PREDICTORS OF DEPRESSION, ANXIETY, GRIEF AND GROWTH AMONG TURKISH OFFSPRING AS CAREGIVERS OF PARENTS WITH ALZHEIMER'S DISEASE: A MULTI-METHOD STUDY

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

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ABSTRACT

PREDICTORS OF DEPRESSION, ANXIETY, GRIEF AND GROWTH AMONG TURKISH OFFSPRING AS CAREGIVERS OF PARENTS WITH ALZHEIMER’S DISEASE: A MULTI-METHOD STUDY

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The main purpose of the current study was to investigate the lived experiences of Turkish adult children as caregivers of parents with Alzheimer’s Disease (AD). A multi-method design was employed to achieve this aim, and a qualitative and quantitative study were performed respectively. In the qualitative strand, semi-structured interviews were conducted with 20 adult children, and data was analyzed through Interpretative Phenomenological Analysis (IPA). Six super-ordinate themes were emerged from the obtained data, which were (1) etiology of the disease, (2) changes and losses, (3) coping strategies, (4) factors helping/hindering caregiving process, (5) unique pathology of the disease, and (6) reluctance to nursing home placement (NHP). The quantitative strand aimed to explore the roles of various background/contextual variables, primary stressors/disease-related factors, secondary stressors, execarbating or mitigating factors in predicting negative (i.e. depression, anxiety, anticipatory grief) and positive (i.e. growth) caregiver outcomes. Data for this strand was collected from 190 informal adult children caregivers of AD. Hierarchical regression analyses revealed that different sets of variables were influential in predicting different caregiver outcomes. While burden, optimistic/seeking-social support, helplessness-coping and perceived social support were associated with caregiver depression and anxiety; only subjective burden and helplessness coping were associated with pre-death grief responses. Additionally, among all other variables, only optimistic/seeking social support was positively associated with growth scores of the caregivers. Moderation analysis revealed that perceived social support had moderated the relationship between caregiver burden and various caregiving outcomes. Besides, problem-solving coping buffered the negative impact of subjective burden on caregiver depression.

Keywords: Alzheimer Disease, Caregiving, Burden, Coping Strategies, Social Support

ÖZ

EBEVEYNİ ALZHEİMER HASTASI OLAN YETİŞKİNLERDE DEPRESYON, KAYGI, YAS VE BÜYÜMEYİ YORDAYAN FAKTÖRLER: BİR ÇOKLU YÖNTEM ARAŞTIRMASI

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Bu araştırmanın temel amacı ebeveyni Alzheimer Hastalığı tanısı almış yetişkin Türk bakım verenlerin bakım verme deneyimlerini incelemektir. Bu hedefe ulaşmak amacıyla çoklu yöntem metolololojisi benimsenmiş ve sırasıyla niteliksel ve niceliksel çalışmalar yürütülmüştür. Niceliksel araştırma kapsamında, 20 yetişkin bakım verenle yarı-yapılandırılmış görüşmeler gerçekleştirilmiş ve elde edilen veriler Yorumlayıcı Fenomenolojik Analiz ile analiz edilmiştir. Analizler sonucunda, (1) hastalığın etiyolojisi, (2) değişimler ve kayıplar, (3) baş etme stratejileri, (4) bakım verme sürecini kolaylaştıran ya da zorlaştıran faktörler, (5) hastalığın kendine özgü patolojik özellikleri, ve (6) hastayı bakım evine yatırma konusundaki isteksizlik olmak üzere 6 üst tema oluşturulmuştur. Niteliksel araştırma sonuçları üzerine temellenen niceliksel araştırmanın amacı ise bağlamsal değişkenler, nesnel birincil stresörler, ikincil stresörler ve şiddetlendirici ya da koruyucu ara değişkenlerin farklı bakım veren ölçümleri üzerindeki etkilerini incelemek olarak belirlenmiştir. Öznel bakım veren yükü, iyimserlik/sosyal destek arayışı, çaresiz baş etme stratejisi ve algılanan sosyal destek bakım verenlerin depresif ve kaygı semptomları ile ilişkiliyken, sadece öznel bakıcı yükü ve çaresiz baş etme stratejisi ölüm öncesi yas belirtileri ile ilişkili olarak bulunmuştur. Ayrıca, diğer değişkenler içinde sadece iyimserlik/sosyal destek arayışı baş etme stratejisinin büyüme ile ilişkili olduğu ortaya koyulmuştur. Hierarşik regresyon analizlerinin ardından, MODPROCESS makrosu kullanarak düzenleyici etki analizleri gerçekleştirilmiştir. Veri analizleri, algılanan sosyal desteğin öznel bakıcı yükü ve depresyon; öznel bakıcı yükü ve kaygı; öznel bakıcı yükü ve gelişme arasındaki ilişkilerde düzenleyici bir rolü olduğunu ortaya koymuştur. Bunlara ek olarak, sorun çözme odaklı baş etme stretejisinin, öznel bakım veren yükü ve depresif belirtiler arasındaki ilişki üzerinde koruyucu bir etkisi olduğu bulunmuştur.

