

THE WELL-BEING OF SIBLINGS OF PATIENTS WITH SCHIZOPHRENIA: AN
EVALUATION WITHIN THE TRANSACTIONAL STRESS AND COPING
MODEL

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ABSTRACT

THE WELL-BEING OF SIBLINGS OF PATIENTS WITH SCHIZOPHRENIA: AN EVALUATION WITHIN THE TRANSACTIONAL STRESS AND COPING MODEL

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Schizophrenia is a chronic mental illness which strongly affects not only schizophrenia patients, but also their families and close relatives. So far, family research on patients with schizophrenia has focused on parents, but has neglected siblings. The present study aims to evaluate the well-being of the siblings of patients with schizophrenia within the Lazarus & Folkman's Transactional Coping and Stress Model. The sample consisted of 103 well siblings of schizophrenia patients. In the present study Socio-demographic Information Form, Subjective Well-being Scale, Rosenberg Self-esteem Scale, Zarit Caregiver Burden Scale, Multidimensional Perceived Social Support Scale, Religiousness Scale, Ways of Coping Scale and, Shortened Perceived Parental Rearing Styles Form were administered to the well siblings. The results of the present study revealed that wellbeing was found to be

associated with perceived mother over-protection by well siblings, social support, problem-focused coping, and indirect coping. Self-esteem which is a strong indicator of well-being as the second outcome measure was found to be predicted by gender, burden, perceived mother rejection, father rejection, mother over-protection, mother warmth, father warmth, religiousness, problem-focused coping, and indirect coping. Furthermore, social support was found to be as a moderator variable between burden and well-being; and two mediators of burden were determined which are problem-focused coping and social support. In the framework of Stress and Coping Theory, the significance of perceived social support and ways of coping of well siblings were validated. Social support seems to be very important factor for well-being and self-esteem of the well siblings. It moderates burden, moreover it mediates the relationship between burden and wellbeing. Therefore, siblings should be provided social support as well as their problem focused coping strategies should be strengthened.

Keywords: well siblings, schizophrenia, well-being, social support, coping

ÖZ

ŞİZOFRENİ HASTALARININ KARDEŞLERİNDE PSİKOLOJİK İYİLİK HALİNİN STRES VE BAŞA ÇIKMA MODELİ İLE DEĞERLENDİRİLMESİ

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Şizofreni, sadece hastaları değil aynı zamanda hastanın yakınındakileri ve aileleri de etkileyen kronik bir ruhsal rahatsızlıktır. Bugüne dek yapılan bilimsel çalışmalar ve psikolojik müdahaleler anne babalar üzerine odaklanırken, şizofreni hastalarının kardeşleri ihmal edilmiş bir grup olagelmıştır. Bu çalışmada, şizofreni hastalarının kardeşlerinin psikolojik iyilik halleri, Lazarus ve Folkman'ın Stres ve Başa Çıkma Kuramı dahilinde incelenmiştir. Çalışmaya 103 şizofreni hastasına sahip kardeş katılmıştır. Çalışmaya katılan şizofreni hastalarının kardeşlerine Sosyodemografik Bilgi Formu, Psikolojik İyilik Hali Ölçeği, Rosenberg Benlik Saygısı Ölçeği, Zarit Bakıcı Yükü Ölçeği, Algılanan Sosyal Destek Ölçeği, Baş Etme Yolları Ölçeği ve Algılanan Anne Baba Tutumları Ölçeği uygulanmıştır. Çalışmanın sonuçları,

anneden algılanan korumacı tutumunun, algılanan sosyal desteğin, problem odaklı baş etme ve dolaylı baş etme stratejilerinin sağlıklı kardeşlerde psikolojik iyilik hali ile ilişkili olduğuna işaret etmektedir. Psikolojik iyilik halinin önemli göstergelerinden biri olan benlik saygısı da, cinsiyet, bakıcı yükü, anneden algılanan reddedilme, korumacılık ve ılımlı tutum ile babadan algılanan reddedilme ve ılımlı tutum, algılanan sosyal destek, dindarlık, problem odaklı ve dolaylı baş etme stratejileri ile ilişkili bulunmuştur. Ayrıca, yapılan çalışmada problem odaklı baş etme stratejisi ile sosyal desteğin bakıcı yükü ve psikolojik iyilik hali arasında aracı bir rolü olduğu ve sosyal desteğin aynı zamanda bakıcı yükünün moderatorü olduğu saptanmıştır. Stres ve Başa Çıkma Modeli ışığında değerlendirildiğinde, şizofreni hastalarının kardeşlerinde algılanan sosyal desteğin ve problem odaklı baş etme stratejisinin önemi doğrulanmıştır. Bu bağlamda, şizofreni hastalarının kardeşleri için sosyal destek sağlanması ve problem odaklı baş etme stratejilerini güçlendirmeyi hedefleyen klinik çalışmalar geliştirilmesi gereklidir.

Anahtar kelimeler: şizofreni hastalarının kardeşleri, şizofreni, psikolojik iyilik hali, baş etme

To My Family

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CHAPTER 1

INTRODUCTION

1.1 Overview

The present study aims to evaluate the well-being of the siblings of patients with schizophrenia. Then, evaluation is conducted within the framework of the Stress and Coping Model.

The introduction section presents reviews and analyses of the literature on the siblings of patients with schizophrenia who were assumed *non-psychotic* referred to as *well siblings*. The first part consists of the description of schizophrenia and its effects on the family, and the burden caused by schizophrenia. This research, especially points to the dearth of research on siblings of the patients with schizophrenia who are “secondary victims” of the disorder.

The second part, presents briefly the caregiver stress models briefly in the literature and elaborates the “Lazarus& Folkman’s Stress and Coping Model” in detail, since this is the model used in the present study to evaluate the well-being of the well siblings.

The third part of the introduction chapter covers the variables related to coping, perceived parental rearing styles and personal resources to evaluate the well-being of the well siblings through the framework of the model which is cited above.

1.2 Patients with Schizophrenia and Their Siblings

Schizophrenia is a severe form of mental illness affecting about 7 per thousand of the adult population, mostly in the age group between 15 to 35. Though the incidence is low (3-10,000), the prevalence is high due to chronicity (World Health Organization, 2008). Schizophrenia is a multidimensional illness with a profound

impact on psychosocial functioning of the patients; it imposes severe hardships not only on the patients but also on their relatives. So far, family research on schizophrenia patients has focused on parents. Most of the support is designed specifically for the parents, but has neglected the siblings (Greenberg, Kim & Greenley, 1997; Lukens, Thorning, & Lohrer, 2002; Anderson & Kinsella, 1996; Friedrich, Lively & Rubenstein, 2008). Siblings, in particular, may feel neglected by their parents and/or by the mental health professionals while their ill sibling gets attention and resources. However, the presence of the brothers and the sisters are essential in many people's lives as providers of a kind of intimacy, confidence, emotional support, and protection. In a study conducted with primary school children, the siblings were favoured over the subjects' fathers as a source of support and help (Kosonen, 1996).

The relationship among the siblings is usually intense as well as greatly significant on individuals' life. First of all, the relationship of the siblings, contrary to many other family members and friends, takes longer durations. It is the most stable and consistent relationship across their life time. Moreover, two siblings share a very large genetic heritage and common biological origin compared to the other family members. Furthermore, they share very common early family experiences that contribute to their sense of life via understandings of a common cultural and social environment. Last, but not the least, their ages are close to each other, which may affect their relationship pattern and help them to develop a distinguished relationship compared to their other significant ones (Lamb & Sutton Smith, 1982; Cicirelli, 1995). Despite the fact that sibling relationships are commonly experienced as positive, many people perceive their sibling as competitors because of the attention and time given by their parents (Cicirelli, 1995).

Schizophrenia, as a common disorder, has the potential to affect lots of siblings who do not themselves have a mental illness. The literature commonly refers to them as *well siblings* who have a sibling with a mental illness and do not have a

mental illness themselves (Blasko, 2008). Therefore, in the present study, the siblings who have a sibling with schizophrenia will be referred as *well siblings* as well.

1.3 Burden among Well Siblings

In the mid-1950s, when a growing number of patients were discharged from psychiatric hospitals and placed into the community, the importance of family caregiving has become more recognized. Nowadays, as a consequence of the policy of deinstitutionalization, patients with schizophrenia and other psychotic disorders live in the community rather than psychiatric clinics (Lamb & Bachrach, 2001). In this manner, deinstitutionalization movement has forced families to become de facto case managers and primary caregivers for their patient (Grella & Grusky, 1989; Intagliata, Willer & Egly, 1986; Lamb & Oliphant, 1978; Solomon & Marcenko, 1992).

Caregiving is an experience that can be rewarding as well as stressful. According to Rector and Beck (2001), the greatest source of stress for caregivers is caring for a family member who has a mental illness.

Caregivers often experience emotional and physical health problems that lead to difficulties in both achieving and managing a balance between the work and family responsibilities which usually result in frequent job absenteeism, exhaustion, and lack of concentration (Merrill, 1997; Papolos & Papolos, 2006; Stephens, Franks, & Atienza, 1997).

There is a comprehensive literature on the effects of being a caregiver of a patient with schizophrenia. The most well-known definition and classification of *burden* were introduced by Hoenig and Hamilton (1966). According to these researchers, two kinds of burden exist: objective burden and subjective burden. The objective burden was defined as practical and observable problems such as financial difficulties, disruptions in leisure and work activities. The subjective burden was defined as psychological reactions to the illness of the family member such as depression, anxiety, and feeling of loss.

Studies revealed that the impacts of the caregiving process of the patients with schizophrenia were not limited to the primary caregivers; all family members are affected from having a mentally ill patient at home (Valiakalayil, Paulson, and Tibbo, 2004). For instance, adolescences were also affected negatively due to having a mentally ill member at home when one of the members of their family such as parents or siblings had been diagnosed by schizophrenia. They had difficulties in dealing with the positive and negative symptoms of schizophrenia if they were uneducated and uninformed about the illness particularly when they had to cope with extra household activities (Valiakalayil, Paulson, and Tibbo, 2004).

In addition to familial burden related to the illness of a family member at home, studies indicated a handover of the parental caregiving duties to the healthy siblings. Elderly parents, particularly older mothers, prefer to transfer the caregiving responsibility to the well sibling of the ill child instead of turning to other elderly relatives (Pruchno, Patrick & Burant, 1996; Smith, Hatfield & Miller., 2000). Aging parents commonly count on siblings who have the ability, resources, and contacts to make arrangements for providing care (Lefley, 1987).

Smith, Hatfield and Miller (2000) note that when asked who they would prefer to assume primary caregiving responsibility of their ill family member, 76 % of the parents indicated the siblings. Although little is known about the experience of burden among these well siblings, who have become pushed caregivers (Horwitz, 1993a, 1993b; Marsh, Appleby, Dickens, Owens, & Young, 1993; Wasow, 1995), it is not difficult to estimate the burden they experienced due to looking after an ill sister, or brother since there is a large amount of siblings engaged in caregiving activities. In the study of Schmid and colleagues, a total of 492 individual statements from well siblings were summarized. The three most often reported burden by the well siblings are handling the symptoms of the illness, emotional burden due to the illness of the sibling and lastly uncertainty in judging the amount of stress that patient can cope with (Schmid, Schielein, Binder, Hajak, Spiessl, 2009).

According to the results of the study conducted by Karla, Nischal, Trivedi, Dalal, and Sinha (2009), siblings experienced more burdens as compared to spouses of the patients with schizophrenia. Findings of another study on the factors associated with the subjective burden on siblings of adults with severe mental illness indicated that the well sibling's experience of burden was significantly correlated with the degree of symptomatology of the illness. Moreover, well siblings who viewed their ill sibling could not have controlled his or her behaviour, reported lower levels of subjective burden than those who viewed the sibling's behaviour as within their control (Greenberg, et al., 1997).

Issues of time, finances, and the perceived need of the ill sibling are found to be related with the objective burden of the well siblings (Hatfield & Lefley, 2000; Horwitz & Reinhard, 1995). Difficulty imposed by financial and time constraints and difficulty in balancing the needs of the new family of the well sibling with their ill sibling's needs were reported (Marsh, 1998).

The gender of the ill sibling seems to affect the level of burden felt by well siblings. Siblings of brothers with schizophrenia experience more burden than do siblings of sisters because female patients seem to experience a less devastating course of schizophrenia than male patients do (McGlashan & Bardenstein, 1990). Cook's (1988) study revealed that among parental caregivers, mothers rather than fathers assumed the primary caregiving role; likewise, Greenberg's study revealed that sisters rather than brothers had more frequent interaction with their ill sibling thus sisters reported more subjective burden (Greenberg, et al., 1997). In the same study, education levels of well siblings and age of the ill siblings were found to have an impact on the subjective burden. The well-educated siblings stated more subjective burden than the relatively less educated ones. Siblings who look after a younger sibling reported less subjective burden than those who provide care for an older patient. In general, older siblings and brothers tended to report lower levels of subjective burden than younger siblings and sisters did (Greenberg, et al., 1997; Greenberg et al., 1993).

In addition to the caregiver burden on the well siblings, they also face the fact of a debilitating disorder of a loved one which eventually leads to an emotionally troubled journey. When a brother or sister is diagnosed with a mental health disorder, illness of their sibling gives a rise to a large amount of ambivalent feelings and confusions about the way their sibling acts. Stalberg, Ekerwald and Hultman (2004) presented a unifying theme as “sibling bond” in order to describe the combination of emotions experienced by the well siblings. Researchers produced the term sibling bond mixed with feelings of love, sorrow, anger, envy, guilt, and shame which were the primary emotions expressed by the well siblings. Researchers indicated that development of those strong feelings is due to the emotional tie between the siblings (Stalberg, Ekerwald & Hultman, 2004).

Kristoffersen and Mustard (2000) pointed out the importance of the feelings in relation to the experience of being a brother or sister of someone who suffers from schizophrenia. They assumed that one of the greatest burdens of a well sibling was related to the mixed emotions towards ill sister or brother which are grief, hope, anger, guilt, and shame. According to their theory of interrupted feelings, those emotions are interrupted by four interconnected dynamics; ambiguous loss, the fluctuating nature of the disorder, an inner prohibition of feelings and the perception of invalidated feelings by others (Kristoffersen & Mustard, 2000). *Ambiguous loss* refers to the pain of the well siblings due to the perception of ill sibling as dead, unavailable to contact with in many ways but who still exists. This kind of grief is different from grieving over a loss of sibling through death, not appropriate for clinical grief work and could not be accepted peacefully by the well sibling. The emotion interrupts by this kind of ambiguous loss (Kristoffersen & Mustard, 2000). *The fluctuating nature of the disorder* makes it difficult to handle the emotions properly, the hope and hopelessness of the well sibling fluctuates according to the course of illness of the ill sibling (Kristoffersen & Mustard, 2000). Well siblings experience the *inner prohibition of feelings* such as guilt because of feeling grief for someone who is present and this is experienced internally by the well sibling as if

she is taking the life of the ill sibling who is still living. Since the sorrow never comes for a present one, the grief process is never completed and the well sibling has to deal with the rise of those mixed feelings (Kristoffersen & Mustard, 2000). Last but not the least, the well sibling experiences the burden for not being understood by others and being unable to share emotions with someone else (Kristoffersen & Mustard, 2000). The feelings of grief, shame, and guilt cannot be validated by the well siblings without affirmation of others (Marsh, 1998).

Survivor's guilt is another hurtful emotion experienced by the well sibling in the form of a burden that is a mental condition that occurs when a person perceives himself or herself to have done wrong by surviving and being well the mental illness when the other sibling did not (Titelman, 1991).

Due to the stigmatizing nature of schizophrenia, the well siblings not only feel selfish for being embarrassed by the illness of the sister or brother, but also concerned about what to tell other people when they ask questions about the ill sibling and his/her acts. They may sometimes feel frustrated by the doctors or family and by the mental health system for not being included in the recovery or treatment plans. On the other hand, they may become frustrated towards the ill sibling for the increased attention and care provided to the latter and may feel that his/her own needs are not met by the parents, the ill sibling does not have responsibilities as much as the well sibling; on the other hand s/he may feel guilty and helpless in addition to the concerns of (not) caregiving for their loved one because of inability to help or make him/her better (Marsh & Dickens, 1997).

With the sense of growing up too fast, s/he may sense the burden of being the perfect child and not cause any trouble by succeeding at everything besides the grief over losing a normal childhood. Resentment at not having a normal family life, having to deal with this pressure for the rest of his/her life rises with the fear of an unknown disorder and a scary future (Marsh & Dickens, 1997).

In conclusion, when a family member is diagnosed with schizophrenia all family members are affected and burdened; however due to different family roles,

the emotional reactions, and the perception of burden could be different. The well siblings appear to have a more voluntary role in caregiving compared to the parents. Nevertheless, the strong emotions described in Stalberg et. al study (2004) suggests that the influence of the sibling bond should not be underestimated when working on the family burden related to schizophrenia.

In the present study, the factors related to the burden of well siblings will be investigated

in the light of the conceptual framework of Lazarus and Folkman's Stress and Coping Model which will be explained in the following section in detail (Lazarus & Folkman, 1984).

1.4 Lazarus & Folkman's Stress and Coping Model

In the literature, there are three main models that can be used to explain caregiver stress. They are the Family Stress Theory (McCubbin & McCubbin, 1993), The Resource Deterioration Model (Ensel & Lin, 1991), and the Transactional Stress and Coping Model (Lazarus & Folkman, 1984). In their Family Stress Theory (1989), McCubbin and McCubbin suggested that during transitions and changes, families have power and competence to improve the growth of the members of the family and to prevent the family from critical disruption and destruction (as cited in Saunders, 1999, p. 97). The second model, namely the Resource Deterioration Model, (Ensel & Lin, 1991), presumes that stressors and outcomes are mediated by coping and support resources. According to this model, when a vulnerable group is exposed to a stressor, the stressor increases the distress by reducing the level of inadequate coping and support both directly and indirectly. The third model, the Stress and Coping Model (Folkman & Lazarus, 1984), suggests that the interaction between demands of situation and individual's coping capacity determines the level of stress. In our study, the third model will be used as a framework in examining the factors of well siblings of patients with schizophrenia.

Definitions of stress encompass a number of facets. In general, however, stress falls into a limited number of broad categories. One major category of stress is conceptualized as the occurrence of significant life events that are interpreted by the person as undesirable (Lazarus & Folkman, 1984; Luthar & Zigler, 1991; Monroe & Peterman, 1988; Monroe & Simons, 1991). Two concepts are central to the psychological stress theory: appraisal, i.e., individuals' evaluation of the significance of what is happening for their well-being, and coping, i.e., individual's efforts in thought and action to manage specific demands (Lazarus, 1993) (Figure 1).

Since its first presentation as a comprehensive theory (Lazarus, 1966), the Lazarus stress theory has undergone several essential revisions (Lazarus, 1991; Lazarus & Folkman, 1984; Lazarus & Launier, 1978). In the latest version (Lazarus, 1991), stress is regarded as a relational concept, i.e., stress is not defined as a specific kind of external stimulation nor a specific pattern of physiological, behavioral, or subjective reactions. Instead, stress is viewed as a relationship ('transaction') between individuals and their environment. *Psychological stress* refers to a relationship with the environment that the person appraises as significant for his/her wellbeing and in which the demands tax or exceed available coping resources' (Lazarus & Folkman, 1984). This definition points to two processes as central mediators within the person - environment transaction: cognitive appraisal and coping. The concept of appraisal, introduced into emotion research by Arnold (1960) and elaborated with respect to stress processes by Lazarus (1966; Lazarus & Launier, 1978), is a key factor for understanding stress-relevant transactions. This concept is based on the idea that emotional processes (including stress) are dependent on actual expectancies that persons manifest with regard to the significance and outcome of a specific encounter. This concept is necessary to explain the individual differences in quality, intensity, and duration of an elicited emotion in environments that are objectively equal for different individuals. It is generally assumed that the resulting state is generated, maintained, and eventually altered by a specific pattern of appraisals. These appraisals, in turn, are determined

by a number of personal and situational factors. The most important factors on the personal side are motivational dispositions, goals, values, and generalized expectancies. Relevant situational parameters are predictability, controllability, and imminence of a potentially stressful event. In his monograph on emotion and adaptation, Lazarus (1991) developed a comprehensive emotion theory that also includes a stress theory (Lazarus, 1993). This theory distinguishes two basic forms of appraisal which are primary, and secondary appraisal (Lazarus, 1966). These forms rely on different sources of information.

Primary appraisal concerns whether something of relevance to the individual's well-being occurs, whereas secondary appraisal concerns with coping options. Within primary appraisal, three components are distinguished: *goal relevance* describes the extent to which an encounter refers to issues about which the person cares. *Goal congruence* defines the extent to which an episode proceeds in accordance with personal goals. *Type of ego- involvement* designates aspects of personal commitment such as self- esteem, moral values, ego-ideal, or ego-identity.

Likewise, three secondary appraisal components are distinguished: blame or credit, coping potential and future expectations. *Blame or credit* results from an individual's appraisal of who is responsible for a certain event. By *coping potential*, Lazarus (1984) refers to a person's evaluation of the prospects for generating certain behavioural or cognitive operations that will positively influence a personally relevant encounter. *Future expectations* refer to the appraisal of the further course of an encounter with respect to goal congruence or incongruence. Specific patterns of primary and secondary appraisal lead to different kinds of stress. Three types are distinguished: harm, threat, and challenge (Lazarus & Folkman 1984). Harm refers to the (psychological) damage or loss that has already happened. Threat is the anticipation of harm that may be imminent. Challenge results from the demands that a person feels confident about mastering. These different kinds of psychological stress are embedded in specific types of emotional reactions, thus illustrating the close conjunction of the fields of stress and emotions. Lazarus (1991) distinguishes

15 basic emotions. Nine of these are negative (anger, fright, anxiety, guilt, shame, sadness, envy, jealousy, and disgust), whereas four are positive (happiness, pride, relief, and love). (Two more emotions, hope and compassion, have a mixed valence.) At a molecular level of analysis, the anxiety reaction, for example, is based on the following pattern of primary and secondary appraisals: there must be some goal relevance to the encounter. Furthermore, goal incongruence is high, i.e., personal goals are thwarted. Finally, ego-involvement concentrates on the protection of personal meaning or ego-identity against existential threats. At a more molar level, specific appraisal patterns related to stress or distinct emotional reactions are described in terms of core relational themes. The theme of anxiety, for example, is the confrontation with uncertainty and existential threat. The core relational theme of relief, however, is 'a distressing goal-incongruent condition that has changed for the better or gone away' (Lazarus, 1991).

