teşekkür ederiz.

Yaşınız:

Cinsiyetiniz: ____ Kadın ____ Erkek

Eğitim Durumunuz: ___ İlkokul ____Ortaokul ____Lise
____ Üniversite ____Üniversite üstü

Mesleğiniz:

Şu anki evlilik durumunuz: _____ Bekar _____ Evli
_____ Boşanmış _____Eşi vefat etmiş

Aylık gelir miktarınız: _____ Düşük _____ Orta _____ Yüksek

Bakımını üstlendiğiniz hasta ya da engelli bir aile bireyiniz var mı?__________

Cevabınız HAYIR ise aşağıdaki 4 soruyu cevaplandırmadan devam ediniz.

- Hastanın nesi oluyorsunuz?_____________
- Yakınınızın hastalığı/engeli nedir?_____________
- Hastalık ne zamandır sürüyor?___________
- Hastanızın bakımını üstlenen başka biri var mı?(varsa kim olduğunu belirtiniz) ___________

Bakımını üstlendiğiniz kaç kişi var? (kimler olduğunu belirtiniz)

____

Herhangi bir fiziksel rahatsızlığınız var mı? (varsa belirtiniz)

____

Herhangi bir psikolojik rahatsızlığınız var mı? (varsa belirtiniz)

____

Fiziksel ya da psikolojik tedavi görüyor musunuz? / Yardım alıyor musunuz? (varsa tedavi şeklini belirtiniz) ______________________

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

APPENDIX C: Mental, Physical and Spiritual Well-being Scale

Bütün soruların yanında cevabınızı işaretleyeceğiniz bir ölçek vardır. Lütfen her soru için ölçekteki seçeneklerden hangisine kendinizi daha yakın hissediyorsanız ona göre bir rakamı daire içine alınız. Lütfen tüm soruları dürüstçe cevaplayınız. Teşekkür ederiz.

Örnek:

Genellikle mutlu bir kişi misinizdir?	1 Sık sık	2	3	4	5 Asla

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1. Zor zamanlarda ruhani yardıma uzanır mısınız (Örnek: Allah / Tanrı ya da daha yüksek bir varlık veya bir ibadet yeri, dua, hoca vs)?	1 Sık sık	2	3	4	5 Asla
2. Bilgi yarışmalarını izler misiniz?	1 Sık sık	2	3	4	5 Asla
3. Roman okur musunuz?	1 Asla	2	3	4	5 Sık sık
4. Etik ya da ahlaki konulardaki tartışmalarla meşgul olur musunuz?	1 Sık sık	2	3	4	5 Asla
5. Son aylarda kendinizi uyuşuk ya da yorgun hissettiniz mi?	1 Sık sık	2	3	4	5 Asla
6. Dini veya ruhani konular hakkında okur ya da çalışır mısınız?	1 Sık sık	2	3	4	5 Asla
7. Bir konu hakkında karar vermeden önce, o konu hakkında olabildiğince fazla bilgi toplamaya çalışır mısınız?	1 Asla	2	3	4	5 Sık sık
8. Geçtiğimiz bir yıl içinde mide bulantısı ve/veya kusma şikayetleriniz oldu mu?	1 Asla	2	3	4	5 Sık sık
9. Zihinsel gelişime yönelik oyunlar oynar mısınız (briç, satranç, bulmaca vs.)?	1 Sık sık	2	3	4	5 Asla
10. Geçtiğimiz bir yıl içerisinde mide ağrısı ve/veya hazımsızlık şikayetleriniz oldu mu?	1 Sık sık	2	3	4	5 Asla
11. Ahlaki davranışlarınızı geliştirmek amacıyla kendi davranışlarınızı ciddiyetle analiz ettiğiniz olur mu?	1 Asla	2	3	4	5 Sık sık
12. Geçen yıl içinde baş ağrısı şikayetleriniz oldu mu?	1 Asla	2	3	4	5 Sık sık
13. Kültür, sanat veya yaratıcılıkla ilgili mekanlara gider misiniz (Örnek: Müze, sanat galerileri, tiyatro vs.)?	1 Sık sık	2	3	4	5