Anahtar Kelimeler: Alzheimer Hastalığı, Bakım Verme Süreci, Bakıcı Yükü, Baş Etme Stratejileri, Sosyal Destek

To my fiance Özgür Karcı and to my new life

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INTRODUCTION

“I will never forget you”

In 2008, my maternal grandfather started to behave in a manner which was not compatible with his usual character. He was immediately becoming frustrated when he realized he confused train schedules that he used frequently for travelling. He demanded the monthly payment from our tenants twice in the same month. He was anxious and angry all the time and did not want to communicate with us as he used to previously. We attributed these changes to the stress related to his strict work schedule and recent family problems. However, we realized something was seriously wrong when one of our relatives called us and said “I found him in the bazaar, he seems confused so I followed him. He is walking aimlessly. Maybe it will be better if you come and pick him up.”

In the same year, he was diagnosed with moderate stage Alzheimer’s Disease (AD). The neurologist informed us that this disease is incurable and the medications would only help to slow down the progression of the disease. He told us “The memory lapses will become more severe over time to the point that he will not recognize you. Eventually, he will need help while eating, bathing and walking. Be prepared.” We were shocked. He was one of the cleverest and most hardworking person I have ever known. He ran a local factory for years organizing tens of workers. He was always intellectually active reading newspapers and books regularly. The doctor’s predictions sounded unreal and impossible to me. In the same year, while he and me were sitting on the sofa as usual, I asked him “Grandpa, you seem to be forgetting things, have you realized?” He looked at me and replied: “I know, but don’t worry, I will never forget you.” That was the last meaningful conversation that we shared as a grandfather and a grandchild.

When I visited my home after four months, everything had changed. My mother took the primary caregiver role. Although she seemed stuck in the caregiving role, there was also a good atmosphere at home. She seemed to form a new relationship with my grandfather which is more intimate and compassionate then before. They were laughing at the funny acts he performed, singing and dancing together. However, there were also tears especially when he could not find the bathroom or asked "Where are we?" There were also momentary anger outbursts when he turned off the oven while my mother was trying to cook a meal or when he insisted on going outside alone. I realized that this disease has changed not only him as a person, but also my mother's well-being, personal life and her roles in our family. She prioritized the immediate needs of my grandfather over my and my brother's needs. Suddenly, she started to behave as if we had a baby brother who needs constant attention, affection and care. In fact, this profound and ever-changing family experience was what compelled me to examine and understand the complex nature and effects of AD and its caregiving on the whole family and, especially on family caregivers.

Accordingly, this thesis aimed to investigate Turkish adult children's experiences of AD and AD caregiving. Particularly, only adult children were included in the current study since caregiving experiences and outcomes differed between adult children and spousal caregivers due to the type of relationship with the patient and the developmental stage of the caregiver (Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010; Frank, 2008; Meuser & Marwit, 2001). In the first chapter, the nature and symptoms of AD will be briefly given, which will be followed by the prevalence rates of the disease both in the world and in Turkey. After highlighting the significance and nature of family caregiving in the context of AD, both negative and positive caregiving outcomes will be presented with relevance to existing models in the literature. Thirdly, factors associated with the impacts of AD on caregiving outcomes (i.e. care recipient and disease related factors, caregiver-related factors and other factors) will be introduced. Finally, detailed description of the aims and research questions of the two studies which were conducted in the scope of this thesis will be given.