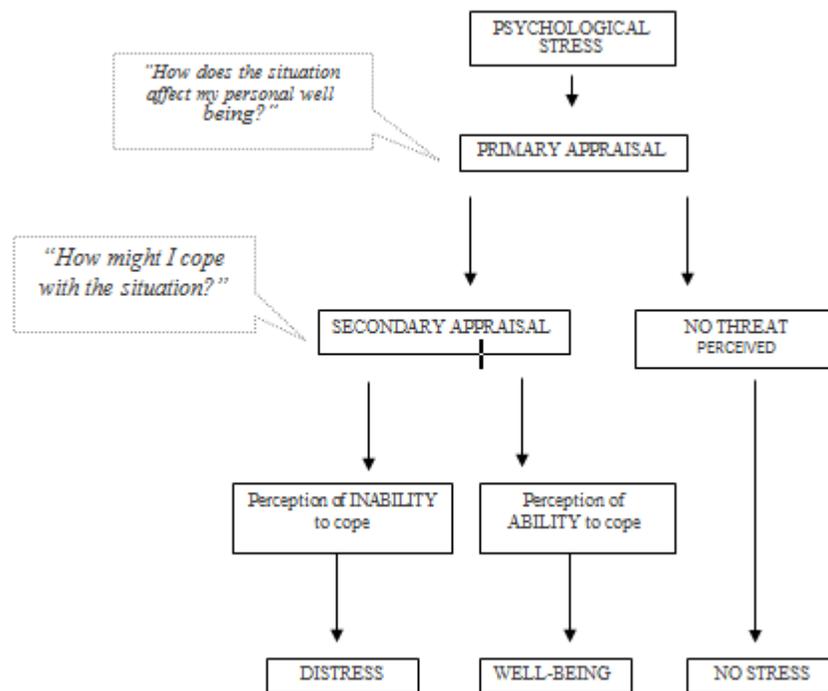


Figure 1. Lazarus & Folkman's Stress and Coping Model (1984)

Coping is intimately related to the concept of cognitive appraisal and, hence, to the stress-relevant person-environment transactions. Most approaches in coping research follow Folkman and Lazarus (1984), who define coping as 'the cognitive and behavioural efforts made to master, tolerate, or reduce external and internal demands and conflicts among them.' This definition contains the following implications:

(a) Coping actions are not classified according to their effects (e.g., as reality-distorting), but according to certain characteristics of the coping process.

(b) This process encompasses behavioural as well as cognitive reactions in the individual.

(c) In most cases, coping consists of different single acts and is organized sequentially to form a coping episode. In this sense, coping is often characterized by the simultaneous occurrence of different action sequences and, hence, an interconnection of coping episodes.

(d) Coping actions can be distinguished by their focus on different elements of a stressful encounter (Lazarus & Folkman, 1984). They can attempt to change the person–environment realities behind negative emotions or stress (problem-focused coping). They can also relate to internal elements and try to reduce a negative emotional state, or change the appraisal of the demanding situation (emotion-focused coping).

1.4.1. Adaptation of Original Model for the Well-being of the Well

Siblings

“Stress and Coping Theory” paradigm is selected as a framework, since it deals directly with the responses of normal people, such as caregivers, to stressful circumstances.

As applied to the well siblings, the *stressor event* is the ill sibling’s illness with its associated behaviours and it is the way in which these are appraised by the well sibling that constitutes the experience of caregiving.

Burden will be taken as a *primary appraisal* which is an external demands or potential threat that has been appraised as a stressor (Lawton, et al., 1984). The siblings’ perceived parental factors, personal resources and coping strategies can be taken as the *secondary appraisal*, linked to the primary appraisal, which may determine the likelihood of the siblings’ well-being. *Outcome* in terms of well-being is regarded as the result of an interaction between the appraisal and the well-siblings’ coping strategies (the cognitive and behavioural efforts aimed at controlling the demands imposed by the stressor). Since well siblings are not patients, it is important that the outcome is constructed in terms of well-being (Figure 2).

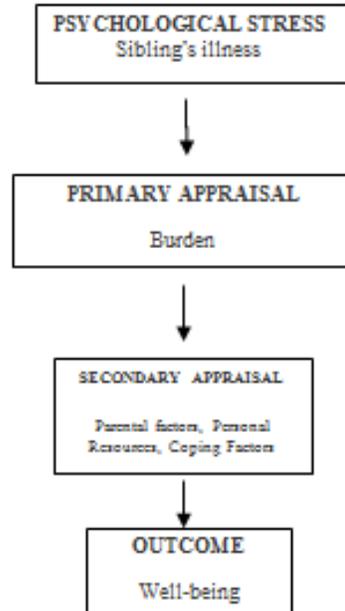


Figure 2. Adapted Mediation Model for the Lazarus & Folkman's Stress and Coping Theory (1984)

Lazarus & Folkman's Stress and Coping Theory, refers the moderating effects of the appraisal as well as mediating effects. The fact that not all individuals who experience significant stress develop a disorder has led, in part, to the recognition that vulnerability processes are important components of psychopathology; such factors predispose some individuals to psychopathology when stress is encountered. This approach refers an interaction of vulnerability and stress as essential for understanding the development of stress (Figure 3).

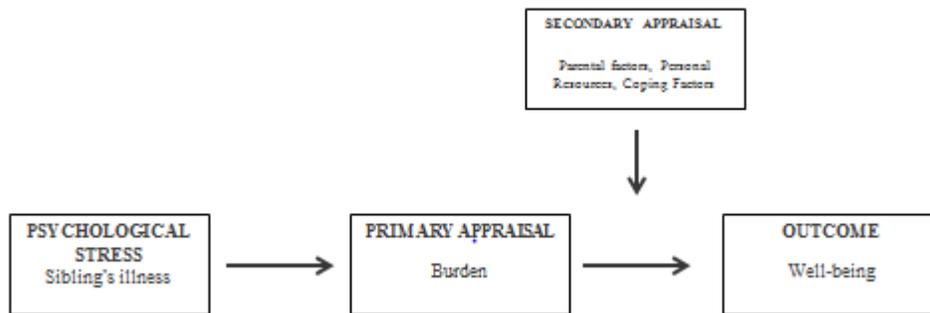


Figure 3. Adapted Moderation Model for the Lazarus & Folkman's Stress and Coping Theory (1984)

1.4.2. Variables Related to the Well-being of the Well Siblings

1.4.2.1 Perceived Parental Rearing Styles among Well Siblings

When a brother or sister is diagnosed with schizophrenia, along with all the family members, well siblings experience considerable burden in their family origin. Schizophrenia is one of the secrets of their childhood. Unlike a physical illness, schizophrenia with its bizarre symptoms is experienced as a childhood trauma by the well siblings. The disorder may be equated with “teenager acting out” for an uninformed child that obstructs the accepting of the schizophrenia diagnosis as an illness which leave the siblings with very little scope to deal with or understand (Taylor, 2009).

The well siblings often state the feeling of invisibility within their family (Lukens, Thorning, & Lohrer, 2004; Marsh, 1998; Marsh & Dickens, 1997) and try hard to get the attention by their parents. They strive for perfection to gratify their parents (Marsh, 1998) which is called the “replacement child syndrome”; they attempt to be successful and thriving in order to recompense their ill sibling (Lukens et al., 2004; Marsh, 1998; Marsh & Dickens, 1997), even some confess acting out to seek attention from their parents (Lukens et al., 2004). They describe themselves as forgotten child with a sense of relinquishment (Marsh & Dickens, 1997) and state

that their family life is built around the ill sibling (Thorning & Lukens, 1996). Since the perception of being an ignored character, they experience feelings of grief for loosing of the normal childhood and family life that ends up with developmental problems regarding trust and intimacy in adult life (Marsh & Dickens, 1997). On the other hand, they report the sense of maturation early for growing up too fast and sometimes having to take on parental roles in their families (Lukens et al., 2004; Marsh & Dickens, 1997).

Recent studies emphasized the unjust neglect of well siblings by their parents and their distress (Schrank, Sibitz, Schaffer, & Amering, 2007; Blasko, 2008). In her study about the well siblings' emotional neglect and coping resources, Blasko (2008) found that well siblings of the patients with schizophrenia perceived more parental rejection than do the siblings of healthy individuals. She argued that emotional neglect was related to lower coping as well as lower perceived coping resources. In other words, well siblings experienced difficulties for not only having an ill sibling, but also being at high risk for emotional neglect; and emotional neglect is a risk factor for developing poor coping skills. On the other hand, perceived parental warmth during the childhood was found to be related with effective coping ways as well as subjective well-being (Blasko, 2008).

1.4.2.2 Personal Resources of Well Siblings

1.4.2.2.1 Self-esteem

Self-evaluation or evaluation of one's self-worth or self-acceptance is known as self-esteem (Rosenberg, 1986). Studies showed the positive relationship between self-esteem and well-being (Cummins & Nistico, 2002; Diener, 1984) and it has been reported to be one of the strongest predictors of well-being (Campbell, 1981; Diener, 1984; Wilson, 1967; Boschen, 1996; Hong & Giannakopoulos, 1994; Lucas, Diener, & Suh, 1996). Self-esteem may be investigated as an outcome when focusing on processes that increase or inhibit self-esteem, or a self-motive in which people

behave in ways that maintain positive appraisals of the self, or as a buffering variable, that is a protector for harmful experiences (Cast & Burke, 2002).

As mentioned before, Cicirelli (1995) reported that the sibling relationship is one of the major determinants of both identity formation and self-esteem. In this instance, when one sibling develops a debilitating illness of any kind, whether medical or psychiatric, the impact on the remaining sibling can be troublesome and profound regardless of the nature of the bond (Judge, 1994; Seligman & Darling, 1997). In conjunction with the use of maladaptive coping skills and perception of parental neglect, well siblings of the patients with schizophrenia have deficits in their self-concept (Marsh, 1994). Self-concept is a construct with many manifestations, but across several studies, well siblings consistently reported difficulties with such aspects of self-concept as self-esteem, self-efficacy, and self-worth (Marsh, 1994) which are the concepts used interchangeably in the literature.

It is generally agreed that self-esteem is a cognition, and can be considered as “liking and respect for oneself” in terms of competence and worth (Rosenberg, 1979). Cast and Burke (2002) defined the worth dimension of self-esteem as the degree to which individuals feel they are of value and the competence dimension of self-esteem as the degree to which individuals see themselves as capable (Cast & Burke, 2002). In this manner, it is likely that well siblings may feel that they do not deserve to be happy or to have close relationships that their sibling with mental illness will never be able to achieve. Several studies describe survivor’s guilt that well siblings may experience in the presence of their sibling’s disease (Titelman, 1991; Marsh, 1994). Previous studies have linked low self-esteem and negative emotions with the use of maladaptive coping (e.g., Kashdan, Barrios, Forsyth, & Steger, 2006). As such, feeling guilt and low self-esteem may lead to sustained use of maladaptive coping.

The symptoms of schizophrenia related to overt behaviour problems and difficulty in communication creates barriers to the relationships between the ill and the well siblings which may not arise with other disabilities (Aguilar, O'Brien,

August, Auon & Hektner , 2001 ; Epkins & Dedmon, 1999). Barak and Solomon (2005), in a study of siblings both with and without a sibling with schizophrenia, found that there was a noticeable difference between the two groups. Those with a schizophrenic sibling may become “secondary victims”, living with anxiety and guilt as well as the effects of perceived shame and stigma. It is apparent that having a family member with schizophrenia is associated with social stigma, and social stigma has effects on one’s own identity (Hatfield, 1978; Holden & Levine, 1982, Lefley, 1998). In addition, other family members such as well siblings’ self-esteem can be overwhelmed due to uncontrollable and unsolvable problems caused by the mental illness (Hatfield, 1978; Holden & Lewine, 1982). The fears of becoming ill one day and being at risk for developing mental illness may also reduce the self-concept of the well family member (Lefley, 1998). In case of sibling relationships from the psycho-analytic view, Bank and Kahen (1982) stated that the effects of schizophrenia on the self-esteem of the well sibling are especially dramatic, since the part of the well sibling’s identity may be derived from having an ill sibling and well siblings often see parts of themselves that they don’t like in their deviant siblings. Their self-esteem may be impaired by the perceived expectation for being the “normal” and “superior” child as demanded by their parents (Bank & Kahen, 1982).

As a consequence of being the invisible child and unimportant victim in the family with aforementioned burdens and confused emotions, it is rather difficult to develop a healthy self-concept for the well siblings of patients with schizophrenia. It is also one of the significant predictors of well-being, for this reason in this study; self-esteem will be taken as the second dependent variable in addition to the well-being.

1.4.2.2.2. Perceived Social Support

Perceived social support can affect the ways of coping to manage stressful situations (Lazarus & Folkman, 1984) and it is often emphasized in the stress literature. In stressful situations, different coping styles produce different responses

derived from the social environment. Certainly, asking for and making use of social support is one of the possible coping styles (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992). The research conducted by Gençöz, Gençöz and Bozo (2006) in a Turkish sample, the authors led to adding the seeking social support factor as a third main dimension of coping to the Turkish Ways of Coping Inventory since seeking social support was empirically addressed as being hierarchically different from the two other factors which are emotion focused and problem focused coping. Perceived social support has been found to be related to appraisal patterns (Dunkel-Schetter, Folkman & Lazarus, 1987), as well as greater feelings of control, self-efficacy, and self-esteem (Shaw, Krause, Chatters, Connell, & Ingersoll Dayton, 2004; Symister & Friend, 2003). Similarly, Cohen and Willis (1985) argued that people who have perceived social support believe that others will provide necessary resources. The belief that support at hand strengthens one's perceived ability to cope with demands, thus changing the appraisal of the situation reduces negative consequences or alters maladaptive coping ways with the stressor. Those approaches are certainly supported by one of the first definitions given by Thoits (1983) which is social support is a *coping assistance* that leads to more benign appraisals of stressful situations.

Studies indicated that one of the highly adaptive coping strategies used by the family members with various disorders is perceived social support (Lopez-Martinez, Esteve-Zarazaga, & Ramirez-Maestre, 2008; Magliano et al., 2000; Tak & McCubbin, 2002; Norberg, Lindblad, & Boman, 2006). Social support acts as a facilitator for setting coping strategies through sharing problems and getting helpful suggestions which help people to face their problems and find constructive problem solving ways (Lazarus & Folkman, 1984).

In their study explaining adaptive coping skills of the family members of persons with schizophrenia, Solomon and Draine (1995) showed that social support was the strongest factor in dealing with the burden of the mental illness. In addition to the friends and co-workers, the most helpful of all were support from family members and people who experienced the same situation.

In a recent study from Indonesia, the perception of high social support is found to be related to more confrontational coping, optimistic coping, and supportive coping in caring for persons with schizophrenia, at the same time negatively related to more fatalistic and avoidant coping (Rafiyah, Suttharangsee & Sangchan, 2011).

According to the results of another study conducted by 746 respondents, the siblings reported that in addition to having a supportive family and talking to others who have an ill family member, contacting with the service providers is also a valuable support resources. They also found support groups such as National Alliance of Mental Illness- NAMI and some religious groups as helpful in coping with the burden (Friedrich, Lively & Rubenstein, 2008).

Eventually, there are three conditions in the effect of social support on the psychological outcomes. In one condition social support may directly affect the psychological outcome as a main effect unrelated with the level of stress (e.g. Kessler & Essex, 1982, cited in Quittner, Glueckauf & Jackson, 1990). In another condition, social support may have an interaction effect with stressors. *“People with strong social support tend to have better health than those with weak social support under stress”* sets an example of moderator effect of social support (Cohen & Willis, 1985). In the last condition, social support mediates the relationship between stressors and psychological outcome (Quittner, Glueckauf & Jackson, 1990). *“Caregivers of patients with greater physical dependency tended to perceive greater levels of social support, which led directly to increased caregiver well-being (Chappel & Reid, 2002)”* points out the mediation effect of social support. In the framework of Lazarus & Folkman Stress Coping Theory, social support takes part as a personal coping resource that buffers negative effects of stress.

1.4.2.2.3 Religiousness

Belief in God and religiousness may affect global well-being in two ways; firstly, religious beliefs provide a calming framework for understanding why bad things happen and secondly, they offer their followers the prospect of an afterlife that

brings a meaning to stressful events (Koenig, 1994). A relationship with God most likely influences the appraisal of the person about a difficult problem. Religious coping includes positive actions such as seeking spiritual support and positive religious appraisal (e.g. problems are God's will, they are tests or they lead us to the path for the good) as well as negative religious coping practices (e.g. blaming God) (Pargament, 1999). A recent study conducted on Muslims showed that the considerable amount of the family members of patients with serious mental illness mobilized religious and spiritual resources to cope with their situation as caregivers (Rafiyah, Suttharangsee & Sangchan, 2011). Most of the subjects in the study prayed or put their trust in God and the relationship with God helped the subjects to perceive their problems in a positive way by providing a purpose and hope to help the subjects to cope with their problems. In this situation, the subjects are more likely to use positive thinking when dealing with the stressful situations while caring for their ill family member (Rafiyah, Suttharangsee & Sangchan, 2011). Perception of seeking support from God directed the caregivers to rely on religious coping (Rafiyah, Suttharangsee & Sangchan, 2011). In addition, a literature review (Baldacchino & Draper, 2000) showed that a relationship with God helped people to cope with their problems because they found meaning, purpose, and hope. Evidence indicates that the less the social support a caregiver has, the more often spiritual help is used as a coping strategy (Magliano et al. 1998; Huang, Sun, Yen & Fu, 2008).

Religious coping is an emotion focused coping strategy which is linked to increased level of well-being and reduced stress in individuals facing diverse stressors such as loss or physical illness (Koenig, Cohen & Blazer, 1992, 1997; McIntosh, Siver & Wortman, 1993). Religious rituals and faith help in coping with life stressors by providing a source of hope and comfort (Pargament, 1999). A study on the role of religion as a way of coping showed that religious beliefs and practices are important resources for family members involved in caring for a mentally ill (Rammohan & Rao, 2002). In line with those studies, caregivers used their religiosity and spirituality as a way of dealing with stress and coming to terms with

their circumstances, asking for help and direction from their religious support were found to be a very important coping strategy in various other studies as well (Chang, Noonan, & Tennstedt, 1998; Stolley, Buckwalter & Koenig, 1999; Pearce, 2005).

Besides, religiosity was found to be associated with greater self-esteem and self-care and less depression among caregivers with mentally ill family members (Murray-Swank, Mahoney & Pargament, 2006). According to Murray-Swank, Mahoney and Pargament (2006) religiosity may enhance self-esteem through fostering personal belief in an intrinsic spiritual worth—for example, “God cares for me and accepts me”— and religiosity may also provide opportunities to enhance self-esteem through participation in the activities of a faith community and its shared traditions or through positive regard received from others in that community.

Koenig (1994) reported that when a stressful situation is uncontrollable, people with fewer social and economic resources may turn to religion for solace when facing situations over which they have little control. Collaborative religious coping was found to be more helpful in uncontrollable situations whereas self-directing religious coping was found to be more supportive in controllable situations (Bickel, et al. cited in Keefe, et al., 2001).

In the theory of transactional stress and coping, religiousness is likely to have an effect on the adjustment to life stress. Both primary and secondary appraisals might be influenced by religious beliefs (Lazarus & Folkman, 1984). Individuals’ religious views may lead to different views about the same life event and they may also affect the perceived availability of coping options. Thus, religiousness may have a stress-buffering role by manipulating the choice of specific coping strategies (Park, Cohen, & Herb, 1990).

1.4.2.3. Coping Ways of Well Siblings

Siblings commonly experience difficulties in coping with schizophrenia and its impact on their lives. Despite the fact that the burden is high among the siblings, little attention has been paid to coping strategies that could reduce the stress

experienced by the well siblings. Because there is a lack of sample homogeneity and reliance on qualitative data, the studies on well siblings are limited and these limitations make it difficult to comprehend the effectiveness of the well siblings' coping ways. However, growing literature on well siblings, which mainly focuses on identification and classification of their coping patterns related with the siblings' psychological well-being, has attracted attention in recent years.

According to Gerace, Camilleri & Ayres (1993), the well siblings commonly used three kinds of coping strategies which are collaborative, crisis oriented and detached. Collaborative siblings are actively involved with parents and mental health professionals in caring for their ill sibling while the detached siblings usually try to exclude the ill sibling from their lives. Crisis oriented strategy is a situation-specific approach to the ill sibling with little or no carryover between situations. The siblings using crisis oriented strategies define their roles as becalming the family with sporadic involvement (Gerace, Camilleri & Ayres, 1993).

In a study of Stalberg, Ekerwald & Hultman (2004), sixteen well siblings were interviewed and the results of the study distinguished five coping patterns which are avoidance, isolation, normalization, grieving and caregiving. Their research suggested that these coping patterns generated a continuum from "distant" to "close" with regard to the sibling bond and in this relational continuum, normalization is the most well-balanced and healthiest coping pattern.

Kinsella and Anderson (1996) distinguished the positive (healthy) and negative (unhealthy) coping skills of the well siblings. Healthy coping skills bring along the successful management of the illness with an appropriate adaption to difficult circumstances without secondary repercussions whereas unhealthy coping skills allow instant relief but produce negative consequences such as weakened functioning in the end. Researchers classified the positive coping skills as constructive escape, seeking support, objectifying the illness, acquiring information and spiritual faith; negative coping skills as internalization of emotions, destructive escape, self-restrictive behaviours and self-isolation (Kinsella & Anderson, 1996).

Similarly, studies indicated that resources for coping with stress are often stated as adaptive and maladaptive (Carver, Scheier, & Weintraub, 1989; Folkman & Lazarus, 1988; Klein, Turvey, & Pies, 2004). Adaptive coping resources serve to reduce stress in both the short and the long term (Folkman & Lazarus, 1988; Matheson, Skomorovsky, Fiocco & Anisman, 2007) matching with the concept positive coping in the study of Kinsella and Anderson (1996). Strategies such as religious or spiritual coping, seeking for instrumental and emotional social support, acquiring greater knowledge of mental illness (Gerace, Camilleri, & Ayres, 1993; Stalberg, Ekerwald & Hultman, 2004; Kinsella & Anderson, 1996), component coping (Han, 1995) are also resources of adaptive coping. On the contrary, maladaptive coping refers to those resources which, despite resulting in short term reduction of stress, create an adverse return of the stress to greater levels in the long term. In other studies, maladaptive coping corresponds to the concept of negative coping in Kinsella and Anderson's (1996), avoidance and isolation in Stalberg's (2004), detached coping in Gerace's (1993), substance abuse and denial of the illness (Marsh & Dickens, 1997, pp. 30-32), attempts such as creating defensive shields to protect themselves from stigma (Lukens et al., 2004).

In the study of Friedrich, Lively, and Rubenstein (2008), 746 siblings were evaluated by the Friederich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIISS). The categories of specific coping strategies in FLIISS included management of the situation, management of meaning, management of distress, social support, and distancing. The most helpful coping strategy identified by siblings was realizing that schizophrenia is an illness, that it is not anyone's fault which is the management of meaning strategy and the least helpful of all coping strategies was having little interaction with the ill sibling which is distancing (Friedrich, Lively & Rubenstein, 2008).