14. Başkalarının da ders alabileceği, hayata dair kazançlar elde ettiğinizde; bunları hangi sıklıkla yakın çevrenizle paylaşırsınız?	1 Asla	2	3	4	5 Sık sık
15. Geçtiğimiz bir yıl içerisinde kabızlık sorunu yaşadınız mı?	1 Asla	2	3	4	5 Sık sık
16. Ölümden sonra yaşama inanır mısınız?	1 Asla	2	3	4	5 Sık sık
17. Geçtiğimiz bir yıl içerisinde zevk için yazdınız mı (Örnek: Mektup, öykü, şiir vs.)?	1 Asla	2	3	4	5 Sık sık
18. İç huzurunuzu sağlamak için ne kadar süredir bir aktivitede bulunuyorsunuz (Örnek: Meditasyon, yoga, dua vs.)?	1 Hiç bulunmadım	2	3 Beş yıldan az	4	5 10 yıldan fazla
19. Geçtiğimiz yıl içerisinde çevrenizi geliştirmek üzere herhangi bir adım attınız mı (ör.evinizi ya da ofisinizi güzelleştirmek, kendinize güzel objeler almak)	1 Sık sık	2	3	4	5 Asla
20. Geçtiğimiz yıl içerisinde kilo vermek ya da almak için diyet yaptınız mı?	1 Asla	2	3	4	5 Sık sık
21. Son aylarda, çoğu sabah dinç ve dinlenmiş olarak mı uyanıyorsunuz?	1 Asla	2	3	4	5 Sık sık
22. Ruhani konuları tartışır mısınız (Örnek: Hayatın amacı, din, iç huzur, ölüm vs.)?	1 Asla	2	3	4	5 Sık sık
23. Harekete geçmeden önce düşünür müsünüz?	1 Asla	2	3	4	5 Sık sık
24. Geçtiğimiz yıl içerisinde kişisel veya ruhani gelişiminizi arttırmaya çalıştınız mı (Örnek: Meditasyon, yoga,dua vs)?	1 Sık sık	2	3	4	5 Asla
25. Genellikle elleriniz ve ayaklarınız yeterince sıcaklar mıdır?	1 Asla	2	3	4	5 Sık sık
26. Haberleri izler, okur ya da dinler misiniz?	1 Sık sık	2	3	4	5 Asla
27. Belgeselleri izler misiniz?	1 Asla	2	3	4	5 Sık sık
28. Ayda en az bir kez ishal şikayetiniz olur mu?	1 Asla	2	3	4	5 Sık sık
29. Geçtiğimiz bir yıl içerisinde hiç ağrı ve sızılarınız oldu mu?	1 Sık sık	2	3	4	5 Asla
30. İç huzurunuzu elde etmek amacıyla meditasyon ve/veya dualardan faydalanır mısınız?	1 Sık sık	2	3	4	5 Asla

APPENDIX D: Beck Depression Inventory

Aşağıda gruplar halinde bazı sorular yazılıdır. Her gruptaki cümleleri dikkatle okuyunuz. Bugün dahil, geçen hafta içinde kandinizi nasıl hissettiğinizi en iyi anlatan cümleyi seçiniz. Seçmiş olduğunuz cümlenin 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) Gelecekten umutsuz değilim.
(b) Geleceğe biraz umutsuz bakıyorum.
(c) Gelecekten beklediğim hiçbir sey 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 başarısızlığımın 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 cezalandırılabileceğimi 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 sinirli değilim.
(b) Her zamankinden daha kolayca sinirleniyor ve kızıyorum.
(c) Çogu 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 degil.
(b) İştahım eskisi kadar iyi degil.
(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 agrı, 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 yaşantımda dikkatimi çeken bir şey yok.
(b) Eskisine oranla cinsel konularla daha az ilgileniyorum.
(c) Şu sıralarda cinsellikle pek ilgili değilim.
(d) Artık cinsellikle hiçbir ilgim kalmadı.