1.1. Definition and Prevalence Rates for Alzheimer's Disease (AD)

Alzheimer's Disease (AD) is a progressive neurological condition which impairs cognitive, physical, emotional and behavioral functioning of an individual (Alzheimer's Society [AS], 2014). Although the causes are not yet fully understood, researchers identified two main brain abnormalities, *plaques and tangles,* as the distinctive markers of the disease development and progression. Simply, certain proteins (i.e. beta-amyloid and tau) build up together in the brain and form abnormal structures that either damage or kill brain cells, and prevent chemical communication between neurons (AS, 2014; Mayo Clinic, 2015) As more brain regions are affected by neural damage over time, symptoms become more severe to the point where the patient loses contact with his/her surrounding, becomes bed-ridden and eventually dies (Alzheimer's Association [AA], 2016; AS, 2014). Although memory loss is the most commonly known symptom of AD, difficulty in thinking and reasoning (e.g. managing finances, multitasking), impaired judgment and decision making, language problems (e.g. inability to find the right word or maintain a meaningful conversation), unusual behaviors (e.g. wandering, shouting, pacing), mood and personality changes (e.g. depression, apathy, anger outbursts), disorientation (e.g. losing track of date and place) and physical function loss (e.g. immobility, difficulty in swallowing) are amongst the other debilitating symptoms of the disease (Alzheimer Society Canada, 2016; National Health Service [NHS], 2016)

Approximately 30 million individuals are diagnosed with AD worldwide. This number is expected to double every 20 year because medical advancements and life style changes have enabled aging people to live longer with chronic conditions (Brodaty & Donkin, 2009). This increasing trend is also evident in US specifically due to the baby boom generation reaching over age 65 (AA, 2016). Alzheimer's Association reported that 5.5 million Americans are living with AD in 2017 and of this, 5.3 million are 65 years old or older. Age is the greatest known risk factor for the disease; as a result, the risk of having AD becomes dramatic especially over the age of 70. While one in nine people over age 65 is having AD (11 %), the risk becomes one in three among individuals who are aged over 85 (32 %) (AA, 2016).

In fact, prevalence of AD in Turkey shows a similar trend to the worldwide statistics. According to the Turkish Alzheimer's Disease Prevalence Study conducted in 2008, the prevalence of AD was reported to be 11 % among individuals who were at age 70 and older (Gurvit et al., 2008). More recently, Turkish Alzheimer Association declared that an estimated 600.000 people are suffering from AD in Turkey (Turkish Alzheimer's Association, 2016). However, there aren't any nationally documented official prevalence rates for AD in Turkey up to date.

1.2. Caregiving Outcomes in Alzheimer's Disease Context

AD is a progressive physical condition in which symptoms worsen over time to the point where patients need 24-hour assistance for daily living activities such as eating, walking, bathing and medication management (AA, 2016; AS, 2014; Frank, 2007). Almost 80 % of the AD patients are community-dwelling and informally cared for at home by family members, friends and/or neighbors. For the most part, a family member takes the primary caregiver role (AA, 2016; Ginzler, 2009; Schulz & Martire, 2004) especially in developing countries where kinship bond is an important determinant of who would provide care (World Health Organization [WHO], 2012). This informal caregiver group is known as an "invisible group" because they usually remain outside of the formal health care system and receive little to no assistance from formal health care sector (WHO, 2012). This is once again specifically the case in developing countries where formal health care services are limited for caregiver groups (WHO, 2012). Besides, caregivers from these countries might not use formal services available since they think that it is their obligation to provide care at home for their loved ones (Ar & Karanci, 2017; Brodaty, Thomson, Thompson & Fine, 2005; Knight & Sayegh, 2010). This unpaid caregiving trend is also prevalent in Turkey where 85 % of people with dementia stay at home until death with their relatives. These patients either live in their own houses or stay in their children’s homes, and care is usually provided by adult children, daughter-in-laws and spouses (Alzheimer Europe, 2016).