There is only one study which compares the stress coping of individuals who have healthy siblings with individuals whose siblings have a diagnosis of schizophrenia and with individuals, whose siblings have a mental illness diagnosis

other than schizophrenia (Morris, 2002). The study found that well siblings of schizophrenics utilize more problem-focused and emotion-focused coping than those whose siblings have a mental illness other than schizophrenia and those whose siblings did not have a mental illness (Morris, 2002).

Marsh (1998) pointed out the coping resources of the well siblings in her book *Troubled Journey* as good mental and physical health, adequate financial and educational possessions, a strong social support system inside and outside the family and spiritual resources that give meaning and reason to life (Marsh and Dickens, 1997).

As Lazarus and Folkman (1984) indicated in their Stress and Coping Model, coping styles of the persons are one of the factors that determinate the level of burden. For this reason, in this study the coping styles of the well-siblings will be examined in order to evaluate the indicators of well-being in the light of the literature.

1.5 Aims of the Study

The main purpose of the present study is to examine the predictive role of the demographic characteristics, parental factors, personal resources, and coping factors on well-being in siblings of patients with schizophrenia in the framework of the Lazarus & Folkman's Stress and Coping Model. The present study also aimed to examine differences in well-being, burden, self-esteem, perceived social support, perceived parental rearing, and coping in siblings with different characteristics (i.e. gender, age, educational level...). Specifically, we aim;

- a. To understand the differences in socio-demographical characteristics of the well siblings.
- b. To examine the relationships between a series of variables identified as central to the stressors and their effects on siblings' well-being.

- c. To capture the complexities of having a sibling with schizophrenia through the use of a transaction model and to measure the effects of the variables in that model on a general well-being indicator.
- d. To provide a model to further explore the relationship between burden and well-being in the search for a greater understanding of the experience of having a sibling with schizophrenia.

1.6 Main Hypotheses of the Study

The first research question of the present study was to understand the differences in socio-demographic characteristics of the well siblings. For this reason, to examine the effects of gender of the well sibling, age of the well sibling at diagnosis time, living status, sibling status and education levels on the variables of the study several group differences analysis will be conducted. Then, within the framework of the stress coping model and in the light of the studies discussed above, the main aim of the current study is to investigate the relationships among the variables which are well-being, self-esteem, burden, parental factors and personal resources, and ways of coping. Accordingly, three groups of hypothesis will be tested.

1.6.1. Hypotheses for predictors of Well-being and Self-esteem

1.6.1.1. Hypotheses for Well-being

It was hypothesised that well-being will be explained by demographic characteristics, stressfulness of the event (i.e. burden), parental rearing styles as mother rejection, father rejection, mother over-protection, father over-protection, mother warmth, father warmth, personal resources as social support and religiousness, and ways of coping which are problem-focused coping, emotion focused coping and indirect coping as depicted in the Figure 3.

1.6.1.2. Hypothesis for Self-esteem

Similarly, for the second outcome, it was hypothesised that self-esteem will be explained by demographic characteristics, stressfulness of the event (i.e. burden), parental rearing styles as mother rejection, father rejection, mother over-protection, father over-protection, mother warmth, father warmth, personal resources as social support and religiousness, and ways of coping which are problem-focused coping, emotion focused coping and indirect coping as depicted in the Figure 3.

1.6.2. Moderation Hypotheses

1.6.2.1. To examine the possible interaction effect of the perceived social support with burden on the well-being, moderated regression analysis will be conducted. Burden and perceived social support will have an interaction effect in determining the well-being. (Figure 4)

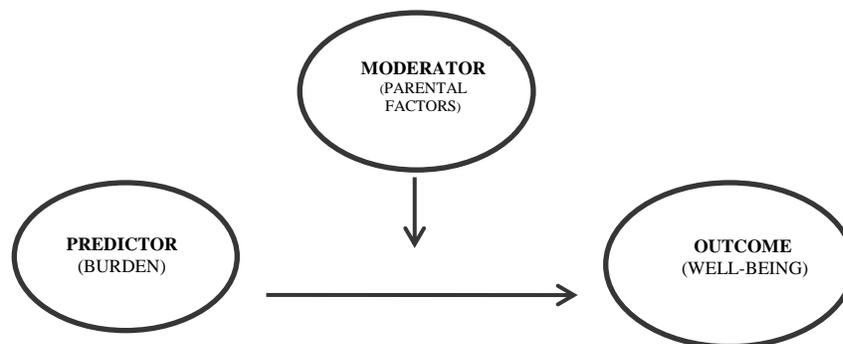


Figure 4. Adapted Moderation Model of Lazarus & Folkman's Stress and Coping Theory for Burden and Parental Factors

1.6.3. Mediation Hypotheses

1.6.3.1. In the light of the model, the relationship between burden and well-being will be mediated by the perceived social support of the well-siblings as seen in the Figure 5.

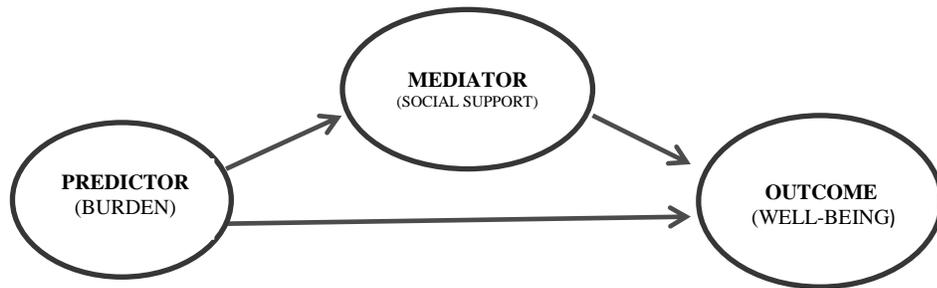


Figure 5. Adapted Mediation Model of Lazarus & Folkman's Stress and Coping Theory

1.6.3.2. The relationship between burden and well-being will be mediated by the problem- focused coping of the well-siblings as seen in the Figure 6.

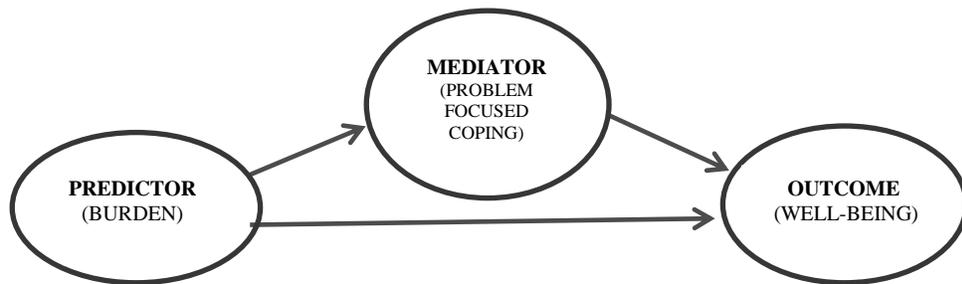


Figure 6. Adapted Mediation Model of Lazarus & Folkman's Stress and Coping Theory

1.7 Importance of the Study

This study has several potential contributions to the current available literature. First of all, the present study aims to improve awareness on the close relatives of patients with schizophrenia. I strongly believe that as a psychologist, we must clearly stress out the burdens which specifically siblings of patients with schizophrenia may be experiencing, and discuss various ways for intervention, that will facilitate the well-being of this rather neglected group.

Secondly, this study will enhance the study on the siblings of the patients with schizophrenia. International research lacks sibling's data on the subject; I have also not come across any study which has investigated the psychological well-being of the healthy siblings in the Turkish literature of the mentally ill patients.

Thirdly, this study will investigate the variables likely to influence the well-being of siblings through a comprehensive model (Lazarus & Folkman's Transactional Stress and Coping Model), which will help us to examine the interactions of all assessed variables relating to the well siblings. This study will also discuss the goodness-of-fit of a proposed model with several mediation/moderation analyses which will enrich the literature.

Last but not the least, this study aims to encourage and support with including data for the future researchers to discuss and develop and enhance several therapeutically beneficial interventions to help struggling well siblings cope better with their current conditions.

CHAPTER 2

METHOD

2.1. Participants

In the present study, 103 well siblings of patients with schizophrenia (44 females and 59 males) whose ages were between 22 and 60 ($M=37.14$, $SD=11.16$) participated. Among the well siblings, 25.2% ($n = 26$) of them were older sisters, 17.5 % ($n= 18$) of them were younger sisters, 29.1 % ($n = 30$) of them were older brothers and 28.2 % ($n=29$) of them were younger brothers. The education levels of the participants were determined due to the last level. Education levels of the well siblings were as follows: 17.5 % primary school ($n = 18$), 34.0 % high school ($n = 35$), and 48.5 % university and above ($n = 50$). Regarding marital status of the well siblings, 51.5% ($n = 53$) of them were single, 39.8 % ($n = 41$) were married and 2.9% ($n = 4$) were widowed or divorced. The well siblings who did not have a job currently consisted 28.2% of the sample ($n = 29$). 48.5 % ($n = 50$) of the well siblings were living together with the ill sibling whereas 51.5% ($n = 53$) of them were living apart from the ill sibling. The characteristics of the well siblings are presented in Table 1.

Table 1. Demographic Characteristics of the Sample

			N
Gender of the well sibling	Female	44	42.7
	Male	59	57.3
Gender of the ill sibling	Female	46	44.7
	Male	57	55.3
Sibling status	Older sister	26	25.2
	Younger sister	18	17.5
	Older brother	30	29.1
	Younger brother	29	28.2
Education	Primary school	18	17.5
	High school	35	34.0
	University and above	50	48.5
Marital status	Single	53	51.5
	Married	41	39.8
	Divorced /widowed	4	2.9
Work	Yes	74	71.8
	No	29	28.2
Living status	With the ill sibling	50	48.5
	Apart from the ill sibling	53	51.5
			Mean
Age of the well sibling			37.14
Age of the ill sibling			35.03
Age of the well sibling when the illness was diagnosed			22.82
Age of the ill sibling when the illness was diagnosed			21.61
Number of hours spent with the ill sibling in a week (living together)			46.89
Number of hours spent with the ill sibling in a week (living away)			10.64
Duration of illness (years)			14.59

2.2 Instruments

2.2.1 Socio-demographic Information Form

The form included demographic questions about age, gender, education of both the sibling and the patient, socioeconomic status of sibling, ordinal position (older/ youngest), sibling's age at the onset of the patient's diagnosis, sibling's relationship to the patient (female with female sibling/ female with male sibling/ male with female sibling/ male with male sibling), duration of face to face contact per week, living together/ away, marital status. In order to gain a deeper understand for the well siblings, several open-ended questions were developed by the researchers regarding the source of information about schizophrenia, burden and related difficulties support resources of the well siblings and, coping strategies. (See Appendix B).

2.2.2 Subjective Well-being Scale (SWS)

The SWS, developed by Tuzgol- Dost, 2005, consists of 46 items. By assessing individuals' cognitive appraisals of their lives and the frequency and intensity with which they experience negative and positive feelings, the scale intends to measure their degree of subjective well-being. The SWS includes evaluative statements about major domains of life and about positive and negative emotionality. A 5-point Likert scale is used: "(5) fully agree;" "(4) mostly agree;" "(3) "agree;" "(2) somewhat agree;" and "(1) disagree." Each item has a score ranging from 1 to 5. There are 26 positive and 20 negative statements. In scoring, regular (positive) items are assigned points 1 to 5, whereas negative items are assigned points 5 to 1. The lowest possible score on the scale is 46 and the highest is 230. Higher scores indicate higher degree of subjective well-being. The internal reliability for the SWS was a Cronbach-alfa coefficient of .93. and test re-test reliability yielded a correlation

coefficient of $r = .86$ (Hisli, 1989). In the present study, the SWS Turkish version alpha coefficient was 0.95.

Examples of such items are “*I enjoy making plans for the future.*”, “*I can be very determined so as to reach my goals.*”, etc. (See Appendix C).

2.2.3 Zarit Caregiver Burden Scale (ZCBS)

It was Zarit, Reever and Bach-Peterson (1980) who first proposed an operational definition of caregiver burden and developed an assessment tool for feelings of caregiver burden, the Zarit Caregiver Burden Scale. The ZCBS is now the instrument most widely used in North America and Europe for assessing the burden experienced by family caregivers who look after the community residing impaired elderly. It comprises of 19 questions graded on a scale from 1 to 5, according to the presence or intensity of an affirmative response, and measures the caregiver’s health, psychological well-being, social life, finances, and the relationship between the caregiver and patient. The ZCBS was adapted to several languages, and the internal consistency ranged from 0.85 to 0.94. It was adapted to Turkish by Özlü, Yıldız and Aker (2009). In the present study, the alpha coefficient of ZCBS was found to be 0.80.

Examples of items are: “*Do you feel like wasting your time while you spend time with your patient?*”, “*How much burdened do you feel to put on your shoulders when you consider the task of taking care of your patient?*” etc. (See Appendix D).

2.2.4 Shortened Perceived Parental Rearing Styles-Child form (EMBU-C)

SPPRS-C is the 23-item shortened form (Arrindell et al., 1999) of PPRS-C (or originally, EMBU-C [Perris et al., 1980]), which evaluates adult perceptions of parental rearing attitudes. The questionnaire consists of 3 scales: rejection, emotional

warmth, and over protection. The SPPRS-C requires a two-fold assessment, for the mother and father.

The psychometric characteristics of SPPRS-C were measured in different countries, such as Italy, Greece, and Sweden (Arrindell et al., 1999; Arrindell et al., 2001), and it was also found to be a reliable and a valid tool in Turkey (Dirik et al., 2004). The internal consistency of the father emotional warmth, rejection, and over protection dimensions was 0.79, 0.82, and 0.79, respectively, and mother emotional warmth, rejection and over protection dimensions was 0.76, 0.80, and 0.76, respectively. In the present study, the alpha coefficient was found to be 0.72.

Examples of items are: “*My parents used to treat me badly without giving any reason.*”, “*I used to feel the affection emanating from my parents.*”*etc.* (See Appendix E).

2.2.5 *Multidimensional Scale of Perceived Social Support (MSPSS)*

For assessing perceived social support, Multidimensional Scale of Perceived Social Support was used. It was developed by Zimet, Dahlem, Zimet, and Farley (1988), and adapted to Turkish by Eker and Arkar (1995) with a Cronbach alpha coefficient between .80 and .95 (Eker, Akar, &Yaldız, 2001). It consists of 12 items and the person rates himself/herself on a 7-point scale ranging between 1 (very strongly disagree) and 7 (very strongly agree). The MSPPS provides information about 3 sources of social support, namely family, friends, and significant other. In the current study, the internal consistency coefficient for the total MSPSS score was found to be .97

Examples of items are: ‘*I have a close friend who helps me to feel relaxed when I feel under stress about my siblings.*’, “*I can discuss my problems between me and my sibling with my friends.*” (See Appendix F).

2.2.6 Rosenberg Self-Esteem Scale (RSS)

The RSES, developed by Rosenberg (1965) is a 10-item self-report measure of global self-esteem. Items are rated from strongly disagree (1) to strongly agree (4). The scores can range from 10 (low level of self-esteem) to 40 (high level of self-esteem). RSES was adapted to Turkish by Çuhadaroğlu (1985) and was shown to be reliable and valid (Toker, 2003; Tuğrul, 1994). The correlation between the scale and psychiatric interview results was found 0.71 for validity of the RSES-Turkish version. The test–retest reliability was reported as 0.75. In the present study, the RSES Turkish version alpha coefficient was 0.93.

Examples of items include: ‘*I am able to do things as well as most other people.*’; ‘*I take a positive attitude toward myself*’ (See Appendix G).

2.2.7 Religious Behaviour Scale (RBS)

Religious Behaviour Scale (RBS) was developed to assess religious resources (Yaparel, 1996). The RBS scale consists of 31 items. Each item is rated on a 5-point scale ranging from “completely wrong” to “completely true”. Yaparel (1996) reported that RBS has four subscales, which are religious beliefs, religious feelings, religious behaviour, and religious knowledge. Only the 10 items religious behaviour subscale was used in the current study in order not to give too much burden to the participants. In addition, one item which is ‘I believed that I am a religious person’ was added. Cronbach Alpha coefficient for the 11 items was found to be 0.95 (Dirik, 2006). In the current study, the RBS Turkish version alpha coefficient was 0.97.

Examples of items include: ‘*I try to fulfil my religious requirements as much as my physical health permits.*’; ‘*I think I am religious person.*’ (See Appendix H).

2.2.8 *Ways of Coping Inventory (WOC)*

It was developed by Folkman and Lazarus (1980) and adapted to Turkish by Siva (1991) with a Cronbach alpha coefficient of .90 (Siva, 1991, cited in Gençöz, Gençöz, & Bozo, 2006). The Turkish version of the scale includes 74 items. In the Gençöz et al. (2006), hierarchical dimensions of coping styles were examined and three higher order factors were identified, namely, problem focused, emotion focused, and indirect coping. The Cronbach alpha coefficients were found to be .90 for problem focused coping subscale, .88 for emotion focused coping subscale, and .84 for indirect coping subscale. In the present study, the alpha coefficient was found to be 0.83; for subscales .91, .89, and .87 respectively.

Examples of items include: *“I choose to focus on the things other than my problems so as to clear my mind.”*; *“I try to reach the best decision by analysing the variables from many perspectives.”* (See Appendix I).

2.3 Procedure

Ethical consent was received from the Middle East Technical University Research Centre for Applied Ethic. Written informed consent was sought from all participants, with the explanation of the purpose of the study, and confidentiality of the personal identity and the data was assured (See Appendix A). The aims of the study were explained to all participants and informed consent form was given. Only volunteers were included in the study by using the snowball recruitment technique from the Solidarity Association of Patients with Schizophrenia and Their Relatives (<http://www.sizofrenifederasyonu.org/>). The questionnaires were distributed and siblings were asked to fill them at their homes. However, some participants had low level of education, the questionnaires were administered to them orally, and the answers were noted down by the researcher. Filling out the questionnaire sets took approximately 45-60 minutes. For association members and participants who do not

live in Ankara, the questionnaires were distributed and collected via their patients. In the data set, the first part was the open ended questions part which the participants answered in writing. Among the participants, 26.7 % participated via e- mail, 17.44 % participated via mail and 55.81 % were directly administered the research instruments.

2.4 Statistical Analysis

The Statistical Package for the Social Sciences 16.00 (SPSS) was used for data analysis in the current study. For each scale used in the current study, internal reliability analyses were conducted.

In order to examine the sibling group differences on the study variables, independent t-Tests, One-way Analysis of Variances (ANOVAs) and Multivariate Analysis of Variances (MANOVAs) were conducted. Prior to the main analyses, a zero-order Pearson correlation analysis was run to investigate the relationship among the study variables. For goodness of fit, two Hierarchical Regression Analyses were run where the Well-being and Self-esteem were dependent variables. Several separate mediation and moderation analyses were run in order to test the mediation and moderation effects on wellbeing.

Finally, qualitative analyses were conducted to reveal the distribution of the answers of well siblings to open-ended questions asked during the interview. Cross tables were given to demonstrate the agreement level of the psychologists and Kappa coefficients were yielded for the inter-rater reliability.

CHAPTER 3

RESULTS

3.1 Preliminary Analysis

3.1.1 Descriptive Information for the Measures of the Study

In order to examine the descriptive characteristics of the measures means, standard deviations, and minimum-maximum ranges, and Cronbach alpha values are provided for Subjective Well-being Scale (SWS); Zarit Caregiver Burden Scale (ZCBS) ; Turkish Ways of Coping Inventory (TWCI) with subscales namely Problem Focused Coping, Emotion Focused Coping and Indirect Coping; Shortened Perceived Parental Rearing Styles-Child Form (EMBU-C) including subscales of Mother Rejection, Father Rejection, Mother Over-Protection, Father Over-Protection, Mother Warmth, Father Warmth; Multidimensional Scale of Perceived Social Support (MSPSS); Rosenberg Self-esteem Scale and Religious Behaviour Scale (see Table 2).

Table 2. Descriptive Information for the Measures

Measures	Alpha Coefficient	Mean	Std. Deviation	Min-Max
TWCI	.83			
Problem focused coping		3.62	.54	2.41-4.55
Emotion focused coping		3.06	.71	1.59-4.5
Indirect Coping		3.45	.85	1.33-5.0
ZCBS	.80	3.97	.97	2.42-6.58
SPPRS-C	.72			
Mother rejection		1.65	.73	1.00-4.00
Father rejection		1.68	.80	1.00-4.00
Mother over-protection		2.39	.60	1.22-4.00
Father over-protection		2.20	.56	1.33-4.00
Mother warmth		2.75	.92	1.00-4.00
Father warmth		2.58	.99	1.00-4.00
MSPSS	.97	5.06	1.47	1.83-7.00
RBS	.97	3.06	1.11	1.00-5.00
RSES	.93	3.31	.56	1.30-4.00
SWS	.95	3.81	.83	1.00-4.00

Note: SWS= Subjective Well-being Scale. ZCBS= Zarit Caregiver Burden Scale. TWCI=Turkish Ways of Coping Inventory. SPPRS-C= Shortened Perceived Parental Rearing Styles-Child form. MSPSS Multidimensional Scale of Perceived Social Support. RSES= Rosenberg Self-Esteem Scale. RBS=Religious Behaviour Scale.

3.2 Group Comparisons for Siblings with Different Characteristics on Some Study Variables

3.2.1 Group Comparisons on the Effects of the Gender of the Well Siblings

There was a significant difference between female and male well siblings on well-being ($t(101) = 3.35, p < .01$). The female siblings got significantly higher scores on wellbeing ($M = 4.15, SD = .78$) than male siblings ($M = 3.61, SD = .84$).

Among personal resources, there was a significant difference between female and male well siblings on perceived social support ($t(101) = 3.15, p < .01$). The female siblings ($M = 5.57, SD = 1.13$) reported higher levels of perceived social support than male siblings ($M = 4.68, SD = 1.61$).

Among the ways of coping variables, there was a significant difference between female and male well siblings on problem focused coping ($F(1, 102) = 5.24, p < .05$) and indirect coping ($F(1, 102) = 11.06, p < .01$). The female siblings got significantly higher scores on problem focused coping ($M = 3.75, SD = .42$) and indirect coping ($M = 3.81, SD = .84$) than male siblings did on problem focused coping ($M = 3.52, SD = .56$) and indirect coping ($M = 3.27, SD = .78$). (See Table 3 and Table 4).