APPENDIX E: Study 2 Demographics and Caregiving History Form

Bu çalışma Orta Doğu Teknik Üniversitesi Psikoloji Bölümü Öğretim Üyesi Dr. Özlem Bozo ve Psk. Dilek Demirtepe tarafından yürütülmekte olan bir yüksek lisans tez çalışmasıdır. Çalışmanın amacı, lösemili çocukların bakımını üstlenen aile bireylerinde "Bakıcı Stres Modeli"ni test etmektir. Çalışmamız hiçbir tehlike içermemekte ve katılım tamamen gönüllülük esasına dayanmaktadır. İstediğiniz zaman hiçbir gerekçe göstermeksizin çalışmadan ayrılabilirsiniz. Çalışmaya katılmak için isminizi yazmanıza gerek yoktur ve vereceğiniz tüm bilgiler tarafımızca gizli tutulacaktır. Araştırmanın sonuçları ya da bu araştırmayla ilgili aklınıza gelen diğer sorular için 0505 226 08 53 numarasından ya da ddemirtepe@yahoo.com adresinden bilgi alabilirsiniz.

Katılımınız için teşekkür ederiz.

Çalışmaya katılmayı kabul ediyorum ☐

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. Hastanın nesi oluyorsunuz?

8. Hastanızın yaşı?

9. Hastanızın belirtileri ne zaman görülmeye başlandı?

10. Hastanızın tanısı ne zaman kondu?

11. Tedavi şu anda hangi aşamada? ____Kemoterapi (ilaç) ____Radyoterapi (ışın)

____Destekleme tedavisi _____ Kemik iliği nakli

____ Diğer (belirtiniz)………………..

12. Evinizde siz dahil kaç kişi yaşıyor?

13. Hastanızın bakımını üstlenen başka biri var mı? (varsa kim olduğunu belirtiniz) _______

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

____

15. Herhangi bir fiziksel rahatsızlığınız var mı? (varsa belirtiniz)

____

16. Herhangi bir psikolojik rahatsızlığınız var mı? (varsa belirtiniz)

____

17. Fiziksel ya da psikolojik tedavi görüyor musunuz? / Yardım alıyor musunuz? (varsa tedavi şeklini belirtiniz) _____________________

18. Hastalıkla ilgili bir dernek ya da kuruluşa üye misiniz? (varsa belirtiniz)___________________

APPENDIX F:Caregiving Tasks Index

Aşağıda, hastanızın bakımı ile ilgili cümleler verilmiştir. Önce, bu cümlelerde belirtilen işleri ne sıklıkla yaptığınızı, sonra da bunları yaparken ne sıklıkla problem yaşadığınızı ilgili kutucuğu işaretleyerek belirtiniz.

Aşağıda belirtilen işleri ne sıklıkla yapıyorsunuz?

	Hiçbir zaman	Nadiren	Ara sıra	Sık sık	Her zaman
Hastanızı giydirme					
Yemek yedirme					
İlaç verme					
Doktora götürme					
Hastanede refakat					
Tuvalete götürme					
Banyo yaptırma					
Diğer………………..					

Aşağıda belirtilen işleri yaparken ne sıklıkla problem yaşıyorsunuz??

	Hiçbir zaman	Nadiren	Ara sıra	Sık sık	Her zaman
Hastanızı giydirme					
Yemek yedirme					
İlaç verme					
Doktora götürme					
Hastanede refakat					
Tuvalete götürme					
Banyo yaptırma					
Diğer………………..					

APPENDIX G: Interpersonal Relationships Index

Aşağıda verilen cümlelerin sizin için ne kadar uygun olduğunu ilgili boşluğa (x) koyarak belirtiniz.

	Hiç uygun değil	Uygun değil	Kararsızım	Uygun	Çok uygun
Yardım beklediğim kişilerden istediğim yardımı alamıyorum.					
Yardıma ihtiyaç duyduğumda yakın çevrem ne yapmaları gerektiğini bilmiyor.					
Arkadaşlarımla görüşmek için zamanım yok					
Yakın çevremdekiler hastama iyi bakamadığımı düşünüyorlar.					
Çevremdekiler hastalık yüzünden bana farklı davranıyorlar.					
Hastamın, hastalık yüzünden dışlanıyor olması beni üzüyor					
Çevremdeki insanlar lösemi ile ilgili yeterli bilgi sahibi değiller.					
Çevreme lösemiyi açıklamakta zorlanıyorum.					
Tedavi süreci sebebiyle sosyal hayatımda olumsuz değişiklikler oldu.					
Yakın çevremdekilerin yanlış yollardan yardım etmeye çalışmaları durumu daha da zorlaştırıyor.					