Typically, females are more likely to be primary caregivers of Alzheimer patients around the world (AA, 2016; Brodaty & Donkin, 2009; The 10/66 Dementia Research Group, 2004). That is, more wives than husbands, and more daughters than sons provide care to the affected individual. Other features of a typical caregiver profile include being a middle aged spouse or adult children of the patient and having less than a college education (AA, 2016; Brodaty & Donkin, 2009; Schneider, Murray, Banerjee, & Mann, 1999; The 10/66 Dementia Research Group, 2004). Although some studies presented contradictory results (Conde-Sala et al. 2010), the number of spousal caregivers are usually higher than adult children caregivers (Brodaty & Donkin, 2009; Gonzalez-Salvador, Arango, Lyketsos, & Barba, 1999). Still, the proportion of spousal and adult children caregivers displayed different patterns in different cultural groups, specifically Koreans, Asians and Latin Americans, where daughters, daughter-in-laws and sons tend to perform caregiving duties due to their cultural obligation to take care of their elderly parents (Alzheimer Europe, 2016; The 10/66 Dementia Research Group, 2004).

Although providing caregiving to a loved one is an inherently stressful experience, researchers suggested that AD caregiving is a unique challenge for caregivers (AA, 2016; Brodaty & Donkin, 2009; Smith, Lauret, Peery, & Mueller, 2001). Firstly, AD caregivers provide assistance for a greater variety of tasks (ranging from self-care needs to managing behavioral symptoms) for extensive time periods ranging from 4 to 20 years (AA,2016; NHS, 2016; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Schulz & Martire, 2004). Secondly, apart from daily living tasks, AD caregivers have to manage neuropsychiatric symptoms resulting from the unique pathology of the disease such as agitation, restlessness, sleep difficulties and wandering (AA, 2016; Mayo Clinic, 2015). Caregivers reported that handling these emotional and behavioral symptoms is much more troublesome than assisting daily living activities (Frank, 2008). Thirdly, relationship quality and intimacy between caregiver and care recipient are greatly endangered by the progressive memory loss and personality changes, which poses an additional relational difficulty for caregivers (AA, 2016; Harris, Adams, Zubatsky, & White 2011). It is possible for caregivers and care recipients in some other chronic illnesses (e.g. cancer) to process disease progression and impending death together, creating a chance for reciprocal support and adaptive resolution. However, such a mutual processing is less likely in AD since cognitive abilities are profoundly impaired (Meuser & Marwit, 2001). Last but not least, the identity and personality of the individual become so changed over time that caregivers feel they have already lost the person they have known for years. Therefore, caregivers start a grieving process long before the physical death, while the person is still physically present, creating a never-ending sense of ambiguity for family members (Austrom Guerrirero & Hendrie, 1990; Doka, 2010; Meuser & Marwit, 2001).

Due to all of the aforementioned difficulties, AD caregivers are more prone to psychological and physical morbidities when compared to other caregiver groups and non-caregiving matched controls (Allen et al., 2016; Brodaty & Donkin, 2009; Kim & Schulz, 2008; Schulz, & Martire, 2004). Their health related problems lead them to engage in more doctor visits, increased use of psychotropic medications and decreased life satisfaction (AS, 2016; Schulz, & Martire, 2004). Additionally, decreased caregiver well-being predicted lower quality of informal caregiving, reduced tolerance to patients' symptoms, increased rates of premature institutionalization and increased behavioral symptoms in patients (Kim, Chang, Rose, & Kim, 2012; McClendon, Smyth, & Neundorfer, 2004; Mittelman, Haley, Clay, & Roth, 2006; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Pinquart & Sörensen, 2003). At a macro level, informal caregivers' unpaid service is also a valuable resource for the society as a whole, considering the huge economical cost formal dementia care puts on states' budgets (Martire & Hall, 2002; Mittelman et al., 2006; Sörensen, Duberstein, Gill, & Pinquart, 2006). Therefore, informal AD caregiving is a significant public health issue that should be addressed both by health care professionals and social policy makers. Although the majority of Turkish dementia patients receive informal care at home, there isn’t a national dementia strategy applied systematically in Turkey supporting care recipients and informal caregivers (Alzheimer Europe, 2016). In that respect, developing and implementing interventions based on policies to optimize conditions of quality home care without sacrificing caregivers’ own physical and psychological needs seems as an important necessity in Turkey. At this point, the first attempt at a clinical level is to understand the multifaceted nature of AD caregiving experience and the interactional nature of related variables associated with caregiver outcomes. Accordingly, two influential models explaining AD caregiver stress process will be presented in detail, which will later be followed by the possible negative and positive caregiver outcomes highlighted in the current literature.