Table 3. Descriptive Statistics and t-test Results for Female and Male Well Siblings

	Male (n=59)		Female (n=44)		t (df=101)	P
	M	SD	M	SD		
Well-being **	3.61	.84	4.15	.78	3.35	.01
Burden	4.18	1.03	3.82	.84	1.88	.06
Self-esteem	3.27	.57	3.35	.52	.77	.44
Perceived social support **	4.68	1.61	5.57	1.13	3.15	.01
Religiousness	3.04	1.09	3.12	1.06	.34	.75

*.p<.05 ; **, p<.01

Table 4. Descriptive Statistics and ANOVA Results for Female and Male Well Siblings

		Male		Female		MANOVA		
		M	SD	M	SD	df	F	P
Coping Factors	Problem-focused coping*	3.52	.56	3.75	.47	(1,102)	5.24	.02
	Emotion-focused coping	3.00	.68	3.18	.70	(1,102)	1.69	.20
	Indirect coping**	3.27	.78	3.81	.84	(1,102)	11.06	.01

*.p<.05 ; **, p<.01

Siblings

3.2.2 Group Comparisons with Age Groups of the Well Siblings at Diagnosis Time

Age groups as “adult siblings” and “adolescent siblings” were formed according to the age of the well sibling at ill siblings’ diagnosis time. The well siblings who were under the age of 16 when the ill sibling was diagnosed by schizophrenia were assigned into “adolescents group” and others were assigned into the “adult group”. This assignment was made by using “recode into different variables” command in SPSS. The only variable that differs in terms of age group

was indirect coping ($F(1,102) = 5.30, p < .05$). The siblings who are in adulthood at diagnosis time ($M = 3.72, SD = .79$) reported higher levels of indirect coping than adolescent siblings ($M = 3.33, SD = .86$).

Table 5. Descriptive Statistics and T-test Results for Adolescent and Adult Well Siblings

	Adolescent		Adult		t (101)	P
	M	SD	M	SD		
Well-being	3.75	.90	3.97	.77	-1.30	.20
Burden	4.10	1.02	3.93	.87	.86	.39
Self-esteem	3.25	.56	3.37	.51	-1.14	.26
Perceived social support	4.83	1.58	5.37	1.29	-1.86	.07
Religiousness	3.06	1.07	3.11	1.06	-.25	.80

Table 6. Descriptive Statistics and ANOVA Results for Adolescent and Adult Well Siblings

		Adolescent		Adult		One Way ANOVA		
		M	SD	M	SD	df	F	p
Parental Factors	Mother rejection	1.72	.75	1.52	.66	1,102	1.95	.16
	Father rejection	1.76	.86	1.58	.68	1,99	1.25	.26
	Mother over-protection	2.37	.59	2.42	.57	1,102	.22	.64
	Father over-protection	2.18	.58	2.20	.49	1,99	.02	.87
	Mother warmth	2.68	1.02	2.91	.78	1,102	1.59	.21
	Father warmth	2.64	1.00	2.45	1.02	1,99	.85	.35
Coping Factors	Problem-focused coping	3.54	.56	3.73	.49	1,102	3.01	.09
	Emotion-focused coping	3.08	.71	3.07	.66	1,102	.01	.91
	Indirect coping*	3.33	.86	3.72	.79	1,102	5.30	.02

* $p < .05$

3.2.3 Group Comparisons with Living Status (together/apart) of the Well Siblings

To examine the group differences on variables, three separate independent samples t-tests and two 2 X 3 ANOVA's were conducted in which living status (living together/living apart) was used as the independent variable (see Table 7, Table 8).

There was a significant difference between living apart from the sibling and living together with the sibling on well-being ($t(101) = 3.28, p < .01$). The living apart siblings got significantly higher scores on wellbeing ($M = 4.10, SD = .66$) than living together siblings ($M = 3.58, SD = .95$).

There was also a significant difference between living apart siblings and living together siblings on burden ($t(102) = -4.17, p < .01$). The living apart siblings got significantly lower scores on burden ($M = 3.67, SD = .87$) than living together siblings ($M = 4.41, SD = .93$).

There was also a significant difference between living apart siblings and living together siblings on self-esteem ($t(101) = 3.21, p < .01$). The living apart siblings got significantly higher scores on self-esteem ($M = 3.46, SD = .48$) than living together siblings ($M = 3.31, SD = .56$).

There was a significant difference between living away from sibling and living together with siblings on social support ($t(101) = 4.14, p < .01$). The living away siblings got significantly higher scores on social support ($M = 5.64, SD = 1.16$) than living together siblings ($M = 4.45, SD = 1.55$).

Among ways of coping variables, conducted MANOVA results showed that the effect of living status on problem focused coping ($F(1,102) = 11.47, p < .01$) was significant. It was found that living apart siblings had significantly higher scores of problem focused coping ($M = 3.79, SD = .49$) than the living together siblings ($M = 3.45, SD = .53$).

Table 7. Descriptive Statistics and T-test Results for Well Siblings who Lives with and Apart from the ill Sibling

	Lives together with the ill sibling		Lives apart from the ill sibling		t	p
	M	SD	M	SD		
Well-being**	3.58	.95	4.10	.66	3.28	.01
Burden**	4.41	.93	3.67	.87	-4.17	.01
Self-esteem**	3.31	.56	3.46	.48	3.21	.01
Perceived social support**	4.45	1.55	5.64	1.16	4.14	.01
Religiousness	3.18	1.04	2.99	1.10	-.89	.38

*.p<.05 ; **.p<.01

Table 8. Descriptive Statistics and ANOVA Results for Well Siblings who Lives with and Apart from the ill Sibling

		Lives together with the ill sibling		Lives apart from the ill sibling		One Way ANOVA		
		M	SD	M	SD	df	F	p
Coping Factors	Problem-focused coping*	3.45	.53	3.79	.49	(1,102)	11.47	.01
	Emotion-focused coping	3.21	.57	2.95	.77	(1,102)	3.83	.05
	Indirect coping	3.36	.85	3.63	.84	(1,102)	2.57	.11

*.p<.05 ; **.p<.01

3.2.4 Group Comparisons with Sibling Ordinal and Gender

To examine the effects of sibling status of the siblings on the study variables, Multivariate Analysis of Variances (MANOVAs) were conducted. For this analysis siblings were grouped into four, namely older sister, younger sister, older brother, and younger brother. The results showed that the effect of siblings status on well-being was significant ($F(3, 102) = 8.14, p < .01$). When the differences between the older brother, younger brother, older sister and younger sister groups were examined with Tukey HSD test, it was found that older sisters had significantly higher levels of well-being ($M = 4.26, SD = .53$) than the younger brother groups ($M = 3.28, SD = .64$).

To examine the effects of sibling status on the ways of coping variables, Multivariate Analysis of Variances were conducted. Results showed that effect of siblings status on problem focused coping was significant ($F(3, 102) = 4.03, p < .05$). When the differences between the older brother, younger brother, older sister and younger sister groups were examined with Tukey HSD test, it was found that older sisters had significantly higher scores of problem focused coping ($M = 3.88, SD = .46$) than the younger brother groups ($M = 3.40, SD = .42$). Moreover, the difference on problem focused coping between younger sister and older brother was not significant. For emotion focused coping, the groups did not yield significant differences, but, for indirect coping, effect of siblings status on indirect coping was significant ($F(3, 102) = 4.66, p < .01$). When the differences between the older brother, younger brother, older sister and younger sister groups were examined with Tukey HSD test, it was found that older sisters had significantly higher scores on indirect coping ($M = 3.85, SD = .65$) than the younger brother groups ($M = 3.09, SD = .85$).

The effects of sibling status was significant on self-esteem ($F(3, 102) = 6.28, p < .01$). When the differences between the older brother, younger brother, older sister

and younger sister groups were examined with Tukey HSD test, it was found that older sisters had significantly higher scores on self-esteem ($M = 3.50$, $SD = .89$) than the younger brother groups ($M = 3.02$, $SD = .46$); the difference between younger sister and older brother was not significant.

Table 9. Descriptive Statistics and ANOVA/ MANOVA Results for Sibling Status of the Well Siblings

		Older Sister		Younger Sister		Older Brother		Younger Brother		M/ANOVA		
		M	SD	M	SD	M	SD	M	SD	df	F	p
Personal Factors	Well-being**	4.26 _a	.53	4.00 _{ab}	1.03	3.94 _{ab}	.89	3.28 _a	.64	3,102	8.14	.00
	Burden	3.61	.81	4.13	.79	4.26	1.42	4.10	.76	3,102	2.42	.07
	Self-esteem**	3.50 _a	.39	3.13 _{ab}	.60	3.49 _{ab}	.57	3.02 _a	.46	3,102	6.28	.00
	Perceived social support**	5.80 _a	.89	5.23 _{ab}	1.34	5.06 _{ab}	1.69	4.27 _a	1.43	3,102	5.61	.00
Coping Factors	Religiousness*	2.79 _{ab}	1.05	3.60 _a	.88	2.77 _b	1.07	3.33 _{ab}	1.03	3,102	3.71	.01
	Problem-focused coping**	3.88 _a	.46	3.58 _{ab}	.42	3.63 _{ab}	.66	3.40 _a	.42	3,102	4.03	.00
	Emotion-focused coping	2.98	.79	3.46	.41	2.97	.65	3.03	.71	3,102	2.41	.07
	Indirect coping**	3.85 _a	.65	3.75 _{ab}	1.07	3.44 _{ab}	.90	3.09 _a	.85	3,102	4.66	.00

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

3.2.5 Group Comparisons with Education Levels

To examine the effects of education of the siblings on the study variables, Multivariate Analysis of Variances (MANOVAs) were conducted. For this analysis, education levels of the well siblings grouped into four, namely primary school, high school, university and above. The results showed that the effect of education on burden was significant ($F(2, 102) = 7.06$, $p < .01$). When the differences between primary school, high school and university and above groups were examined with Tukey HSD test, it was found that primary school group ($M = 4.47$, $SD = .75$) and high school group ($M = 4.29$, $SD = .55$) had significantly higher scores of burden

than the university and above group (M =3.68, SD = 1.13). The primary school group and high school group did not yield significant difference on burden.

To evaluate the effects of education level of the siblings on religiousness, Multivariate Analysis of Variances (MANOVAs) were conducted. The results showed that the effect of education on religiousness was significant (F (2, 102) = 6.31, p < .01). When the differences between primary school, high school and university and above groups were examined with Tukey HSD test, it was found that primary school group (M = 3.85, SD =.77) had significantly higher scores of religiousness than the high school (M =2.92, SD = .70) and the university and above group (M =2.91, SD = 1.24). Moreover, primary school group and high school group did not yield significant difference on religiousness.

The results showed that the effect of education on emotion coping was also significant (F (2, 102) = 13.86, p < .01). When the differences between primary school, high school and university and above groups were examined with Tukey HSD test, it was found that primary school group (M = 3.47, SD =.44) had significantly higher scores of emotion focused coping than the high school (M =3.34, SD = .47) and the university and above group (M =2.74, SD =.73). Moreover, primary school group and high school group did not yield significant difference on emotion focused coping.

Table 10. Descriptive Statistics and ANOVA/ MANOVA Results for Education Level of the Well Siblings

		Primary School		High School		University and Above		M/ANOVA		
		M	SD	M	SD	M	SD	df	F	p
Personal Factors	Well-being	3.81	.69	3.60	.89	4.03	.85	2,102	2.82	.06
	Burden**	4.47 _a	.75	4.29 _a	.55	3.68 _b	1.13	2,102	7.06	.00
	Self-esteem	3.24	.40	3.15	.57	3.43	.55	2,102	2.84	.06
	Perceived social support	4.76	1.69	4.70	1.38	5.41	1.41	2,102	2.92	.06
	Religiousness**	3.85 _a	.77	2.92 _b	.70	2.91 _b	1.24	2,102	6.31	.00
Coping Factors	Problem-focused coping	3.60	.41	3.49	.48	3.71	.59	2,102	1.77	.17
	Emotion-focused coping**	3.47 _a	.44	3.34 _a	.47	2.74 _b	.73	2,102	14.86	.00
	Indirect coping	3.77	.73	3.29	1.00	3.55	.74	2,102	2.01	.13

*.p<.05 ; **, p<.01

3.3 Inter-correlations between Variables used in the Multiple Regression Analyses

Table 11 presents the inter-correlations between variables used in the multiple regression analysis. As can be seen from the table, mother rejection ($r=-.66$, $p<.01$), father rejection ($r=-.67$, $p<.01$), burden ($r=-.42$, $p<.01$) and emotion focused coping ($r=-.33$, $p<.01$) were negatively and significantly correlated with well-being. On the other hand, mother over-protection ($r=.32$, $p<.01$), father over-protection ($r=.35$, $p<.01$), mother warmth ($r=.75$, $p<.01$), father warmth ($r=.65$, $p<.01$), social support ($r=.72$, $p<.01$), problem focused coping ($r=.77$, $p<.01$) and indirect coping ($r=.67$, $p<.01$) were positively and significantly correlated with well-being. There was a high positive correlation between well-being and self-esteem ($r=.83$, $p<.01$). Mother rejection ($r=-.55$, $p<.01$), father rejection ($r=-.57$, $p<.01$) and burden ($r=-.45$, $p<.01$) were negatively and significantly correlated with self-esteem whereas mother over-protection ($r=.29$, $p<.01$), father over-protection ($r=.27$, $p<.01$), mother warmth ($r=.59$, $p<.01$), father warmth ($r=.66$, $p<.01$), social support ($r=.60$, $p<.01$), problem-focused coping ($r=.72$, $p<.01$) and indirect coping ($r=.53$, $p<.01$) were positively and significantly correlated with self-esteem.

Table 11. Inter-correlations between Multiple Regression Variables

	Mother rejection	Father rejection	Mother over protection	Father over protection	Mother warmth	Father warmth	Self-esteem	Social support	Religiousness	Burden	Problem focused coping	Emotion focused coping	Indirect coping
Wellbeing	-.662**	-.677**	.321**	.355**	.754**	.653**	.529**	.724**	.008	-.416**	.774**	-.332**	.665**
Mother rejection		.737**	-.596**	-.503**	-.715**	-.499**	-.553**	-.672**	-.094	.386**	-.532**	.326**	-.626**
Father rejection			-.523**	-.598**	-.660**	-.755**	-.570**	-.707**	-.058	.526**	-.604**	.313**	-.510**
Mother overprotection				.669**	-.443**	-.405**	.391**	-.445**	.064	.507**	-.407**	.435**	-.302**
Father overprotection					-.440**	-.458**	.370**	-.535**	-.018	.392**	-.394**	.182	-.347**
Mother warmth						.763**	.590**	.707**	-.087	-.471**	.613**	-.336**	.512**
Father Warmth							.664**	.600**	-.193	-.502**	.552**	-.262**	.542**
Self-esteem								.597**	-.172	-.452**	.723**	-.376**	.525**
Social support									.102	-.516**	.553**	-.154	.626**
Religiousness										.148	.040	.294**	.553**
Burden											-.436**	.565**	-.130
Problem focused coping												-.481**	.447**
Emotion focused coping													.037
Indirect coping													

3.4. Hierarchical Regression Analysis for Well-being

A five-step hierarchical multiple regression was conducted with Well-being as the dependent variable. Demographic variables (age, gender) were entered in the first step of the formulated regression equation. The impact of the stressful event (burden) was entered in the second step, the Parental Variables (mother rejection, father rejection, mother over-protection, father over-protection, mother warmth and father warmth) in the third step; Personal Resources (religiousness, and perceived social support) in the fourth step and Coping Factors (problem focused coping, emotion focused coping and indirect coping) in the fifth step. The variables were entered in this order as it seemed chronologically plausible and fitting the model. Inter correlations between the multiple regression variables were shown in Table 11 and the regression statistics for Well-being are presented in Table 12.

Considering the zero-order correlation analysis, the variables “age” ($r=.22$, $p<.05$) and “gender” ($r= -.32$, $p<.01$) revealed moderate correlation with Well-being, indicating that female well siblings and participants who are older tended to feel more Well-being. Therefore, these variables were entered into the regression equation in the first step where Well-being was the dependent variable. In the first step, the hierarchical multiple regression equation revealed that Demographic Variables contributed significantly to the regression model [$F_{change} (2,97) = 6.51$, $p < .001$], explained 10% variance of Well-being. When the impact of the stressful event was included in the second step of the regression model, burden was also a significant predictor of Well-being as well, in the second step explained variance increased to 22%, [$F_{change} (1,96) = 15.70$, $p < .001$].

In the third step, adding Parental Variables to the regression model, the explained variance increased to 62 %, $F_{change} (6,90) = 18.08$, $p < .001$. Among Parental Variables, mother over-protection ($pr=.35$, $\beta=.38$, $t (90)=3.48$, $p<.01$) was found to be associated with Well-being, indicating that well siblings who perceived over-protection from their mother in their childhood tended to feel more levels of subjective Well-being.

In the fourth step, the addition of Personal Variables to the regression model, led to a significant increase in explained variance to 68%, ($F_{change} (2, 88) = 9.33, p < .001$). Among Personal Variables, perceived social support ($pr=.29, \beta=.14, t(88) = 2.81, p<.01$) by the well siblings was found to be a significant predictor of Well-being, showing that the more they perceived social support, the more they reported well-being.

On the last step, Coping Variables explained an additional 13 % of the variation in Well-being and explained variance increased to 81% , $F_{change} (3, 85) = 22.08, p<.001$. Among Coping Variables, problem focused coping ($pr=.47, \beta=.55, t(85)=4.85, p<.01$) and indirect coping ($pr=.45, \beta=.32, t(85)=4.71, p<.01$) were found to be significantly associated with Well-being. Together the five independent variable sets accounted for 81% of the variance in Well-being and the summary of the regression equation is displayed in Table 12.

Table 12. Variables Associated with Well-being

Order of Entry of Data Set	β	<i>t</i> for within set predictors	Within set partial correlation (<i>pr</i>)	F change	d. f. for the F value	Model R ²
1. Demographic Variables						
Age	-.09	-1.85	-.20	6.51	(2,97)	.10
Gender	.03	.56	.06			
2. Stressfulness of event						
Burden	.03	.46	.05	15.70	(1,96)	.22
3. Parental Variables						
Mother rejection	-.01	-.05	.01			
Father rejection	.08	-.68	-.07			
Mother over-protection	.38	3.48**	.35	18.08	(6,90)	.62
Father over-protection	-.00	-.02	-.00			
Mother warmth	.17	1.89	.20			
Father warmth	.08	.91	.10			
4. Personal Variables						
Social support	.14	2.81**	.29	9.33	(2,88)	.68
Religiousness	-.02	-.54	-.06			
5. Coping Variables						
Problem focused coping	.55	4.85**	.47			
Emotion focused coping	-.16	-1.82	-.19	22.08	(3,85)	.81
Indirect coping	.32	4.71**	.45			

**;*p*<.001, *;*p*<.05

3.5. Hierarchical Regression Analysis for Self-esteem

Similarly, a five step hierarchical multiple regression analysis was conducted where the Self-esteem was the dependent variable. Considering the zero-order correlation analysis, “living status of the well sibling” ($r=-.30, p<.01$) and “gender” ($r= -.30, p<.01$) revealed moderate correlations with Self-esteem, indicating that well siblings who lives away from the ill siblings and female participants showed higher levels of Self-esteem. Therefore, these Demographic Variables were entered into the regression equation in the first step where Self-esteem was the dependent

variable. The impact of the stressful event (burden) was entered in the second step followed by the Parental Variables (mother rejection, father rejection, mother over-protection, father over-protection, mother warmth and father warmth) in the third step; Personal Resources (religiousness and perceived social support) in the fourth step and Coping Factors (problem focused coping, emotion focused coping and indirect coping) in the fifth step. These variables were entered in this order as it seemed chronologically plausible and fitting the model.

In the first step, the hierarchical multiple regression analysis revealed that Demographic Variables contributed significantly to the regression model ($F_{change}(2,97) = 1.17, p < .05$) and explained 3% of the variance. Among Demographic variables, gender ($pr=.38, \beta=.23, t(97)=3.82, p<.01$) was found to be significantly associated with Self-esteem, indicating that female well siblings tended to develop higher levels of Self-esteem than male well siblings.

In the second step, introducing the Stressfulness of the event (i.e. burden) to the regression equation, the explained variance increased to 18 % of the variation was explained in Self-esteem, $F_{change}(1, 96) = 21.62, p < .001$. Burden as the stress factor ($pr=-.23, \beta=.17, t(96)=-2.21, p<.01$) is a significant predictor of Self-esteem, indicating that higher levels of burden among well siblings related to the sibling's illness leads to a decrease in Self-esteem.

In the third step, the addition of Parental Variables increased to explained variance to 54 %, $F_{change}(6, 90) = 13.80, p < .001$. Except father warmth, all other Parental Variables were found to be associated with Self-esteem. Perceived rejection from both mother ($pr=-.24, \beta=-.25, t(90)=-2.32, p<.01$) and father ($pr=-.22, \beta=-.25, t(90)=-2.04, p<.01$) in the childhood was found to be significantly and negatively associated with Self-esteem of the well siblings. On the other hand, the well siblings who perceived mother warmth ($pr=.31, \beta=.33, t(90)=3.05, p<.01$) and father warmth ($pr=.47, \beta=.56, t(90)=4.90, p<.01$) in their childhood, reported higher levels of Self-esteem. Lastly, in the thirds step, a significant and positive association between mother over-protection ($pr=.38, \beta=.30, t(90)=3.76, p<.01$) and Self-esteem was

yielded, indicating that perceived mother warmth in the childhood leads to higher Self-esteem in well siblings.

In the fourth step, by adding Personal Variables to the regression model, the explained variance increased to 60% , $F_{change} (2, 88) = 7.68, p < .001$. Among Personal Variables, religiousness ($pr=-.33, \beta=-.18, t(88)=-3.26, p<.01$) was found to be associated with Self-esteem, indicating that participants who reported lower levels of religiosity reported higher levels of Self-esteem.

In the last step, Coping Variables also contributed significantly to the regression model ($F_{change} (3,85) = 23.52, p< .05$) and explained an additional 18% of variation in Self-esteem. Among Coping Variables, problem focused coping ($pr=.54, \beta=.44, t(85)=5.87, p<.01$) and indirect coping ($pr=.47, \beta=.36, t(85)=4.84, p<.01$) were found to be significantly associated with Self-esteem. Together the five independent variable sets accounted for 78% of the variance in Self-esteem and the summary of the regression equation is displayed in Table 13.