APPENDIX H: The Ways of Coping Inventory

Aşağıda, önemli olabilecek olaylar karşısında kişilerin davranış, düşünce ve tutumlarını belirten bazı cümleler verilmiştir. Lütfen her cümleyi dikkatle okuyunuz. Yaşamınızda karşılaştığınız 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 degil	Pek uygun degil	Uygun	Olduk ça uygun	Çok uygu n
1. Aklımı kurcalayan şeylerden kurtulmak için değişik işlerle uğraşırım					
2. Bir sıkıntım olduğunu kimsenin bilmesini istemem					
3. Bir mucize olmasını beklerim					
4. İyimser olmaya çalısırım					
5. "Bunu da atlatırsam sırtım yere gelmez" diye düşünürüm					
6. Çevremdeki insanlardan problemi çözmede bana yardımcı olmalarını beklerim					
7. Bazı seyleri büyütmemeye üzerinde durmamaya çalışırım					
8. Sakin kafayla düsünmeye ve öfkelenmemeye çalışırım					
9. Bu sıkıntılı dönem bir an önce geçsin isterim					
10. Olayın degerlendirmesini yaparak en iyi kararı vermeye çalısırım					
11. Konuyla ilgili olarak başkalarının ne düşündüğünü anlamaya çalışırım					
12. Problemin kendiliğinden hallolacağına inanırım					
13. Ne olursa olsun kendime direnme ve mücadele etme gücü hissederim					
14. Başkalarının rahatlamama yardımcı olmalarını beklerim					
15. Kendime karsı hoşgörülü olmaya çalışırım					
16. Olanları unutmaya çalışırım					
17. Telaşımı belli etmemeye ve sakin olmaya çalışırım					

18. “Basa gelen çekilir” diye düşünürüm					
19. Problemin ciddiyetini anlamaya çalışırım					
20. Kendimi kapana sıkışmış gibi hissederim					
21. Duygularımı paylastığım kişilerin bana hak vermesini isterim					
22. Hayatta neyin önemli olduğunu keşfederim					
23. “Her işte bir hayır vardır” diye düşünürüm					
24. Sıkıntılı olduğumda her zamandakinden fazla uyurum					
25. İçinde bulunduğum kötü durumu kimsenin bilmesini istemem					
26. Dua ederek Allah’tan yardım dilerim					
27. Olayı yavaşlatmaya ve böylece kararı ertelemeye çalışırım					
28. Olanla yetinmeye çalışırım					
29. Olanları kafama takıp sürekli düşünmekten kendimi alamam					
30. İçimde tutmaktansa paylaşmayı tercih ederim					
31. Mutlaka bir yol bulabileceğime inanır, bu yolda uğraşırım					
32. Sanki bu bir sorun değilmiş gibi davranırım					
33. Olanlardan kimseye söz etmemeyi tercih ederim					
34. “İş olacağına varır” diye düşünürüm					
35. Neler olabileceğini düşünüp ona göre davranmaya çalışırım					
36. İşin içinden çıkamayınca “elimden bir sey gelmiyor” der, durumu olduğu gibi kabullenirim					
37. İlk anda aklıma gelen kararı uygularım					
38. Ne yapacağıma karar vermeden önce arkadaşlarımın fikrini alırım					
39. Her şeye yeniden başlayacak gücü bulurum					
40. Problemin çözümü için adak adarım					
41. Olaylardan olumlu bir şey çıkarmaya çalışırım					
42. Kırgınlığımı belirtirsem kendimi rahatlamış hissederim					
43. Alın yazısına ve bunun değişmeyeceğine inanırım					
44. Soruna birkaç farklı çözüm yolu ararım					