Table 13. Variables Associated with Self-esteem

Order of Entry of Data Set	β	<i>t</i> for within set predictors	Within set partial correlation (<i>pr</i>)	F change	d. f. for the F value	Model R ²
1. Demographic Variables						
Living Status	-.04	-.65	-.07	1.17	(2,97)	.03
Gender	.23	3.82**	.38			
2. Stressfulness of event						
Burden	-.17	-2.21*	-.23	21.62	(1,96)	.18
3. Parental Variables						
Mother rejection	-.25	-2.32*	-.24			
Father rejection	-.25	-2.04*	-.22			
Mother over-protection	.30	3.76**	.38	13.80	(6,90)	.54
Father over-protection	-.01	.17	.02			
Mother warmth	.33	3.05**	.31			
Father warmth	.56	4.90**	.47			
4. Personal Variables						
Social support	.19	1.90	.20	7.68	(2,88)	.60
Religiousness	-.18	-3.26**	-.33			
5. Coping Variables						
Problem focused coping	.44	5.87**	.54	23.52	(3,85)	.78
Emotion focused coping	-.01	-.18	-.19			
Indirect coping	.36	4.84**	.47			

3.6. Tests of Moderation and Mediation Models

3.6.1. Moderation Model for Well-being

3.6.1.1. Social Support as a Moderator of Burden

In order to test the moderating role of social support for burden, two sets of multiple regressions were generated using the procedure suggested by Baron and Kenny (1986) both of the independent variables were centered. In the first regression analysis, centered social support and centered burden were entered in the first step. The interaction term was entered in the second step. In the second step, the interaction of social support and burden revealed a significant relationship with well-

being ($\beta = .58$, $t(103) = 2.19$, $p < .05$). The interaction of social support and burden explained 19% of variance of well-being ($\Delta R^2 = .08$, $F_{change}(1, 103) = .03$, $p < .001$). Thus, social support was a significant moderator of the relationship between burden and well-being. Participants of different levels of social support did not differ in well-being scores under conditions of low burden, however large differences were noted under the conditions of high burden; individuals who had high social support reported significantly higher levels of well-being than individuals reporting low levels of social support. This is shown in Figure 7.

Table 14. Hierarchical Regression Analysis for Moderating Effect of Social Support on the Relationship between Burden and Well-being

	B	S.E	β	R^2	R^2 Change	F Change
Dependent Variable :Well-being						
Step 1						
Burden	-.14	.12	-.29	.05	.05	.12
Step 2						
Social Support	.40	.15	.34	.12	.07	.05
Step 3						
Burden x Social Support	.30	.14	.58	.19	.08	.03

Note. B,S.E., and β reflect values from the final regression equation.

*: $p < .05$

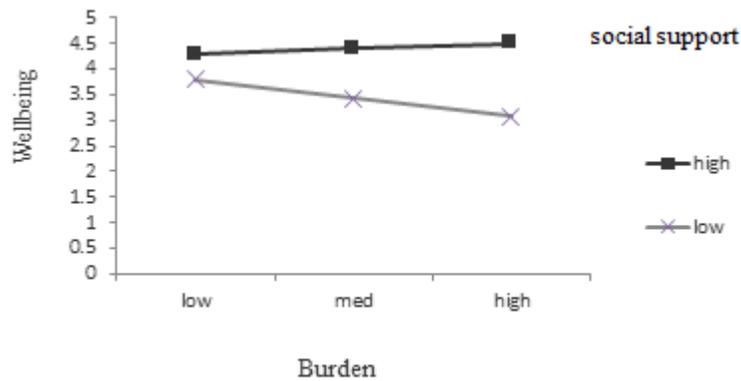


Figure 7. Interaction of social support and burden on well- being

3.6.2. Mediation Models for Well-being

3.6.2.1. Social Support as Mediator between Well-being and Burden

According to Baron and Kenny (1986), four criteria are required to reveal a mediator effect. First, the predictor variable (burden) must be related to the mediator variable (social support). Second, the predictor variable must be related to the outcome variable (well-being). Third, the mediator variable must be related to the outcome variable. Fourth, after controlling for the effects of the mediator on the outcome, the relation between the predictor and the outcome must be significantly decreased. To test for a mediation effect of social support on the relationships between burden and well-being, a series of three regressions were conducted. The relationship between burden (stressor) and well-being was mediated by social support. Burden was a significant predictor of well-being ($\beta = -.45, p < .001$) and social support ($\beta = .37, p < .001$), and after controlling for burden, social support was a significant predictor of well-being ($\beta = -.69, p < .001$). The final condition of mediation was also met: The standardized regression coefficient between burden and well-being decreased significantly (from $\beta = -.45, p < .001$ to $\beta = -.10, p <$

.001). The mediating role of social support between burden and well-being was confirmed by Sobel test (Sobel $z = -4.58$, $p = .001$). Therefore, social support mediated the relationship between burden and well-being (See Figure 8)

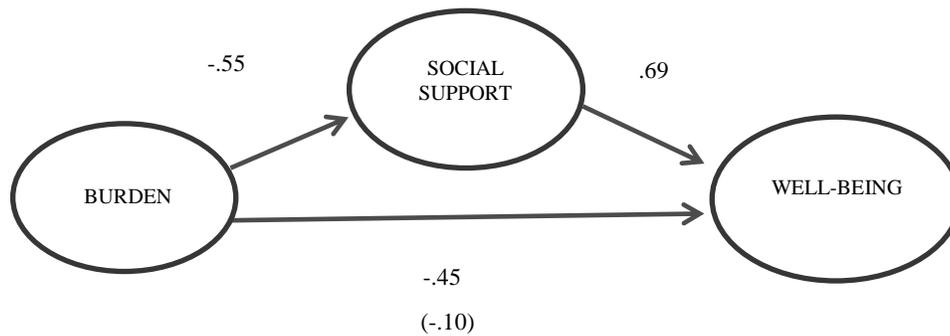


Figure 8 Model of the mediational role of social support in the relationship between burden and well-being. Value in parentheses is the reduced correlation coefficient when the mediator is present. All Beta Coefficients are significant at .001 level.

3.6.2.2. Problem-focused Coping as Mediator between Wellbeing and Burden

To test for a mediation effect of problem-focused coping on the relationships between burden and well-being, a series of three regressions were conducted. First, problem-focused coping was regressed on burden ($\beta = -.26$, $p < .001$). Burden contributed a significant amount of variance to problem-focused coping (22%). Second, well-being was regressed on burden ($\beta = -.45$, $p < .001$). Burden explained a significant amount of variance to well-being (17%). In the third equation, well-being was simultaneously regressed on both problem-focused coping ($\beta = .35$, $p < .001$) and burden ($\beta = .28$, $p < .001$). Finally, the regression model contributed a significant amount of variance to well-being (28%). The results of regression analyses testing mediation effects of problem-focused coping on the relationship between burden and well-being are presented in Figure. 9. As shown Figure. 9, the beta weight when burden was regressed alone on well-being was .45. The beta weight dropped from

.45 to -.10 when problem-focused coping was added into the equation. The Sobel Test revealed that problem-focused coping significantly mediated the relationship between burden and well-being ($z=-6.65, p<.001$). According to Baron and Kenny (1986), full mediation obtains if the predictor variable (burden) has no significant effect on the outcome variable (well-being) when the mediator (problem-focused coping) is controlled. Therefore, these results indicated that problem-focused coping only partially mediated the relationship between burden and well-being.

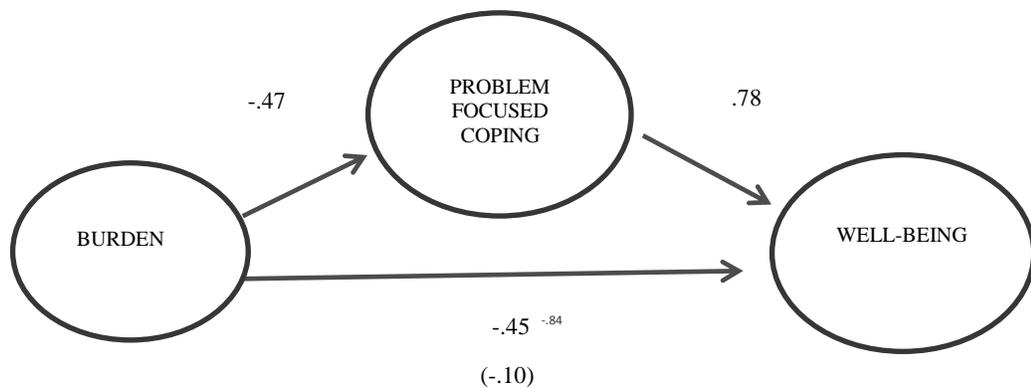


Figure 9. Model of the mediational role of problem focused coping in the relationship between burden and well-being. Value in parentheses is the reduced correlation coefficient when the mediator is present. All Beta Coefficients are significant at .001 level.

3.7. Qualitative Analysis

3.7.1. Answers to open-ended questions

Along with the objective measures that were displayed in the previous section, the well siblings were asked by open ended questions before they were given the self-report questionnaires. The answers to the open ended questions were categorized by the current researcher. Then, the statements were evaluated by two

independent researchers who are working with the patients with schizophrenia and their families, and had a master degree in Clinical Psychology. The following distributions of answer categories were prepared with the help of the two psychologists and an inter-rater reliability of $\kappa = 0.81$ was found for the answers. Only the forms of 90 participants were completed that were used for this analysis.

Table 15. Distribution of the answers of the well siblings to the Open-ended Interview Questions

1. What were your sources of information about the disorder?	n	%
<i>Doctors and nurses</i>	83	92
<i>People with similar experiences and the association</i>	65	72
<i>TV and newspapers</i>	42	47
<i>Internet and books</i>	40	44
2. Can you tell me about your relationship with your sibling? (Do you find him/her friendly? Is he/she easy to get along with? Are you close with him/her? In which aspects would you have liked him/her to be different? In what ways does he/she annoy you?)	n	%
<i>It is hard to live with him/her.</i>	77	86
<i>He/she doesn't love me at all, he/she is mad at me.</i>	60	67
<i>We are very close to each other.</i>	57	63
<i>I always support him/her.</i>	55	61
<i>We share little.</i>	50	56
<i>There isn't enough communication or interaction between us.</i>	48	53
<i>We are not close to each other.</i>	47	52
<i>He/she doesn't talk much with me.</i>	42	47
<i>We share much.</i>	35	39
<i>He/she only cares about himself/herself.</i>	33	37
<i>He/she always supports me.</i>	11	12
<i>We support each other, share a lot and we are close to each other.</i>	7	8
<i>I think that she is friendly and sincere, and that he/she is the only person in the world who understands me.</i>	5	6
3. Who supported you while you went through a difficult time due to your sibling's	n	%

disorder?		
<i>My family.</i>	84	93
<i>Doctors.</i>	72	80
<i>My friends.</i>	59	66
<i>My wife/husband.</i>	62	69
<i>The association.</i>	45	50
<i>My children.</i>	29	32
<i>My girlfriend/boyfriend.</i>	20	22
<i>No one.</i>	5	6
4. How did they support you?	n	%
<i>By giving me emotional support.</i>	75	83
<i>By listening to me.</i>	57	63
<i>By giving me financial support.</i>	49	54
<i>They told me I was right.</i>	43	48
<i>They empathized with me and they didn't reproach me.</i>	39	43
<i>They gave me support when we went to the hospital and helped me contact the doctor in cases of emergency.</i>	36	40
<i>By consoling me.</i>	30	33
5. What kinds of difficulties have you experienced due to having a sibling with schizophrenia?	n	%
<i>Financial burden.</i>	82	91
<i>Emotional burden.</i>	78	87
<i>I was sad.</i>	78	87
<i>I was scared.</i>	69	77
<i>Anxiety.</i>	67	74
<i>I was tired.</i>	64	71
<i>I was angry.</i>	59	66
<i>I was worried about my parents.</i>	57	63
<i>I got mad.</i>	42	47
<i>I was disappointed.</i>	39	43
<i>I felt guilty.</i>	37	41
<i>I was ashamed.</i>	23	26
6. How did you cope with these difficulties?	n	%
<i>I consulted doctors.</i>	87	97

<i>I tried to get information.</i>	77	86
<i>I gave him/her support.</i>	69	77
<i>I tried to understand the disorder.</i>	67	74
<i>I alleviated my guilt by helping him/her.</i>	45	50
<i>I received support.</i>	43	48
<i>I tried to act as if nothing happened.</i>	42	47
<i>I tried to think that he/she wasn't my sibling.</i>	39	43
<i>I kept away from him/her.</i>	37	41
<i>I dedicated myself to him/her.</i>	37	41
<i>I didn't see him/her much.</i>	36	40
<i>I smoked more.</i>	12	13
<i>I went to another city to study.</i>	7	8
7. Compared to the period before the diagnosis of the illness, has your parents' attitude towards you and your sibling changed? Would you share it with me?	n	%
<i>Yes, it has changed.</i>	80	89
<i>They spend more time with us.</i>	75	83
<i>They are more protective.</i>	55	61
<i>I was oppressed and ignored.</i>	55	61
<i>They love us more.</i>	36	40
<i>They isolate him/her and protect me.</i>	31	34
<i>They spoil him/her.</i>	25	27
<i>No, it hasn't changed</i>	10	11
<i>I was always the "bad boy."</i>	9	10
<i>I became my family's favorite.</i>	7	8
8. If your family began to behave differently towards you after your sibling developed the disorder, how did you cope with that?	n	%
<i>My family began to behave differently but I tried to understand this change as my sibling was ill.</i>	72	80
<i>I became distant from them.</i>	39	43
<i>I built my own life.</i>	36	40
<i>I did not mind or make much of it.</i>	27	30
<i>My family did not behave differently.</i>	9	10
9. How did your sibling's disorder affect you in general?	n	%
<i>Negative.</i>	83	92

<i>I am exhausted.</i>	68	76
<i>I am exasperated.</i>	62	69
<i>I shouldered the entire burden.</i>	60	67
<i>I became a patient and selfless person.</i>	57	63
<i>I began to live with the constant fear that something might happen to him/her and I feared that he/she might have an attack.</i>	57	63
<i>I am sad.</i>	55	61
<i>I had to live in anxiety.</i>	55	61
<i>I have no power or energy left.</i>	49	54
<i>I learned to take responsibility.</i>	42	47
<i>I stood on my own two feet.</i>	40	44
<i>I became mature.</i>	39	43
<i>I was ignored.</i>	35	39
<i>I learned to be self-sufficient.</i>	35	39
<i>I was ashamed.</i>	31	35
<i>I was stigmatized.</i>	29	32
<i>I wasn't loved.</i>	21	23
<i>Nobody understood me.</i>	17	19
<i>Positive.</i>	11	12

As can be seen from the Table 15, for the first question, the prominent answers of the well siblings regarding their information resources were mental health workers (92%) and other people who have the same experiences in their family (72%). When the well siblings were asked about their relationship with the ill sibling, most of them stated that it was hard to live with the ill sibling (77%). Second prominent answers were about feeling of not loved by the ill sibling (60%). The most positive answer to this question were given by only few well siblings (6%) which is “*I think that she is friendly and sincere, and that he/she is the only person in the world who understands me.*”. The well siblings defined their family (93 %) and friends (80%) as their most powerful social support resources whereas 6% of the wellsiblings reported that no one supported them when he/she went through difficult time due to the sibling’s disorder. Regarding the type of support, the well sibling

stated emotional support mostly (83%) followed by “to be listened” (63 %) and financial support (54%). Financial burden (91%), emotional burden (87%), sadness (87%), fear (77%) and anxiety (74%) were the answers for the difficulties of having an ill sibling. 41% of the well siblings reported guilt and 26 % of them reported shame. When they asked how to cope with those difficulties, the prominent answers were consulting doctors (97%) and trying to get information (86%) were the prominent answers. 8% of the well siblings reported that they escaped to another city to work. Regarding perceived parental attitudes, 80% of the well siblings mentioned a change whereas 10% reported no change after the diagnosis of the sibling’s illness. Among the well siblings who mentioned changed, 80% of them tried to cope with the change by developing an understanding towards family, 39% of them became more distant from the parents and 36% of them stated that they had built their own life. Regarding the general effect of the sibling’s illness, 83% of the well siblings said “positive” whereas 12% of them said “negative”. The negative effects were as follows; exhaustion (76%), exasperation (69%), shouldering the entire burden (60%), constant fear (63%), sadness (61%), anxiety (61 %) and the positive ones as follows; gaining responsibility (47%), maturation (39%), being self-sufficient(35 %).

CHAPTER 4

DISCUSSION

In this chapter, the findings will be discussed within the relevant literature, the strengths and limitations of the study will be presented, and ideas for future research and recommendations for mental health practice will be provided.

4.1 Main Aims and Major Findings

Schizophrenia is a multidimensional illness with a profound impact on psychosocial functioning of the patients; it also imposes severe hardships not only on patients but also on their relatives. With all these difficulties, it also has the potential to affect siblings, referred to as well siblings who do not themselves have a mental illness. The literature review for the current research, especially pointed out the dearth of research on well siblings who seemed to be “secondary victims” of the disorder. In the light of the literature, the present study aimed to examine the relationships between a series of variables identified as central to the stressors and their effects on siblings’ well-being and to explore the relationship between burden and well-being in the search for a greater understanding of the experience of having a sibling with schizophrenia.

The present study indicated several group differences related to characteristics of well siblings in well-being, burden, coping styles, and personal resources. The well siblings’ gender was found to be related with well-being and perceived social support. The results showed that, the female well siblings reported higher levels of subjective well-being compared to male well siblings. The female well siblings also reported higher levels of perceived social support. According to the

framework theory of this study, social support acts as a facilitator for setting coping strategies through sharing problems and getting helpful suggestions which help people to face their problems and find constructive problem solving ways for well-being (Lazarus & Folkman, 1984). This theoretical approach supports our next finding that the female well siblings reported problem focused coping more frequently than males as they also reported more social support than males. Another significant gender difference as seen in indirect coping styles of the well siblings, again the female well siblings reported using indirect coping strategies more frequently than male well siblings did. Studies on gender differences in terms of experienced burden of well siblings (Greenberg et al., 1997; McGlashan & Bardenstein, 1990) showed that sisters reported significantly greater subjective burden compared to brothers. However, in the present study, no significant gender difference was observed in burden. Despite not significant, the male well siblings scored slightly higher in burden compared to female siblings. A reason for this discrepancy between the literature and our findings might be the effect of culture on care-giving roles in Turkey; despite the fact that female siblings provide caregiving for their ill siblings more often, they may not perceive that as a burden because of their traditional gender role.

Regarding timing, siblings of persons with schizophrenia vary greatly as to the timing in their own lives when their brother or sister's illness first occurs. Some siblings were adults and living independently when their brother or sister became ill, whereas other siblings were children or adolescents at that time. In this study, age groups were created for this reason and no differences were seen except for coping ways of the well siblings. When the sibling's illness was diagnosed at adulthood of the well sibling, they reported that they used indirect coping more frequently than adolescents did. This may be related to their independence as adults and finding a way to distance themselves from their families. However, there is no research which is specific on this topic; this is the area needs more research for an explanation.

Well siblings who live away from the ill sibling scored higher in well-being, self-esteem, problem-focused coping, and perceived social support measures meaning that building a physically apart life away from the ill sibling has a positive effect on well siblings. According to Kinsella and Anderson (1996), living away from the ill sibling may be a constructive escape and a healthy coping style for well siblings. In parallel with this finding, Samuels and Chase (2007) showed that well siblings who moved away from their families in late adolescence, experienced personal growth, after their re-involvement to the family, feeling of responsibility of the ill sibling emerged again and the guilt became the primary feeling of their lives. Furthermore, the well siblings usually experience stigma by association because of the presence of the ill sibling that isolates them from friends and other social networks which leads to poor self-esteem along with the low social support (Schene, Wijngaarden & Koeter, 1998). It may be said that living status which is not so close to the ill sibling but close enough to help him/her solve problems and crises has an important factor for well siblings. On the other hand, well siblings who live with the ill siblings, experienced more levels of burden. In their book, Marsh and Dickens (1997) claimed that those who were still living in the parental home when the brother or sister was first diagnosed may be socialized to take on heavier family caregiving responsibilities than those who live away from the ill sibling and they tend to continue their caregiving roles as well as feeling burdened by their siblings' illness.

When the differences between the older brother, younger brother, older sister, and younger sister groups were examined the older siblings, especially the older sisters seemed to have a more advantageous existence. The scores of well-being, self-esteem and effective coping styles (problem focused coping & emotion focused coping) measures were significantly higher than the younger ones'. These findings were similar to Greenberg et al.'s (1997) research conducted on well siblings. His study was also coherent with the present study revealing that well siblings' age was negatively related with levels of burden, stigma, and fears. Though not to a

significant degree, older siblings tended to worry less about their ill sibling's future care than did younger siblings (Greenberg et al., 1997). Thus, care efforts need to be emphasized more to younger siblings in support programmes.

In the present study, education levels of well siblings were found to have an impact on the subjective burden. The present study showed that the well-educated siblings stated low levels of burden than the relatively less educated ones. A reason for this might be, better educated siblings may have more information on current theories of the causes of severe mental illness, and therefore be more likely to attribute their sibling's behaviour to an illness. Emotion focused coping styles and religious beliefs of the well siblings also differed according to the education levels. Better educated well siblings reported that they do not prefer to take refuge in religious beliefs nor using emotion focused coping as much of compared to well siblings who are relatively less educated. Considering the religiousness as a type of emotion focused coping, these findings are parallel with the burden literature (Li, 1997; Palisi & Canning, 1991).

The main aim of the present study was to examine the predictors of well-being among well siblings. Hierarchical regression analysis revealed that well-being can be predicted by perceived mother over-protection during the childhood, perceived social support, problem-focused and indirect coping. In the parental rearing literature, over-protection seems to be a toxic factor in the family; it is also emphasized as a toxic factor in the literature of expressed emotion by parents towards the patient with schizophrenia (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). However, in the present study, unlike the results of the Western studies, perception of mother over-protection by the well siblings may be associated with a happy childhood as making the child feel more comfortable and appreciated, particularly in the presence of an ill sibling. A reason for this, in the Turkish culture having protective attitudes, may be emotionally involving to the lives of the children and showing positive remarks may be perceived as not a terrible experience for the child, far from it, this kind of protective attitudes may be perceived as warmth and

positive attitude. In a study conducted by Karanci and İnandılar (2002) the toxic effect of emotional over-involvement and over-protection is not valid for Turkish culture. The second predictor was social support associated with well-being among well siblings. The well siblings who perceived higher levels of social support tended to report higher levels of well-being. This finding is strongly consisted with the social support literature (Greenberg , Kim & Greenley, 1997). In the framework of Lazarus & Folkman Stress Coping Theory, social support takes part as a personal coping resource that buffers negative effects of stress (Lazarus & Folkman, 1984). As the framework model indicates, the coping styles of the well siblings determined their level of well-being. Among the ways of coping of well siblings, problem focused coping and indirect coping were found to be related with their subjective well-being. Problem focused coping involves three components which are taking control, information seeking and evaluating of the pros and cons. When it is applied to well siblings, the well siblings who used problem focused coping, try to change the relationship between the person and the source of stress by escaping from the stressor. It seems alike aforementioned concept which is constructive escape defined by Kinsella (1997). They prefer to move away sometimes to protect themselves. In information seeking which involves the well siblings trying to understand the situation (e.g. using the internet) and putting into place cognitive strategies to avoid it in future. Information seeking is a cognitive response to stress. They try to understand the sibling's illness, to have contact with doctors or to communicate other patients' families. Lastly, they use the strategy of evaluating the pros and cons of different options for dealing with the illness of the sibling.

Indirect coping was the last predictor of well-being in well siblings of patients with schizophrenia. Indirect coping is described as a healthy way of coping by escaping rather than focusing on the siblings' illness and burden which involves physically or mentally escaping their environment in order to gain relief from the pressures of living with a sibling with schizophrenia. They engaged in outlets or activities, inside and outside of the home, that occupied their time and attention, and

that brought them pleasure. In the study of Kinsella and Anderson, the mentioned activities were play, art, reading, music, and school-related or organized social activities (1996). A group of researchers brought a new point of view for indirect coping which supported our findings. Gençöz, Gençöz and Bozo (2006) discussed in their study that indirect coping may be renamed as “social support seeking” indicating that seeking social support was empirically addressed as being hierarchically different from the two other factors of Ways of Coping Inventory which are emotion focused and problem focused coping. Thus, indirect coping through social support seeking may be an effective path for maintaining well-being status in the presence of an ill sibling.

In the present study, the mediating role of social support between burden and well-being was confirmed in addition to the moderator role of social support. Social support was a significant moderator of the relationship between burden and well-being. Well siblings of different levels of social support did not differ in well-being scores under conditions of low burden, but large differences were noted under the conditions of high burden; well siblings who had high social support reported significantly higher levels of well-being than well siblings did with low levels of social support. This finding was parallel with other studies (Chang, Brecht, & Carter, 2001; Magliano et al., 2000). Moreover, lots of studies illustrated that social support acted as a buffer against the negative features of family caregiving (Houde, 1998; Palmer & Glass, 2003) and moderates the stressful life events and the possible negative outcomes (Brown, Bhrolchain & Harris, 1975). In the present study, social support was also found to be a mediator between burden and well-being. This relationship may relate to a positive function of social support because social support resources can facilitate the well siblings to use confrontation. The well siblings may be supported by their own family as the data in the present study showed that 93% of the well siblings had family members who helped them in difficulties of an ill sibling. This support can facilitate the subjects to set coping strategies through sharing problems, providing sympathy, and giving helpful suggestion

which help the well siblings to confront the situation, face up to the problems, and constructive problem solving (Suls as cited in Lazarus & Folkman, 1984). Thus, the burden of the well siblings may shrink and well being may rise in the presence of social support. This is in line with the previous studies on the mediator role of social support (Szmukler & Bloch, 1997).

The second dependent variable of the present study was self-esteem as a strong indicator for well-being. Self-esteem is an extensively researched area (Cast & Burke, 2002; Lucas, et al., 1996; Rosenberg, 1979), and academics and laymen alike are becoming increasingly aware of the importance of this factor in the well-being. Due to the popularity of this area of study, there are many definitions and conceptualizations of the construct available. Self-esteem has been investigated as an outcome (focusing on processes that produce or inhibit self-esteem), a self-motive (in which people behave in ways that maintain positive evaluations of the self), and as a buffer (providing protection from experiences that are harmful) (Cast & Burke, 2002). For the purpose of this study, self-esteem was identified as an outcome measure and was considered as the second outcome variable since it had a high correlation with well-being. Gender was found to be a significant predictor of self-esteem; being female was significantly associated with self-esteem. Aforementioned gender differences of the present study were also indicating that female well-siblings reported higher levels of self-esteem. Burden, the second predictor, was found to be negatively related with self-esteem (Tsang, Tam, Chan, & Chang, 2003). Among parental variables, perceived parental warmth and mother overprotection predicted self-esteem. Well siblings who perceived mother warmth and father warmth in their childhood, reported higher levels of self-esteem. Nonetheless, a significant and positive association between mother over-protection and self-esteem was observed, indicating that perceived mother over-protection in the childhood leads to higher self-esteem in well siblings. On the other hand, perceived rejection from both mother and father in the childhood found to be significantly and negatively associated with Self-esteem of the well siblings. These findings on perceived rejection were similar to

the other studies reported (Rohner, 1975; Conte, Plutchik, Picard, Buck, and Karasu, 1996; Buri, Murphy, Richtsmeier & Komar, 1992; Hussain, & Munaf, 2012). Unexpectedly, religiousness was found to be negatively associated with self-esteem although a positive relationship between belief in God and self-esteem has been repeatedly demonstrated (Benson & Spilka, 1973; Aydin, Fischer, & Frey, 2010; Gebauer, Sedikides & Neberich, 2012). This finding may be related to the scale used for the measurement of the religious behaviors of the well siblings. Well siblings were asked whether they describe themselves as a religious person and that kind of question may be perceived as covering all the religious requirements, such as performing namaz, avoiding alcohol or fasting for a Muslim culture and meaning that if you don't do devotions, you are not a religious person. Thus, well siblings may not have described themselves as a religious person and this may lead to a negative relationship between religiousness and self-esteem. It would be a better way for future research to measure spirituality or religiousness as described in the literature by focusing on beliefs rather than devotions for Islam. The last predictors of self-esteem were coping styles of well-siblings. Problem focused and indirect coping were found to be positively associated with self-esteem similar to well-being. The well siblings who reported that they used problem focused coping more frequently also reported higher levels of self-esteem. This finding was parallel with the previous studies conducted on the relationship between self-esteem and problem focused coping (Constantine, Donnelly, & Myers, 2002). Correspondingly, indirect coping also predicted self-esteem. Aforementioned activities that involved in indirect coping such as organized social activities, distracting avocations, hobbies and seeking social support might have a positive effect in self-esteem.

In addition to objective measures, the present study also focused on answers to the open-ended questions. The well siblings were asked questions about their source of information about schizophrenia, their relationship with the ill sibling, their support resources, difficulties derived from the ill siblings, attitudes of their parents toward them before and after the diagnosis of the illness and coping strategies. The

categories derived from the answers seemed to be in agreement with the results from the objective measures used in the study. Their answers brought much important information about the emotions of the well-siblings which were not measured by the self-report objective scales of the study.

The prominent answers of the participants regarding their information resources were mental health workers and other people who have the same experiences in their family. At this point, the Schizophrenia Association as a solidarity effort seems to be a good resource for both getting in touch with experienced families and a contact point with mental health workers. There are lots of volunteer psychology students who are working there, as the authors of the present study we have conducted monthly family meetings for five years in which siblings can participate and several psychiatrists are also available in the Association. This finding made us feel proud of our efforts in the Association since most of the well siblings are aware of the resources from which they can receive information.

As Goetting (1986) points out that the most important tasks of sibling-ship throughout the life cycle are companionship, friendship, comfort, and affection; the answers of well siblings varied from *“I think that she is friendly and sincere, and that he/she is the only person in the world who understands me”* to *“He/she doesn’t talk much with me.”* when they were asked about their relationship with the patient. A reason for the negative answers and their high frequency may be due to the nature of the schizophrenia. Especially negative symptoms of the schizophrenia may lead to decrease in the quality of the relationship between siblings that breaks friendship.

When support resources were asked to the well siblings, they reported the family and doctors prominently. The most reported category was related with emotional support; as discussed in the emotional burden chapter, they mostly needed to be listened by their families, wishing to be understood by the people around them and almost half of the well siblings defined *“hearing that they were right”* as the most valuable support style. A reason for this might be the severity of the guilt they feel and their mental confusion. Confirmation by others about doing the right thing

in the presence of the ill sibling seems to be one of the most relieving factors perceived by the well siblings.

Emotional burden was a common reported category in terms of experienced difficulty. Marsh (1998) described the condition of a having a sibling with schizophrenia as an emotionally troubled journey. When a brother or sister is diagnosed with a mental health disorder, illness of their sibling gives a rise to a large amount of ambivalent feelings and confusions about the way their sibling acts. The statements of the well siblings are quite close to the definition of Marsh (1998) such as *“I was ashamed... I was angry... I was scared.... I was sad...”* Stalberg, Ekerwald and Hultman (2004) presented a unifying theme as “sibling bond” in order to describe the combination of emotions experienced by the well siblings. Researchers produced the term sibling bond, reflecting mixed feelings of love, sorrow, anger, envy, guilt, and shame which were the primary emotions expressed by the well siblings. Researchers indicated that development of those strong feelings is due to the emotional tie between the siblings (Kristoffersen and Mustar, 2000; Stalberg, Ekerwald & Hultman, 2004).

The coping ways given to the open-ended questions showed a broader range than the ways of coping inventory factors in the study. The categories which can be merged under the problem focused coping were “I tried to get information.”, “I tried to understand the disorder.”, “I consulted doctors”; “smoking more” might be considered as indirect coping; and finally examples for emotion focused coping activities such as *“I tried to think that he/she wasn’t my sibling.” I tried to act as if nothing happened”, “I alleviated my guilt by helping him/her” and “I dedicated myself to him/her”.* Some of the well siblings described their way of coping as *“escaping” or “moving away for a while”.* This is similar to Kinsella (1998)’s classification presented previously as *“constructive escape” and “destructive escape.”*

Overall, the answers for the question of effect of the ill sibling on the well sibling’s life were highly negative. A few well siblings indicated positive effects (12

%) whereas the majority of them (92%) stated negative effects of the disorder on their lives. In the literature, in several studies, the well siblings mentioned positive outcomes for having a sibling with schizophrenia such as maturity, responsibility, sense of humour and patience (Marsh & Dickens, 1998). Likewise, in the present study, the answers of the well siblings were such “*I became a patient and selfless person, I learned to take responsibility, I became mature, I stood on my own two feet*”. On the other hand, negative ones like; *I have no power or energy left, I am exhausted, I am sad, I am exasperated, I was ignored, I wasn't loved, I began to live with the constant fear that something might happen to him/her and I feared that he/she might have an attack, I shouldered the entire burden, I had to live in anxiety, nobody understood me, I was stigmatized, I was ashamed*” were stated.

4.2 Clinical Implications

Before all else, the identification of risk groups among well siblings should be included in the psychiatry clinics. Mental health workers should focus on the psychological state of the well siblings as well as the patients with schizophrenia, and they should screen them routinely for their psychological well-being.

Parents also should be informed about the impact of the illness on the non-psychotic sibling, the concerns about future and perceived parental attitudes by the well siblings. It may be helpful to add the well siblings' perspectives in the family psycho-education programs and emphasizing the parental behaviours towards the well siblings. For our culture, the perception of love and concern from mothers, means overprotection unlike other cultures, thus mothers should be given that awareness, overly protecting the well-siblings make them feel valuable and appreciated in the presence of the ill sibling.

Social support seems to be a very important variable for well-being and self-esteem. It seems to moderate burden; furthermore, it mediates the relationship between burden and well-being. Therefore, well siblings should be provided social support from professionals and encouraged to engage in social activities. If culturally

acceptable, they should be encouraged to disclose themselves and share their problems with their friends. At this point, stigma by association should be considered by the mental health workers and the well-siblings should be relieved that the illness of the sibling is not a shame for the well-sibling. In psychiatry services, psychological interventions to support well siblings must be developed. Mental health service providers should create supporting services for families, especially siblings which are adequately funded and promoted by the service providers. In addition to family-oriented services, sibling-oriented support services to assist well siblings are needed. An example for this emerged in the United States (Landeem et al., 1992) under the National Alliance of Mental Health (NAMI), namely National Sibling Network which is a large network that coordinates well-established well siblings- oriented services. Mental health professionals should also encourage well siblings to seek social support from family, friends, and organizations such as NAMI, to better cope with the demands of the illness. According to Marsh and Johnson (1997) the family-oriented services include psycho-education, family education, family consultation, and family support and advocacy groups. Those kinds of services that are created to be addressed families' concerns should be adapted for well siblings to specifically suit their needs.

As Heller (1997) pointed out, the concerns of well siblings are generally neglected by mental health services and their needs are often unmet. For this reason, support groups should be employed which are cost-effective and widespread resources for families and well siblings as well. Siblings support groups may give them a chance to share their emotions, caregiving difficulties, and individual experiences through interpersonal learning in a communicative and supportive environment. Not only the well siblings who have the caregiving roles for the ill siblings, but also the well siblings who do not have a considerable caregiving role, but suffering from emotional problems regarding the ill sibling may benefit from the support groups. They may learn more about the illness and adequate coping ways for their emotional hitches. Additionally, the well siblings who seek out individual

psychotherapy should be encouraged to contact with a clinical psychologist. They may highly much profit by the psychotherapy sessions by discussing the meaning of schizophrenia in their lives, effect of the ill sibling to his/her daily life or interpersonal relationships, and may be informed by his/her therapist about schizophrenia as a chronic disorder. They may have an opportunity to discuss their unresolved issues or concerns and their typical emotions such as guilt, anger, and so forth may be worked through individual psychotherapy. Even, they may work on their grief through psychotherapy and get over mourn about the loss of their healthy siblings and move toward accepting the illness.

Last but not the least, the clinical efforts for the well siblings should also involve the training of crises management and communication skills for well siblings. As indicated in the present study, problem focused coping mediates the relationship between burden and well-being. Thus, problem solving techniques and problem focused coping strategies should be strengthening within the programmes for well-siblings. In those programmes, the value of indirect coping strategies should be stressed and as given in the answers to open-ended questions, they should be encouraged to orient some activities that suspends ill sibling's burden and provides respite time.

4.3 Limitations and Recommendations for Further Studies

The prominent limitations of the present study were its small sample size and non-random recruitment of the well siblings. Since the design of the study is cross-sectional, causal conclusion and detailed long term analysis could not be made. It is well known that it is hard to recruit siblings with good or poor/little contact with the patient. Because of the stigma by associate, not all of the siblings around could be reached (for example, if the well sibling is married, she refused to participate since her husband doesn't know the illness of his wife's sibling.). Since the controls are needed to eliminate alternate explanations of the results, lack of control group was another important limitation of the study. Generalibility of the results were weak

because of the outcome measures and their correlates were based on regression analyses, therefore further studies should be specifically conducted in detail.

Regarding with the measurement of perceived parental rearing, there are criticisms of all parental styles questionnaires. Retrospective studies in which adolescent/adult reports of their parents rearing style may be subject to a number of biases. The first bias may be “retrospective bias” described by McCrae and Costa (1988) who concluded that retrospective methods are not entirely trustworthy in that there may be systematic errors of omission and commission such that, for instance, neurotics remember more negative experiences than stable individual, so suggesting direct relationships which are mediated by gender (Furnham and Cheng, 2000). Thus, well siblings with high self-esteem are more likely to look back at their childhoods in a positive light. Another bias may result from subjects concerning social desirability. It is plausible to suggest that a strong desire to be socially acceptable may induce well siblings to be less self-critical and to minimise their reports of any adverse perceived parenting experiences.

In the present study, objective scales were employed, together with the open ended questions but it is well known that in depth-qualitative interviews and longitudinal approach would have allowed us to more fully capture the well sibling’s views and experiences over time. A focus group or series of in-depth interviews with father, mother, and sibling caregivers may also offer further insight into the family dynamics that they experience and the ways in which they perceive support for an affected relative. Furthermore, the perception of parents about the well siblings should be examined whether they see their non-psychotic child as he/she doesn’t need attention just because the well sibling is not diagnosed by schizophrenia.

Future researchers may examine well siblings reports of well-being before and after an intervention (affiliation with a family self-help group, participation in a psycho-educational program) or a “pivotal moment” in their siblings’ illness (relapse, hospitalization, or involvement with legal system).

Further research is needed with a more diverse sample, with well siblings from other cultural and socioeconomic backgrounds who might have different experiences caring for a brother or sister with schizophrenia. This study could be extended to other groups of siblings who have siblings with different diagnosis.

A future comparative study of non-caregiving and caregiving siblings may prove beneficial in better understanding the reasons behind why some provide support, others do not, and how we can get siblings more involved in the caregiving of their brother or sister.

Another research question in the future could be the ways in which well sibling caregivers balance their own lives with their supportive role and manage this juggling act.

4.4 Conclusions

In conclusion, this study indicates the significant amount of the burden experienced by the well siblings of patients with schizophrenia. The burden among well-siblings was found to be significantly related with their self-esteem which mostly depends on the perception of parental rearing factors of the well siblings and significantly related with their well-being. In the framework of Stress and Coping Theory, the significance of perceived social support and ways of coping of well siblings on well-being was reported. Social support seems to be the most important factor for well-being. It moderates burden, moreover it mediates the relationship between burden and wellbeing. Therefore, siblings should be provided social support as well as their problem focused coping strategies should be strengthened. It was claimed that when having an ill sibling is considered as a stressful life event, the Lazarus Stress Coping Theory may be adapted for the well siblings and it was validated as an appropriate beginning point for developing interventions for the well siblings in the future. However, more research is needed on well siblings of the patients with schizophrenia.

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APPENDICES

APPENDIX A

Informed Consent

Açıklama;

Kişinin şizofreni gibi kronik bir hastalığa sahip kardeşinin olması psikolojik olarak kişiyi derinden etkileyebilmektedir. Bizler bu çalışmada şizofreni hastası olan kardeşe sahip bireylerin yaşayabilecekleri olası sıkıntılar, sıkıntıların nedenleri ve bunları azaltmak ile ilgili bilgiler toplamayı amaçlamaktayız. Soruların, doğru ya da yanlış cevapları yoktur. Sorulara samimi cevaplar vermeniz araştırmadan elde edilen sonuçların geçerli ve güvenilir olmasını sağlayacaktır. Vereceğiniz tüm bilgiler saklı tutulacaktır. Bütün cevaplar grup halinde araştırma amacıyla değerlendirileceği için isim vermeniz gerekmemektedir.

Araştırmaya katılmak gönüllüdür.

Aşağıdaki soruları cevaplayarak araştırmaya katılacağınızı umuyoruz.

Yardımlarınız için şimdiden çok teşekkür ederiz

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Orta Doğu Teknik Üniversitesi /

Psikoloji

Bölümü

APPENDIX B

Socio-Demographic Information Form

1. Ad ve soyad baş harfleri:
2. Cinsiyet: () Kız () Erkek
3. Eğitim: () İlkokul () Ortaokul () Lise () Üniversite () Yüksek lisans/ doktora
4. Doğum tarihi:/...../.....
5. Hastanın doğum tarihi:/...../.....
6. Kardeşlik statüsü: () Abla () Küçük kız kardeş () Abi () Küçük erkek kardeş
7. Varsa başka kardeşler:
 - a) Doğum tarihi:/...../.....
Cinsiyet: () Kız () Erkek
 - b) Doğum tarihi:/...../.....
Cinsiyet: () Kız () Erkek
 - c) Doğum tarihi:/...../.....
Cinsiyet: () Kız () Erkek
8. Medeni durum: () Bekar () Evli () Boşanmış () Dul
9. Varsa çocuk sayısı:
 - a) Doğum tarihi:/...../.....
Cinsiyet: () Kız () Erkek
 - b) Doğum tarihi:/...../.....
Cinsiyet: () Kız () Erkek
 - c) Doğum tarihi:/...../.....
Cinsiyet: () Kız () Erkek
10. Çalışıyor musunuz? () Evet () Hayır
11. Mesleğiniz?.....
12. Kimlerle yaşıyorsunuz:
13. Kardeş ile birlikte yaşıyorlar ise ;

- a) Evdeki oda sayısı:
b) Hastanın kendine ait odası var mı?
c) Sizin kendinize ait odanız var mı?
d) Ortalama haftada kaç saati birlikte geçiriyorsunuz?

14. Kardeş ile ayrı yaşıyorlar ise;

- a) Kendi eviniz kardeşinizin yaşadığı eve yakın mı?. () Evet () Hayır
b) Kardeşinizi haftada kaç kez ziyaret ediyorsunuz?..... kez
c) Ortalama haftada kaç saati birlikte geçiriyorsunuz?..... saat

15. Hastalık ortaya çıktığında kaç yaşındaydınız?

16. Hastalık ortaya çıktığında kardeşiniz kaç yaşında idi?

17. Hastalık hakkındaki bilgi kaynaklarınız nelerdir?

.....

...

18. Kardeşinizle ilişkinizi anlatır mısınız? (Onu dostça bir kişi buluyor musunuz?

Onunla anlaşmak kolay mıdır? Onunla yakın olabiliyor musunuz? Onun ne bakımlardan farklı olmasını isterdiniz? Ne bakımlardan sinirinize dokunuyor?)

.....

...

19. Kardeşinizle ilgili sıkıntılarınızda size kimler destek oldu, ne yaparak destek oldular?

.....

...

20. Şizofreni hastası bir kardeşe sahip olmak size ne gibi yükler zorluklar getirdi?

.....

...

21. Bu yüklerle neler yaparak nasıl başa çıktınız?

.....

...

22. Anne- babanızın size ve kardeşinize yönelik tutumlarında bir fark var mıdır? Benimle paylaşır mısınız? (hastalık tanısı öncesi)

.....
.....

23. Hastalık sonrasında aileniz size yönelik farklı bir tutum geliştirdiyse nasıl başa çıktınız?

.....
...

24. Genel olarak tüm hastalığı düşündüğünüzde kardeşinizin hastalığı sizi nasıl etkiledi?

.....
...

APPENDIX C

Subjective Well-being Scale (SWS)

Bu envanterde kişiliğinizin ve yaşamınızın çeşitli yönlerine ilişkin ifadeler bulunmaktadır . Bu ifadeleri tek tek okuyarak, ifadenin size ne derece uygun olduğuna karar veriniz. İfade size “ tamamen uygunsa” cevap kağıdındaki (5); “çoğunlukla uygunsa” (4); “orta derecede uygunsa” (3); “biraz uygunsa” (2); “hiç uygun değilse” (1) numaralı alanı daire içine alarak işaretleyiniz. Lütfen tüm ifadeleri boş bırakmadan cevaplayınız.