45. Basıma gelenlerin herkesin başına gelebilecek şeyler olduğuna inanırım					
46. “Olanları keşke değiştirebilseydim” derim					
47. Aile büyüklerine danışmayı tercih ederim					
48. Yaşamla ilgili yeni bir inanç geliştirmeye çalışırım					
49. “Her şeye rağmen elde ettiğim bir kazanç vardır” diye düşünürüm					
50. Gururumu koruyup güçlü görünmeye çalışırım					
51. Bu işin kefaretini (bedelini) ödemeye çalışırım					
52. Problemi adım adım çözmeye çalışırım					
53. Elimden hiçbir şeyin gelmeyeceğine inanırım					
54. Problemin çözümü için bir uzmana danışmanın en iyi yol olacağına inanırım					
55. Problemin çözümü için hocaya okunurum					
56. Her şeyin istediğim gibi olmayacağına inanırım					
57. Bu dertten kurtulayım diye fakir fukaraya sadaka veririm					
58. Ne yapılacağını planlayıp ona göre davranırım					
59. Mücadeleden vazgeçerim					
60. Sorunun benden kaynaklandığını düşünürüm					
61. Olaylar karşısında “kaderim buymus” derim					
62. Sorunun gerçek nedenini anlayabilmek için başkalarına danışırım					
63. “Keşke daha güçlü bir insan olsaydım” diye düşünürüm					
64. Nazarlık takarak, muska taşıyarak benzer olayların olmaması için önlemler alırım					
65. Ne olup bittiğini anlayabilmek için sorunu enine boyuna düşünürüm					
66. “Benim suçum ne” diye düşünürüm					
67. “Allah’ın takdiri buymuş” diye kendimi teselli ederim					
68. Temkinli olmaya ve yanlış yapmamaya çalışırım					
69. Bana destek olabilecek kişilerin varlığını bilmek beni rahatlatır					

70. Çözüm için kendim bir seyler yapmak istemem					
71. “Hep benim yüzümden oldu” diye düşünürüm					
72. Mutlu olmak için baska yollar ararım					
73. Hakkımı savunabileceğime inanırım					
74. Bir kişi olarak iyi yönde değistiğimi ve olgunlaştığımı hissederim					

APPENDIX I:Multidimensional Scale of Perceived Social Support (MSPPS)

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

APPENDIX J: Beck Anxiety Inventory

Aşağıda insanların kaygılı ya da endişeli oldukları zamanlarda yaşadıkları bazı belirtiler verilmiştir. Lütfen her maddeyi dikkatle okuyunuz. Daha sonar, her maddedeki belirtinin, bugün dahil son bir haftadır sizi ne kadar rahatsız ettiğini aşağıdaki ölçekten yararlanarak maddelerin yanındaki uygun yere (x) işareti koyarak belirtiniz.

0 hiç	2 orta derecede
1 hafif derecede	3 ciddi derecede

	0 hiç	1 hafif	2 orta	3 ciddi
1. Bedeninizin herhangi bir yerinde uyuşma veya karıncalanma				
2. Sıcak/ ateş basmaları				
3. Bacaklarda halsizlik, titreme				
4. Gevşeyememe				
5. Çok kötü şeyler olacak korkusu				
6. Baş dönmesi veya sersemlik				
7. Kalp çarpıntısı				
8. Dengeyi kaybetme korkusu				
9. Dehşete kapılma				
10. Sinirlilik				
11. Boğuluyormuş gibi olma korkusu				
12. Ellerde titreme				
13. Titreklik				
14. Kontrolünü kaybetme korkusu				
15. Nefes almada güçlük				
16. Ölüm korkusu				
17. Korkuya kapılma				
18. Midede hazımsızlık/ rahatsızlık hissi				
19. Baygınlık				
20. Yüzün kızarması				
21. Terleme (sıcağa bağlı olmayan)				

APPENDIX K:Symptom Checklist

Aşağıda zaman zaman herkeste olabilecek yakınma ve sorunların bir listesi vardır. Lütfen her birini dikkatlice okuyunuz. Sonra bu durumun bugün de dahil olmak üzere son bir ay içinde sizi ne ölçüde huzursuz ve tedirgin ettiğini göz önüne alarak aşağıda belirtilen tanımlamalardan uygun olanının numarasını karşısındaki boşluğa yazınız. Düşüncenizi değiştirirseniz ilk yazdığınız numarayı tamamen siliniz. Lütfen başlangıç örneğini dikkatle okuyunuz ve anlamadığınız bir cümle ile karşılaştığınızda uygulayan kişiye danışınız.