	Hiç Uygun Değil	Biraz Uygun	Kısmen Uygun	Çoğunlukla Uygun	Tamamen Uygun
Geleceğe yönelik planlar yapmaktan hoşlanırım.	1	2	3	4	5
Yaşamımda zevk alarak yaptığım etkinlik sayısı azdır.	1	2	3	4	5
Genel olarak kendimi neşeli hissediyorum.	1	2	3	4	5
Geriye dönüp baktığımda istediklerimin çoğunu elde edemediğimi görüyorum.	1	2	3	4	5
Kişilik özelliklerimden genel olarak memnunum.	1	2	3	4	5
İstediğim nitelikte ve sayıda arkadaşım olmamasına üzülüyorum.	1	2	3	4	5
Günlük yaşamımdaki sorumluluklarımı başarıyla yerine getiririm.	1	2	3	4	5

Ulaşmak istediğim ideallerim var.	1	2	3	4	5
İlgi ve yeteneklerime uygun etkinliklerin yaşamımdaki yeri istediğim ölçüdedir.	1	2	3	4	5
Küçük sorunları bile büyütürüm.	1	2	3	4	5
Kendimi genel olarak canlı ve enerjik hissederim.	1	2	3	4	5
Yakın gelecekte yaşamımda güzel gelişmeler olacağına inanıyorum.	1	2	3	4	5
Kişilerarası ilişkilerde sıklıkla hayal kırıklığı yaşıyorum.	1	2	3	4	5
Yaşamıma beni ona bağlayacak anlamlar katmakta zorlanmam.	1	2	3	4	5
Beni eğlendiren faaliyetlere yeterince katılamıyorum.	1	2	3	4	5
Umutlarımın gerçekleşeceğine inanıyorum.	1	2	3	4	5
Mümkün olsa geçmiş hayatımı değiştirim.	1	2	3	4	5
Ailemle olan ilişkilerimden memnunum.	1	2	3	4	5
Genelde hüzünlü ve düşünceliyim.	1	2	3	4	5
Yaşamımda yapmam gerekenleri düşünmek hoşuma gider.	1	2	3	4	5
Kendimi yalnız hissediyorum.	1	2	3	4	5
Amaçlarıma ulaşmak için çevremdeki olanakları etkili bir şekilde	1	2	3	4	5

kullanabilirim.					
Genel olarak kendimi huzurlu hissediyorum.	1	2	3	4	5
Başkalarının mutlu görüldüğü kadar mutlu olmayı isterdim.	1	2	3	4	5
Sorunları yaşamın öğretici ve doğal bir parçası olarak görürüm.	1	2	3	4	5
Çevremdeki insanların yaşamlarına imreniyorum.	1	2	3	4	5
Amaçlarıma ulaşmak için yeterince kararlı davranabilirim.	1	2	3	4	5
Yaşamımı genel olarak monoton ve sıkıcı buluyorum.	1	2	3	4	5
Sosyal ilişkilerimdeki girişkenlik yanımdan hoşnutum.	1	2	3	4	5
Kendime hedefler koymakta zorlanıyorum.	1	2	3	4	5
İç dünyamın zaman geçtikçe zenginleştiğini hissediyorum.	1	2	3	4	5
Tanıdığım insanların çoğundan daha fazla sıkıntım var.	1	2	3	4	5
Yaşamın zorluklarıyla başetme gücüme güveniyorum.	1	2	3	4	5
Sevilen ve güvenilen biri olduğumu hissediyorum.	1	2	3	4	5
Geçmişte yaptığım hatalardan dolayı yoğun suçluluk duygusu yaşıyorum.	1	2	3	4	5
Serbest zamanlarımda zevkle vakit	1	2	3	4	5

geçirecek bir uğraşı bulurum.					
Yaşamım başarısızlıklarla dolu.	1	2	3	4	5
Güçlükler karşısında çabuk pes ederim.	1	2	3	4	5
Çevremde ihtiyaç duyduğumda destek alabileceğim insanlar var.	1	2	3	4	5
Sıklıkla ümitsiz ve çökkün hissediyorum.	1	2	3	4	5
Okumak ve çalışmak benim için zevkli uğraşlardır.	1	2	3	4	5
İsteklerime ve değerlerime uygun bir hayat sürüyorum.	1	2	3	4	5
Ailemle olan ilişkilerimde sorunlar yaşıyorum.	1	2	3	4	5
Yaşama iyimser bir açıyla bakabilme yönümden memnunum.	1	2	3	4	5
Arkadaşlarıma kendimi istediğim gibi ifade edemiyorum.	1	2	3	4	5
Başkalarına yardım edebilme ve onlara destek olma becerimden hoşnutum.	1	2	3	4	5

APPENDIX D

Zarit Caregiver Burden Scale (ZCBS)

Aşağıda insanların bir başka insanın bakımını üstlendiğinde kendini nasıl hissedebileceğini yansıtan ifadelerden oluşan bir liste yer almaktadır. Her ifadeden sonra sizin ne kadar sık böyle hissettiğinizi belirtiniz. Asla, nadiren, ara sıra, oldukça sık, nerdeyse her zaman seçeneklerinin arasından size en uygun olanı işaretleyiniz. Yanlış ya da doğru cevap bulunmamaktadır.

	Asla	Nadiren	Ara sıra	Oldukça sık	Nerdeyse her zaman
1- Hastanızla geçirdiğiniz zaman yüzünden kendiniz için yeterli zamanınız olmadığını hisseder misiniz?	1	2	3	4	5
2- Hastanıza bakma ve aileniz yada işinizle ilgili diğer sorumlulukları yerine getirmeye çalışma arasında kalmaktan dolayı kendinizi sıkıntılı hisseder misiniz?	1	2	3	4	5
3- Hastanızla birlikteyken kızgınlık hisseder misiniz?	1	2	3	4	5
4- Hastanızın şu anda ailenin diğer üyeleri ya da arkadaşlarınızla olan ilişkinizi olumsuz şekilde etkilediğini	1	2	3	4	5

hissediyor musunuz?					
5- Hastanızın geleceği ile ilgili korkuyor musunuz?	1	2	3	4	5
6- Hastanızın size bağımlı olduğunu düşünür müsünüz?	1	2	3	4	5
7- Hastanızla birlikteyken kısıtlanmış hisseder misiniz?	1	2	3	4	5
8- Hastanızla uğraşmaktan dolayı sağlığınızın bozulduğunu hissediyor musunuz?	1	2	3	4	5
9- Hastanız yüzünden istediğiniz düzeyde bir özel hayatınız olmadığını düşünür müsünüz?	1	2	3	4	5
10-Hastanıza bakmanız nedeniyle sosyal hayatınızın bozulduğunu hissediyor musunuz?	1	2	3	4	5
11- Hastanız nedeniyle arkadaşlarınızı davet etmekten rahatsızlık duyar mısınız?	1	2	3	4	5
12-Hastanızın sanki sırtını dayayabileceği tek kişi sizmişsiniz gibi, sizden ona bakmasını beklediğini düşünür müsünüz?	1	2	3	4	5
13-Kendi harcamalarınıza ek olarak hastanıza bakacak kadar paranız olmadığını düşünür	1	2	3	4	5

müsünüz?					
14- Hastanız hastalandığından beri yaşamınızı kontrol edemediğinizi hissediyor musunuz?	1	2	3	4	5
15- Hastanızın bakımını biraz da başkasına bırakabilmiş olmayı diler misiniz?	1	2	3	4	5
16- Hastanızla ilgili ne yapacağınız konusunda kararsızlık hisseder misiniz?	1	2	3	4	5
17- Hastanız için daha fazlasını yapmanız gerektiğini düşünüyor musunuz?	1	2	3	4	5
18- Hastanızın bakımı ile ilgili daha iyisini yapabilirdim diye düşünür müsünüz?	1	2	3	4	5
19-Tümüyle değerlendirdiğinizde hastanızın bakımı ile ilgili kendinizi ne kadar yük altında hissedersiniz?	1	2	3	4	5

APPENDIX E

Shortened Perceived Parental Rearing Styles-Child form (EMBU-C)

Lütfen aşağıdaki maddeleri dikkatle okuyun ve her maddenin altındaki 4 cevap şikkından, size en uygun olanını daire içine alarak işaretleyiniz. Anne ve baba için ayrı ayrı değerlendiriniz.

		Hayır hiçbir zaman	Evet arada sırada	Evet sık sık	Evet çoğu zama		Hayır hiçbir zaman	Evet arada sırada	Evet sık sık
1	Anne ve babam, nedenini söylemeden bana kızarlardı ya da ters davranırlardı.	1	2	3	4		1	2	3
2	Anne ve babam, beni överlerdi.	1	2	3	4		1	2	3
3	Anne ve babamın yaptıklarım konusunda daha az endişeli olmasını isterdim.	1	2	3	4		1	2	3
4	Anne ve babam, bana hak ettiğimden daha çok fiziksel ceza verirdi	1	2	3	4		1	2	3
5	Eve geldiğimde, anne ve babama ne yaptığımın hesabını vermek	1	2	3	4		1	2	3
6	Anne ve babam, ergenliğimin uyarıcı, ilginç ve eğitici olması için	1	2	3	4		1	2	3
7	Anne ve babam, beni başkalarının önünde eleştirirdi	1	2	3	4		1	2	3

8	Anne ve babam, bana birşey olur korkusuyla başka çocukların varmasına izin	1	2	3	4	1	2	3
9	Anne ve babam, her şeyde en iyi olmam için beni teşvik ederlerdi	1	2	3	4	1	2	3
10	Anne ve babam davranışları ile, örneğin üzgün görünerek, onlara kötü davrandığım için kendimi	1	2	3	4	1	2	3
11	Anne ve babamın bana birşey olacağına ilişkin endişeleri abartılıydı.	1	2	3	4	1	2	3
12	Benim için birşeyler kötü gittiğinde, anne ve babamın beni rahatlatmaya ve yüreklendirmeye çalıştığını hissedirdim.	1	2	3	4	1	2	3
13	Bana ailenin 'yüz karası' yada 'günah keçisi' gibi davranılırdı.	1	2	3	4	1	2	3
14	Anne ve babam, sözleri ve hareketleriyle beni	1	2	3	4	1	2	3
15	Anne ve babamın, erkek yada kız kardeşimi(lerimi) beni sevdiğilerinden daha çok sevdiğilerini hissedirdim.	1	2	3	4	1	2	3
16	Anne ve babam, kendimden utanmama neden olurlardı.	1	2	3	4	1	2	3
17	Anne ve babam, pek fazla umursamadan, istediğim yere gitmeme izin verirlerdi.	1	2	3	4	1	2	3

18	Anne ve babamın, yaptığım herşeye	1	2	3	4	1	2	3
19	Anne ve babamla aramda sıcaklık ve sevecenlik olduğunu hissedirdim.	1	2	3	4	1	2	3
20	Anne ve babam, yapabileceklerim ve yapamayacaklarımla ilgili kesin sınırlar koyar ve bunlara	1	2	3	4	1	2	3
21	Anne ve babam, küçük kabahatlerim için bile beni cezalandırırlardı.	1	2	3	4	1	2	3
22	Anne ve babam, nasıl giyinmem ve görünmem gerektiği konusunda karar vermek	1	2	3	4	1	2	3
23	Yaptığım birşeyde başarılı olduğumda, anne ve babamın benimle gurur duyduklarını hissedirdim.	1	2	3	4	1	2	3

APPENDIX F

Multidimensional Scale of Perceived Social Support (MSPSS)

Aşağıda on iki cümle ve her birinde de cevaplarınızı işaretlemeniz için 1 den 7 ye kadar rakamlar verilmiştir. İşaretleme yaparken şizofreni hastası olan kardeşinizle ilgili konuları düşününüz. Her cümlede söylenenin sizin için ne kadar çok doğru olduğunu veya olmadığını belirtmek için o cümle altındaki rakamlardan yalnız bir tanesini daire içine alarak işaretleyiniz. Bu şekilde on iki cümlenin her birinde bir işaret koyarak cevaplarınızı veriniz.

		Kesinlikle hayır	→					Kesinlikle evet
1	İhtiyacım olduğunda yanımda olan özel bir insan var.	1	2	3	4	5	6	7
2	Sevinç ve kederlerimi paylaşabileceğim özel bir insan var.	1	2	3	4	5	6	7
3	Ailem bana gerçekten yardımcı olmaya çalışır.	1	2	3	4	5	6	7
4	İhtiyacım olan duygusal yardımı ve desteği ailemden alırım.	1	2	3	4	5	6	7
5	Beni gerçekten rahatlatan özel bir insan var.	1	2	3	4	5	6	7
6	Arkadaşlarım bana gerçekten yardımcı olmaya çalışırlar.	1	2	3	4	5	6	7
7	İşler kötü gittiğimde arkadaşlarıma güvenebilirim.	1	2	3	4	5	6	7
8	Sorunlarımı ailemle konuşabilirim.	1	2	3	4	5	6	7
9	Sevinç ve kederlerimi paylaşabileceğim arkadaşlarım var.	1	2	3	4	5	6	7

APPENDIX G

Rosenberg Self-Esteem Scale (RSS)

Lütfen aşağıdaki maddeleri dikkatle okuyun ve her maddenin altındaki 4 cevap şikkından, size en uygun olanını daire içine alarak işaretleyin.

		Çok Doğru	Doğru	Yanlış	Çok Yanlış
1	Kendimi en az diğer insanlar kadar değerli buluyorum.	1	2	3	4
2	Bazı olumlu özelliklerim olduğunu düşünüyorum.	1	2	3	4
3	Genelde, kendimi başarısız biri olarak görme eğilimindeyim.	1	2	3	4
4	Ben de diğer insanların bir çoğunun yapabildiği kadar, birşeyler yapabilirim.	1	2	3	4
5	Kendimde gurur duyacak fazla birşey bulamıyorum.	1	2	3	4
6	Kendime karşı olumlu bir tutum içindeyim .	1	2	3	4
7	Genel olarak kendimden memnunum.	1	2	3	4
8	Kendime karşı daha fazla saygı duyabilmeyi isterdim.	1	2	3	4
9	Bazen kesinlikle bir işe yaramadığımı düşünüyorum.	1	2	3	4
10	Bazen hiç de yeterli bir	1	2	3	4

insan olmadığımı düşünüyorum.				
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APPENDIX H

Religious Behaviour Scale (RBS)

Aşağıda kişilerin kendi duygu, düşünce ve görüşleri ile ilgili bir takım ifadeler yer almaktadır. Sizden bu maddeleri dikkatlice okuyup her birinde belirtilen duygu, görüş ve davranışların sizin için ne kadar doğru veya yanlış olduğunu belirtmeniz istenmektedir. lütfen sizin için en uygun seçeneği gösteren numarayı daire içine alınız

		Kesinlikle yanlış	Yanlış	Ne doğru ne yanlış	Doğru	Kesinlikle doğru
1	Dini inancımın gereği olan ibadetleri sağlığım elverdiğince yerine getiriyorum.	1	2	3	4	5
2	Dinde yasak edildiğinden içki içmemeye özen gösteriyorum.	1	2	3	4	5
3	Kumar oynamak günah olduğu için kumar oynamaktan kaçınıyorum.	1	2	3	4	5
4	Evlilik dışı cinsel ilişki (zina) dinde yasaklandığı için bu tür iliksiden kaçınıyorum	1	2	3	4	5
5	Rüşvet alıp vermek günah olduğu için rüşvet alıp	1	2	3	4	5

	vermekten kaçınıyorum.					
6	İnsanları aldatmak dini inancıma aykırı olduğu için kimseyi aldatmamaya özen gösteriyorum.	1	2	3	4	5
7	Dini inancıma göre doğru sözlü olmak gerektiğinden, doğru söylemeye gayret ediyorum.	1	2	3	4	5
8	Ana-babaya iyi davranmayı Allah emrettiği için anne-babama iyi davranıyorum.	1	2	3	4	5
9	Söz verildiğinde sözünde durmak dini bir kural olduğundan verdiğim sözü tutuyorum.	1	2	3	4	5
10	Komsulara iyi davranmak dini bir prensip olduğundan komsularıma iyi davranıyorum.	1	2	3	4	5
11	Dindar olduğuma inanıyorum	1	2	3	4	5

APPENDIX I

Turkish Ways of Coping Inventory (WOC)

Bir genç olarak çeşitli sorunlarla karşılaşılıyor ve bu sorunlarla başa çıkabilmek için çeşitli duygu, düşünce ve davranışlardan yararlanıyor olabilirsiniz. Sizden istenilen KARDEŞİNİZLE İLGİLİ karşılaştığınız sorunlarla başa çıkabilmek için neler yaptığınızı göz önünde bulundurarak, aşağıdaki maddeleri cevap kağıdı üzerinde işaretlemenizdir. Lütfen her bir maddeyi dikkatle okuyunuz ve cevap formu üzerindeki aynı maddeye ait cevap şıklarından birini daire içine alarak cevabınızı belirtiniz.

	Hiç uygun Değil	Pek uygun değil	Uygun	Oldukça uygun	Çok uygun
Aklımı kurcalayan şeylerden 1. kurtulmak için değişik işlerle uğraşırım	1	2	3	4	5
2. Bir sıkıntı olduğumu kimsenin bilmesini istemem	1	2	3	4	5
3. Bir mucize olmasını beklerim	1	2	3	4	5
4. İyimser olmaya çalışırım	1	2	3	4	5
5. “ Bunu da atlattıysam sırtım yere gelmez ” diye düşünürüm	1	2	3	4	5
6. Çevremdeki insanlardan problemi çözmede bana yardımcı olmalarını beklerim	1	2	3	4	5
7. Bazı şeyleri büyütmemeye üzerinde durmamaya çalışırım	1	2	3	4	5
8. Sakin kafayla düşünmeye ve öfkelenmemeye çalışırım	1	2	3	4	5
9. Bu sıkıntılı dönem bir an önce geçsin isterim	1	2	3	4	5

Olayın deęerlendirmesini yaparak 10. en iyi kararı vermeye alıřırım	1	2	3	4	5
Konuyla ilgili olarak bařkalarının 11. ne dūřündüğünü anlamaya alıřırım	1	2	3	4	5
Problemin kendilięinden 12. hallolacağına inanırım	1	2	3	4	5
Ne olursa olsun kendimde 13. direnme ve mūcadele etme gücü hissederim	1	2	3	4	5
Bařkalarının rahatlamama 14. yardımcı olmalarını beklerim	1	2	3	4	5
Kendime karřı hořgörölü olmaya 15. alıřırım	1	2	3	4	5
16. Olanları unutmaya alıřırım	1	2	3	4	5
ve sakin olmaya alıřır ım	1	2	3	4	5
17. Telařımı belli etmemeye	1	2	3	4	5
dūřün 18. “ Bařa gelen ekilir ” diye ürüm	1	2	3	4	5
Problemin ciddiyetini anlamaya 19. alıřırım	1	2	3	4	5
Kendimi kapana sıkıřmıř gibi 20. hissederim	1	2	3	4	5
Duygularımı paylařtıęım kiřilerin 21. bana hak vermesini isterim	1	2	3	4	5
Hayatta neyin önemli olduęunu 22. keřfederim	1	2	3	4	5
” diye dūřünü 23. “ Her iřte bir hayır vardır rüm	1	2	3	4	5

Sıkıntılı olduğumda her 24. zamankinden fazla uyurum	1	2	3	4	5
İçinde bulunduğum kötü durumu 25. kimsenin bilmesini istemem	1	2	3	4	5
Dua ederek Allah'tan yardım 26. dilerim	1	2	3	4	5
Olayı yavaşlatmaya ve böylece 27. kararı ertelemeye çalışırım	1	2	3	4	5
Olanla yetinmeye çalışırım 28.	1	2	3	4	5
Olanları kafama takıp sürekli 29. düşünmekten kendimi alamam	1	2	3	4	5
İçimde tutmaktansa paylaşmayı 30. tercih ederim	1	2	3	4	5
Mutlaka bir yol bulabileceğime 31. inanır, bu yolda uğraşırım	1	2	3	4	5
Sanki bu bir sorun değilmiş gibi 32. davranırım	1	2	3	4	5
Olanlardan kimseye söz etmemeyi 33. tercih ederim	1	2	3	4	5
” diye 34. “ İş olacağına varır düşünürüm	1	2	3	4	5
düşünüp ona göre 35. Neler olabileceğini davranmaya çalışırım	1	2	3	4	5
İşin içinden çıkamayınca “ 36. elimden birşey gelmiyor ” der, durumu olduğu gibi kabullenirim	1	2	3	4	5
İlk anda aklıma gelen kararı 37. uygulardım	1	2	3	4	5
38. Ne yapacağıma karar vermeden	1	2	3	4	5

önce					
arkadaşlarımın fikrini alırım					
Herşeye yeniden başlayacak gücü 39. bulurum	1	2	3	4	5
Problemin çözümü için adak 40. adarım	1	2	3	4	5
Oylardan olumlu birşey 41. çıkarmaya çalışırım	1	2	3	4	5
Kırgınlığımı belirtirsem kendimi 42. rahatlamış hissederim	1	2	3	4	5
Alın yazısına ve bunun 43. değişmeyeceğine inanırım	1	2	3	4	5
Soruna birkaç farklı çözüm yolu 44. ararım	1	2	3	4	5
Başıma gelenlerin herkesin başına 45. gelebilecek şeyler olduğuna inanırım	1	2	3	4	5
“ Olanları keşke 46. değiştirebilseydim ” derim	1	2	3	4	5
Aile büyüklerine danışmayı tercih 47. ederim	1	2	3	4	5
Yaşamla ilgili yeni bir inanç 48. geliştirmeye çalışırım	1	2	3	4	5
“ Herşeye rağmen elde ettiğim bir 49. kazanç vardır ” diye düşünürüm	1	2	3	4	5
Gururumu koruyup güçlü 50. görünmeye çalışırım	1	2	3	4	5
Bu işin kefaretni (bedelini) 51. ödemeye çalışırım	1	2	3	4	5
Problemi adım adım çözmeye 52. çalışırım	1	2	3	4	5
Elimden hiç birşeyin 53. gelmeyeceğine inanırım	1	2	3	4	5

Problemin çözümü için bir 54. uzmana danışmanın en iyi yol olacağına inanırım	1	2	3	4	5
Problemin çözümü için hocaya 55. okunurum	1	2	3	4	5
Herşeyin istediğim gibi 56. olmayacağına inanırım	1	2	3	4	5
Bu dertten kurtulayım diye fakir 57. fukaraya sadaka veririm	1	2	3	4	5

APPENDIX J

TURKISH SUMMARY

1. Literatür özeti

Şizofreni, sadece hastaları değil aynı zamanda hastanın yakınındakileri ve aileleri de etkileyen kronik bir ruhsal rahatsızlıktır. Bugüne dek yapılan bilimsel çalışmalar ve psikolojik müdahaleler çoğunlukla anne babalar üzerine odaklanırken, şizofreni hastalarının kardeşleri ihmal edilmiş bir grup olagelmıştır (Greenberg, Kim & Greenley, 1997; Lukens, Thorning, & Lohrer, 2002; Anderson & Kinsella, 1996; Friedrich, Lively & Rubenstein, 2008). Bu çalışmada, şizofreni hastalarının kardeşlerinin psikolojik iyilik halleri ve yordayıcıları Lazarus ve Folkman'ın Stres ve Başa Çıkma Kuramı dahilinde incelenmiştir.

Lamb ve Sutton'a (1982) kardeşlik ilişkilerinin, yaşam boyu kurulan diğer kişiler arası ilişkilerden farklarını ve önemini ortaya koymuştur. Araştırmacılara göre, kardeşler arası ilişkiler diğer aile üyelerinden farklı olarak daha uzun süreye sahiptir. Diğer aile üyelerine göre iki kardeş oldukça geniş bir ortak genetik yapı paylaşırlar. Kardeşlerin erken çocukluk dönemine ait çok fazla ortak aile deneyimleri vardır. Yaşları yakın olması, onların ilişki paternlerini de etkilemektedir ve aralarında diğer bireylerden bağımsız farklı bir ilişki geliştirmektedirler (Lamb & Sutton Smith, 1982). Buna karşılık şizofreni alanında yapılan aile çalışmaları, sıklıkla anne ve babaları konu edinmiş, kardeşi şizofreni hastası olan bireyleri dışlamıştır. Bu bireylerin de en az anne babaları kadar şizofreni hastalığından kaynaklanan yükleri bulunmaktadır. Özellikle 1950'lerde şizofreni hastalarının toplumla tekrar bütünleşebilmelerini ve kapalı servislerden çıkartılmalarını kapsayan politikalarla birlikte, şizofreni hastaları evlerinde bakım verilmek üzere ailelerinin yanına gönderilmiştir (Lamb & Bachrach, 2001). Böylelikle aileler şizofreni hastalarının birincil bakımvericileri durumuna gelmişlerdir. Beck'e (2011) göre ailelerin birincil stresleri de bakımverici rollerinden kaynaklanmaktadır (Beck, 2001). Literatürde iki

çeşit yükten söz edilmektedir; maddi yükler, boş zaman aktivitelerinde azalma vb. sıkıntılara işaret eden ölçülebilir objektif yükler ve bakımvericinin hasta olan bireye karşı hissettiği duygulara işaret eden depresyon, kaygı ve yas gibi subjektif yüklerdir (Hoenig & Hamilton, 1966). Literatürde, kardeşi şizofreni hastası olan kardeşlerin bakımverici yüklerin yanı sıra kardeşlerinin hastalığından kaynaklanan sevgi, üzüntü, yas, kızgınlık ve öfke, utanç ve damgalanma gibi duygusal yüklerinden de söz edilmektedir (Kristoffersen and Mustar, 2000; Stalberg, Ekerwald and Hultman, 2004). Kardeşi şizofreni hastası olan bireylerin aile içi yaşantılarına göz atıldığında da yine algıladıkları anne baba tutumlarından kaynaklanan duygusal yükleri göze çarpmaktadır (Lukens, Thorning, & Lohrer, 2004; Marsh, 1998; Marsh & Dickens, 1997). Kardeşinin hastalığından sonra sağlıklı kardeşler kendilerini aile içinde unutulmuş bireyler olduklarından, aile içinde kendilerini görünmez hissettiklerinden, anne babalarının reddedici ve umursamaz tavırlarına maruz kaldıklarından ve tüm ilginin ve odağın hasta kardeşin üzerinde olduğundan söz etmişlerdir (Lukens, Thorning, & Lohrer, 2004; Marsh, 1998; Marsh & Dickens, 1997). Kardeşleri en çok tedirgin eden, gerginlik yaratan durum ileride ne olacağını bilememektir. Ne yapacağını bilememek kardeşleri öfkeliendirebilir. Öfkeyi bastırmak ve kendilerine yöneltmek ya da hastaya kızmak, bağırarak, müdahale etmek ve suçlamak kardeşlerin sıkça karşı karşıya geldiği zorluklardır. Anne baba hayatta olmadığı durumlarda veya anne babanın hayatta olduğu ama hasta kardeşe bakım veremediği durumlarda ne olacağına ilişkin endişeler de kardeşi şizofreni hastası olan bireylerin deneyimlediği zorluklardır (Lukens, Thorning, & Lohrer, 2004). Yapılan çalışmalar, kardeşi sağlıklı olan bireylerle karşılaştırıldığında, kardeşi şizofreni hastası olan bireylerin daha fazla duygusal red yaşadıklarını, deneyimlenen duygusal reddin de etkin olmayan başa çıkma yolları ile ilişkili olduğunu ortaya koymuştur (Lukens, Thorning, & Lohrer, 2004). Kardeşi şizofreni hastası olan bireylerde başa çıkma konusunda da literatürde çok az sayıda çalışma mevcuttur. Stålberg ve arkadaşları (2004) kardeşi şizofreni hastası olan bireylerin başa çıkma yollarını kaçınma, izolasyon, normalizasyon, bakım verme/sürece dahil olma ve yas tutma olarak beşe

ayırıştır. Gerace (1993) ise iş birliği yapan kardeşler, kriz odaklı kardeşler ve kopuk kardeşler olarak üç grupbaşa çıkma yolu tanımlamıştır. Son olarak, Kinsella ve Anderson'a (1996) göre kardeşler sağlıklı başa çıkma ve sağlıklı başa çıkma olmak üzere iki çeşit başa çıkma yolu kullanmaktadırlar. Sosyale destek bireylerin başa çıkma yolunu tayin eden belirleyicilerden bir tanesidir. Literatürde sosyale desteğin üç işlevine dikkat çekilmektedir. İlki, bağımlı değişkenin üzerinde doğrudan etkisi olan ana etkisidir (Kessler & Essex, 1982, Quittner, Glueckauf & Jackson, 1990) . İkinci olarak sosyale desteğin, bağımlı değişken ile etkileşimine dikkat çekilmektedir (Cohen & Willis, 1985) ve son olarak sosyale destek literatürde bağımlı değişken ve bağımsız değişken arasındaki aracı değişken olarak tanımlanmaktadır (Quittner, Glueckauf & Jackson, 1990). Her üç durumda da sosyale desteğin streslerle karşı karşıya kalındığında olumlu etkisinden söz edilmektedir. Dindarlık ise araştırmamızın bağımlı değişkeni olan psikolojik iyilik hali ve başa çıkma yolları ile ilişkili bir diğer değişkendir . Ancak, dindarlık ile psikolojik iyilik hali arasındaki ilişkiyi inceleyen çok az sayıda araştırma bulunmaktadır. Müslüman bir toplum üzerinde yapılan bir çalışmada, dindarlığın ve maneviyatın bir başa çıkma yolu olarak kullanıldığı durumlarda bakımverenlerin stres düzeyinin daha düşük olarak saptandığı görülmüştür (Rafiyah, Suttharangsee & Sangchan, 2011).

Bu çalışmada, tüm bu literatürde sözü edilen değişkenler Lazarus ve Folkman'ın Stres ve Başa Çıkma Modeli çerçevesinde değerlendirilmiş olup, kardeşi şizofreni hastası olan bireylerin deneyimledikleri yük "stres" kapsamında ele alınmıştır. Lazarus ve Folkman, bugüne dek stres kavramının en kapsamlı tanımını ortaya koyan araştırmacılarıdır. Lazarus ve Folkman'a göre stres "*kişi-çevre etkileşiminde, kişinin uyumunu tehlikeye sokan ve mevcut kaynakları zorlayan ya da aşan çevre talepleridir*". Yapılan çeşitli stres tanımları incelendiğinde çoğunlukla stresin olumsuz ve zararlı bir anlamda ele alındığı görülmektedir. Oysa stres kişiyi zora soksa da, uyumunu tehlikeye düşürse de, acı ve bunaltı verse de, stresle başa çıkıldığında kişiyi aynı zamanda daha ileriye, mutluluğa, başarıya götüren bir özelliğe de sahiptir . Lazarus ve Folkman'a göre bilişsel değerlendirmeler birincil ve

ikincil olmak üzere iki biçimde yapılabilir. Birincil değerlendirmede kişi kendisinin "tehlikede" olup olmadığına karar verir. Eğer bir olay kayıba yol açıyor, kişiye zarar veriyor ya da onu tehdit ediyorsa "tehlikeli" şeklinde değerlendirilir. Bazı yazarlar ise bir olay ya da durumun ne kadar stres verici olduğunun değerlendirilmesinde olay ya da durumun "tehlikeli" olması dışında farklı özelliklerin de rol oynadığına dikkat çekmişlerdir. Yine olay ya da durumun ortaya çıkmasının ne kadar "istenmez" olduğu ve olay ya da durumun ortaya çıkmasında kişinin kendini ne kadar "sorumlu" gördüğü ile depresyon arasında anlamlı ilişkiler saptanmıştır. Lazarus ve Folkman'a göre birincil değerlendirme ile eşzamanlı olarak ikincil değerlendirme de başlar. İkincil değerlendirmede kişi kendi kaynaklarını, sağlığını, kişiliğini, sosyal desteklerini, moralini vb. dikkate alarak "ne yapabilirim?" sorusunu cevaplamaya çalışır. Bu cevaba göre kişi nasıl davranacağına karar verir. Böylece kişinin belli bir durum ile ilgili yaptığı birincil ve ikincil değerlendirmeler o kişinin o durumla başa çıkabilmek için başvuracağı yolları belirler. Başa çıkma yolları ile ilgili bir model geliştiren Lazarus ve Folkman başa çıkmayı "*stresli olay ya da durumların yol açtığı duygusal gerilimi azaltma, yok etme ya da bu gerilime dayanma amacıyla gösterilen bilişsel, davranışsal ve duygusal tepkilerin bütünü*" şeklinde tanımlamışlardır. Bu modele göre başa çıkma kişinin iç ve dış taleplere karşı gösterdiği başarılı ya da başarısız tüm çabaları kapsar. Belli bir stres durumuyla başa çıkmada kullanılan yolların başarılı olup olmadığı ancak uyum üzerindeki etkilerine göre belirlenebilir. Başa çıkma modeline göre başa çıkma davranışlarının rahatsızlık yaratan kaynağı ortadan kaldırmak ya da azaltmak, stres yaratan durumla ilgili değerlendirmeleri değiştirmek ve rahatsızlığa yol açan duyguları düzenlemek gibi amaçları vardır. Lazarus ve arkadaşları başa çıkmada kullanılan yolları "duygulara odaklanan" ve "soruna odaklanan" başa çıkma yolları şeklinde adlandırmışlardır. Soruna odaklanan başa çıkma yolları, durumu değiştirmeye yönelik aktif, mantıklı, serinkanlı, bilinçli çabaları içerirken; duygulara odaklı başa çıkma yolları genellikle uzaklaşma, kendini kontrol etme, sosyal destek arama, kabullenme gibi davranışları içermektedir.

Yapılan çalışmada, kardeşi şizofreni hastası olan bireylerdeki yük ve yüke ilişkin bilişsel değerlendirmeleri ile çocuklukta algıladıkları anne baba tutumları ile algıladıkları sosyal destek ve dindarlık düzeyleri gibi kişisel kaynakları ve başa çıkma yolları araştırmanın bağımsız değişkenlerini oluştururken, araştırmanın bağımlı değişkenleri öznel psikolojik iyilik hali ve benlik saygısı olarak belirlenmiştir.

2. Yöntem

Katılımcılar ve İşlemler

103 şizofreni hastasına sahip kardeş çalışmanın örneklemini oluşturmuştur. Katılımcıların yaş ortlaması 37.14'tür. Çalışmaya katılan şizofreni hastasına sahip kardeşler Anara Şizofreni Hastaları ve Yakınları Dayanışma Derneği'nden (<http://www.sizofrenifederasyonu.org/>) kar topu yöntemine dayanılarak çalışmaya alınmışlardır. Uygulanan ölçeklerin yanıtlanması yaklaşık olarak 45-60 dakika sürmüştür. Data seti şizofreni hastası kardeşlerine yüz yüze uygulanmış olup, Ankara dışında yaşayanlar için e-mail ve posta yöntemi kullanılmış ve aynı yöntemle toplanmıştır. Uygulanan data setinin ilk bölümü açık uçlu sorulardan oluşmuştur. Katılımcıların %26.7'sine data seti yüz yüze uygulanmış, %17.44'üne e-mail ve %55.81'ine ise posta yoluyla ulaşılmıştır.

Ölçüm araçları

Sosyodemografik Bilgi Formu ve Açık uçlu Sorular: Katılımcıların demografik bilgilerini almak ve hastalık hakkındaki bilgi kaynakları, sosyal destek kaynakları ve kardeşlerinin hastalığı ile ilgili sıkıntılarında yakınlarında kimlerin kendilerine nasıl destek oldukları, başa çıkma yolları, kardeşlerinin hastalığı öncesinde ve sonrasında çocukluklarına dair hatırladıkları anne baba tutumlarına ilişkin açık uçlu sorularla bilgi almak amacıyla oluşturulmuş formdur.

Öznel İyi Oluş Ölçeği : Kardeşi şizofreni hastası olan bireylerde öznel psikolojik iyilik halini ölçmek için Tuzgöl-Dost (2005) tarafından geliştirilen Öznel İyi Oluş

Ölçeđi kullanılmıřtır. Ölçek, öznel iyi oluřun farklı boyutları ile birlikte bireyin genel olarak öznel iyi oluřunu ölçen, 46 maddeden oluřan ve 5 dereceli likert tipi bir ölçektir.

Rosenberg Benlik Saygısı Ölçeđi: Kardeři řizofreni hastası olan bireylerde benlik saygısını ölçmek için Rosenberg (1985) tarafından geliřtirilen ve ülkemizde geçerlik ve güvenilirlik çalıřması Çuhadarođlu (1985) tarafından yapılmıř olan ve 63 maddeden oluřan Rosenberg Benlik Saygısı Ölçeđi Kullanılmıřtır.

Zarit Bakıcı Yükü Ölçeđi: Kardeři řizofreni hastası olan bireylerde bakıcı yükünü ölçmek için Zarit ve arkadaşları (1985) tarafından geliřtirilen Zarit Bakıcı Yükü Ölçeđi (ZBYÖ) kullanılmıřtır. Ölçek bakıcının kendisinin yanıtlayacađı 22 sorudan oluřmaktadır.

Çok Boyutlu Algılanan Sosyal Destek Ölçeđi: Kardeři řizofreni hastası olan bireylerin algıladıkları sosyal desteđi ölçmek için Zimmet ve arkadaşları (1988) tarafından geliřtirilen ve Türkçe geçerlik ve güvenilirlik çalıřmaları Eker ve Arkar (1988) tarafından yapılan Çok Boyutlu Algılanan Sosyal Destek Ölçeđi kullanılmıřtır. Toplam 12 maddeden oluřan bu ölçek “kesinlikle hayır” ve “kesinlikle evet” arasında deđiřen 7 dereceli likert tipi bir ölçektir.

Çocuklukta Algılanan Anne Baba Tutumları Ölçeđi: Kardeři řizofreni hastası olan bireylerin çocukluklarında algıladıkları anne baba tutumlarını ölçmek için Castro ve arkadaşları (1993) tarafından geliřtirilen ve 40 maddeden oluřan Çocuklukta Algılanan Anne Baba Tutumları Ölçeđi kullanılmıřtır.

Bařa Çıkma Yolları : Kardeři řizofreni hastası olan bireylerin bařa çıkma yollarını ölçmek için Folkman ve Lazarus (1980) tarafından geliřtirilen, Siva tarafından uyarlama çalıřması yapılan ve 74 maddeden oluřan bařa çıkma yolları ölçeđi kullanılmıřtır.

3. Temel bulgular

Yapılan birinci regresyon analizi sonuçları kardeři řizofreni hastası olan bireylerin öznel psikolojik iyilik hallerinin, anneden algılanan korumacı tutumunun,

algılanan sosyal desteğin, problem odaklı baş etme ve dolaylı baş etme stratejilerinin sağlıklı kardeşlerde psikolojik iyilik hali ile ilişkili olduğuna işaret etmektedir. Çocuklukta daha fazla korumacı anne tutumuna maruz kalan, etraftan yüksek düzeyde sosyal destek algılayanları, sıkıntılarıyla soruna odaklanarak başa çıkma stratejisini benimseyen bireylerin öznel psikolojik iyilik hallerinin de yüksek düzeyde olduğu saptanmıştır.

Psikolojik iyilik halinin önemli göstergelerinden biri olan benlik saygısı da yapılan ikinci regresyon analizi ile incelendiğinde, cinsiyet, bakıcı yükü, anneden algılanan reddedilme, korumacılık ve ılımlı tutum ile babadan algılanan reddedilme ve ılımlı tutum, algılanan sosyal destek, dindarlık, problem odaklı ve dolaylı baş etme stratejileri ile ilişkili bulunmuştur. Buna göre kardeşi şizofreni hastası olan kadınların benlik saygısı erkeklere göre daha yüksek olarak saptanmıştır. Bakıcı yükü ile benlik saygısının negatif yönde ilişkili olduğu saptanmıştır. Çocuklukta annesinden ve babasından reddedici tutum algılayan bireylerin benlik saygısı daha düşük olarak gözlenirken; annesinden korumacı tutum ile annesinden ve babasından ılımlı tutum algılayan bireylerin benlik saygısı ise daha yüksek olarak gözlenmiştir.

Ayrıca, yapılan çalışmada kardeşi şizofreni hastası olan bireylerin problem odaklı baş etme stratejisi ile algıladıkları sosyal desteklerinin bakıcı yükü ve psikolojik iyilik hali arasında aracı bir rolü olduğu ve sosyal desteğin aynı zamanda bakıcı yükünün moderatorü olduğu da saptanmıştır.

4. Değerlendirme, Sonuç ve Öneriler

Araştırmalarda daha ayrıntılı olarak kardeşlere odaklanması ve kontrol grubu olan çalışmalar yapılması gerekliliğinin olduğu görülmüştür. Yapılan araştırmalarda örneklem sayısının artırılmasının ve nicel analizler kadar nitel çalışmalara (açık uçlu sorular, mülakatlar, içerik analizi vb.) da ağırlık verilmesinin önemi ortaya çıkmaktadır. Yapılan bu çalışma kesitsel bir çalışma olması nedeni ile sınırlı bilgi vermektedir. Bu nedenle boylamsal çalışmalara yönelmenin daha fazla bilgi sağlayıcı olması açısından tercih edilebileceği görülmektedir. Şizofreni

hastalığının, kardeşi şizofreni hastası olan bireylerin çocukluklarını zedeleme ve benlik saygısı geliřtirmelerini engelleme gibi olumsuz etkilere sahip olacağı görüldüğünden bu bireylerin iyilik hali ve benlik saygısı açısından değerlendirilmelerinin uygun olacağı düşünülmektedir. Yükleri ne kadar çok olursa olsun, sosyal destek ve sağlıklı başa çıkma yolları kullanmanın aracı etkilerinin bu bireylerin psikolojik iyilik hallerini olumlu yönde etkileyeceği düşünülmektedir. Kardeşi şizofreni hastası olan bireyler de tıpkı anne baba ve eşler gibi tedavi programları ve psikoeğitim gibi aile çalışmalarına dâhil edilmelidir. Bu programlarda ailelere, özellikle anne babalara sadece hasta çocuğa değil, sağlıklı çocuğa da gösterdikleri davranışlar ve bu davranışların sonuçları konusunda yol gösterilmelidir. Kardeşlerin sosyal destek kaynaklarının artırılmasının da negatif duygularını çözümlmek ve sağlıklı başa çıkma yolları kullanmaları konularında fayda sağlayacağı ve bu bağlamda dayanışma gruplarına katılmalarının işlevsel olacağı düşünülmektedir. Bu araştırmanın gerçekleştirildiği Ankara Şizofreni Hastaları ve Yakınları dayanışma Derneği'nin önemi büyüktür, Türkiye genelinde yaygınlaşan bu tür sivil toplum kuruluşlarına kardeşlerin de yönlendirilmesinin gerekliliği kaçınılmazdır.

Kardeşi şizofreni hastası olan bireylerin, kardeşlerinin hastalığı ile ilgili yaşadıkları zorluklara yönelik kullandıkları başa çıkma yolları açısından değerlendirilmelerinin, işlevsel olmayan başa çıkma yolları konusunda uyarılmalarının ve problem odaklı başa çıkma yolları geliřtirilmeleri konusunda yönlendirilmelerinin önemli olduğu görülmektedir.

5. Çalışmanın Başlıca Katkıları

Yapılan çalışmanın literature önemli katkıları bulunmaktadır. Öncelikle, bu çalışma şizofreni hastalarının yakınlarına, özellikle kardeşler grubuna dikkat çekmektedir. Bugüne dek yapılan çalışmaların sadece anne baba odaklı olması, yapılan bu çalışmayı literatürde özel bir yere oturtmaktadır. Mevcut durum sadece Türkçe çalışmalar için geçerli olmayıp, yapılan uluslararası çalışmaların da kardeşi

şizofreni hastası olan bireylere yönelik araştırma ve müdahaleleri ihmal ettikleri görülmektedir. Bu çalışmanın kapsamlı bir modele dayanıyor olması da çalışmanın bir diğer güçlü tarafını teşkil etmektedir. Lazarus ve Folkman'ın Stres ve Başa Çıkma Modeli dahilinde çalışmanın tüm değişkenleri kullanılarak, model, kardeşi şizofreni hastası olan bireylere uyarlanarak literature katkı sağlanmıştır. Son olarak bütün bu elde edilen veriler, ihmal edilmiş bir grup olan kardeşi şizofreni hastası olan bireylere yönelik müdahale geliştime çabalarında da bir başlangıç noktası oluşturmaktadır. Araştırmanın uygulanan iki regresyon analizi sonuçlarına dayanması genellenebilirliğini düşürse de, problem odaklı başa çıkma ve sosyal destek kavramlarının stresle ilişkisini ortaya koyması bakımından son derece önemlidir.

APPENDIX K

TEZ FOTOKOPİSİ İZİN FORMU

ENSTİTÜ

Fen Bilimleri Enstitüsü	<input type="checkbox"/>
Sosyal Bilimler Enstitüsü	<input checked="" type="checkbox"/>
Uygulamalı Matematik Enstitüsü	<input type="checkbox"/>
Enformatik Enstitüsü	<input type="checkbox"/>
Deniz Bilimleri Enstitüsü	<input type="checkbox"/>

YAZARIN

Soyadı : YÜKSEL
Adı : MUAZZEZ MERVE
Bölümü : PSİKOLOJİ

TEZİN ADI (İngilizce) : THE WELL-BEING OF SIBLINGS OF PATIENTS WITH SCHIZOPHRENIA: AN EVALUATION WITHIN THE TRANSACTIONAL STRESS AND COPING MODEL

TEZİN TÜRÜ : Yüksek Lisans Doktora

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

TEZİN KÜTÜPHANEYE TESLİM TARİHİ:

APPENDIX L

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College	Ankara Atatürk Anatolian High School	2002

WORK EXPERIENCE

Year	Place	Enrollment
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2010- Present	ASELSAN, Employee Assistance Unit	Psychologist
2008-2010	Municipality of Ankara	Psychologist

FOREIGN LANGUAGES

English