<u>Örnek :</u>	<u>Tanımlama :</u>
Aşağıda belirtilen sorundan	0 Hiç
ne ölçüde rahatsız olmaktasınız?	1 Çok az
Cevap	2 Orta derecede
	3 Oldukça fazla
	4 Aşırı düzeyde

1. İçinizdeki sinirliilik ve titreme hali ....
2. Baygınlık, baş dönmesi ....
3. Bir başka kişinin sizin düşüncelerinizi kontrol edeceği fikri ....
4. Başınıza gelen sıkıntılardan dolayı başkalarının suçlu olduğu duygusu ....
5. Olayları hatırlamada güçlük ....
6. Çok kolayca kızıp öfkelenme ....
7. Göğüs (kalp) bölgesinde ağrılar ....
8. Meydanlık (açık) yerlerden korkma duygusu ....
9. Yaşamınıza son verme düşünceleri ....
10. İnsanların çoğuna güvenilmeyeceği hissi ....
11. İştahta bozukluklar ....
12. Hiçbir nedeni olmayan ani korkular ....
13. Kontrol edemediğiniz duygu patlamaları ....
14. Başka insanlarla beraberken bile yalnızlık hissetmek ....
15. İşleri bitirme konusunda kendini engellenmiş hissetmek ....
16. Yalnız hissetmek ....
17. Hüzünlü, kederli hissetmek ....
18. Hiçbir şeye ilgi duymamak ....
19. Ağlamaklı hissetmek ....
20. Kolayca incinebilme, kırılmak ....

21. İnsanların sizi sevmediğine, kötü davrandığına inanmak ....
22. Kendini diğerlerinden daha aşağı görme ....
23. Mide bozukluğu, bulantı ....
24. Diğerlerinin sizi gözlediği ya da hakkınızda konuştuğu duygusu ....
25. Uykuya dalmada güçlükler ....
26. Yaptığınız şeyleri tekrar tekrar doğru mu diye kontrol etmek ....
27. Karar vermede güçlükler ....
28. Otobüs, tren, metro gibi umumi vasıtalarla seyahatlerden korkmak ....
29. Nefes darlığı, nefessiz kalmak ....
30. Sıcak soğuk basmaları ....
31. Sizi korkuttuğu için bazı eşya, yer ya da etkinliklerden uzak kalmaya çalışmak ....
32. Kafanızın ‘bomboş’ kalması ....
33. Bedeninizin bazı bölgelerinde uyuşmalar, karıncalanmalar ....
34. Günahlarınız için cezalandırılmanız gerektiği ....
35. Gelecekle ilgili umutsuzluk duyguları ....
36. Konsantrasyonda (dikkati birşey üzerinde toplama) güçlük/zorlanmak ....
37. Bedeninizin bazı bölgelerinde zayıflılık, güçsüzlük hissi ....
38. Kendini gergin ve tedirgin hissetmek ....
39. Ölme ve ölüm üzerine düşünceler ....
40. Birini dövme, ona zarar verme, yaralama isteği ....
41. Birşeyleri kırma dökme isteği ....
42. Diğerlerinin yanındayken yanlış birşeyler yapmamaya çalışmak ....
43. Kalabalıklarda rahatsızlık duymak ....
44. Başka bir insana hiç yakınlık duymamak ....
45. Dehşet ve panik nöbetleri ....
46. Sık sık tartışmaya girmek ....
47. Yalnız bırakıldığında/ kalındığında sinirlilik hissetmek ....
48. Başarılarınız için diğerlerinden yeterince takdir görmemek ....
49. Yerinde duramayacak kadar tedirgin hissetmek ....
50. Kendini yetersiz görmek/ değersizlik duyguları ....
51. Eğer izin verirseniz insanların sizi sömüreceği duygusu ....
52. Suçluluk duyguları ....
53. Aklınızda bir bozukluk olduğu fikri ....