1.2.1. Models of Negative Caregiving Outcomes

One of the most influential model to understand AD caregiving and negative caregiver outcomes was developed by Pearlin and his colleagues in 1990 (Figure 1). This model conceptualized AD caregiving as a “stress process” where several contextual variables, objective and subjective stressors, intervening factors and negative caregiving outcomes interacted with each other in a dynamic fashion creating a stress process. This model aimed not only to identify conditions associated with the stress process, but also to investigate the ever-changing nature of relations among various stress-related variables (Kim et al., 2012; Pearlin, Mullan, Semple, & Skaff, 1990). Four main components comprised the stress process model were: (1) *the background and context of stress process,* (2) *primary and secondary stressors,* (3) *mediators* and (4) *negative caregiving outcomes*. *The background and context of stress process* involved age, gender, socio-economicstatus (SES) along with the cultural characteristics, race, ethnicity, education, family composition and caregiving history. The very notion underlying this component was that the conditions under which stress developed and experienced had a profound impact on how stressors were evaluated and managed at a personal and societal level. The statuses ascribed to individuals determined not only the type and intensity of stressors, but also the familial and public resources available to the patients and caregivers. This component also included family caregiving history taking into account the type of relation between caregiver and care-recipient (e.g. whether the caregiver is a spouse or adult child) and the quality of past relationship between them.

The second component of the stress process model included the *stressors*, both primary and secondary to the care provision. Pearlin and his colleagues (1990) proposed that this component was the corner stone of the model directing the subsequent processes arousing from these stressors. *Primary stressors* were described as problematic experiences and conditions developed in response to the direct patient and caregiving needs. Cognitive status was one important primary stressor related directly with the patient's current condition. The extend and range of caregiving tasks became more challenging as the patients' memory loss, communication problems and recognition difficulties become more severe over time creating a constant state of flux for caregivers (AA,2016; NHS, 2016; Pearlin et al., 1990). The second primary stressor, which was somehow related with cognitive decline, was the problematic behaviors of the patient. Behavioral disturbances such as shouting, repetition, wandering and lack of inhibition necessitated caregivers to take constant precautions to prevent patients from harming either themselves or others. Apart from the pressure of constant supervision of damage control, caregivers also continuously witnessed the profound changes in patient's personality and identity upon each behavioral symptom, which created a unique stressor for this caregiver group. The third primary stressor was the functional dependence of patient. It referred to how much the patient was dependent upon the caregiver on various daily living activities such as bathing, eating and walking. This indicator also consisted of instrumental activities that caregivers had to perform such as house chores, transportation and paying bills. *Secondary stressors* were, in fact, just by-products of the primary stressors. They included stressors not related with direct caregiving tasks, but rather additional stressors in different areas of life resulting from direct caregiving demands. To illustrate, higher functional dependence of the patient and longer caregiving periods (primary stressor) might wear off social resources over time thereby leading to social isolation (secondary stressor) among caregivers. Secondary stressors were also categorized into two sub-groups in itself, which were specified as role strains and intrapsychic strains. Role strains referred to the struggles and role confusions experienced in different areas of caregiver life other than caregiving. Family conflicts over care division, occupational issues (e.g. missing work or a promotion due to caregiving role), economic strains (e.g. high expense of dementia treatment), and limited participation in social and recreational activities were all examples belonging to the role strains subgroup. Intrapsychic strains, on the other hand, concerned with the features of the caregivers' mental state and identity which became compromised over time due to exposure to persistent caregiving stress. The main indicators of this subcategory were lower sense of self-esteem and mastery, reduced competence, role captivity, and loss of self.

The third component of the stress process model are mediators, which were proposed as coping strategies and social support in the original model. In fact, this component was integrated to the conceptual framework to explain how caregivers with similar kinds and intensity of stressors differed in their caregiving outcomes. While these variables might directly influence stressors and caregiving outcomes at each level, they could also lessen the deleterious effects of various primary and secondary stressors on caregiver outcomes.

The final component of the model is the negative caregiving outcomes, which simply corresponded to the well-being of caregivers and care recipients. From a psychological perspective, they referred to the symptoms of depression, anxiety, hostility, irritability and cognitive disturbances. At a physiological level, objective indicators of stress (e.g. biomarkers), sleep patterns, subjective physical health perception and harmful health behaviors were measured.

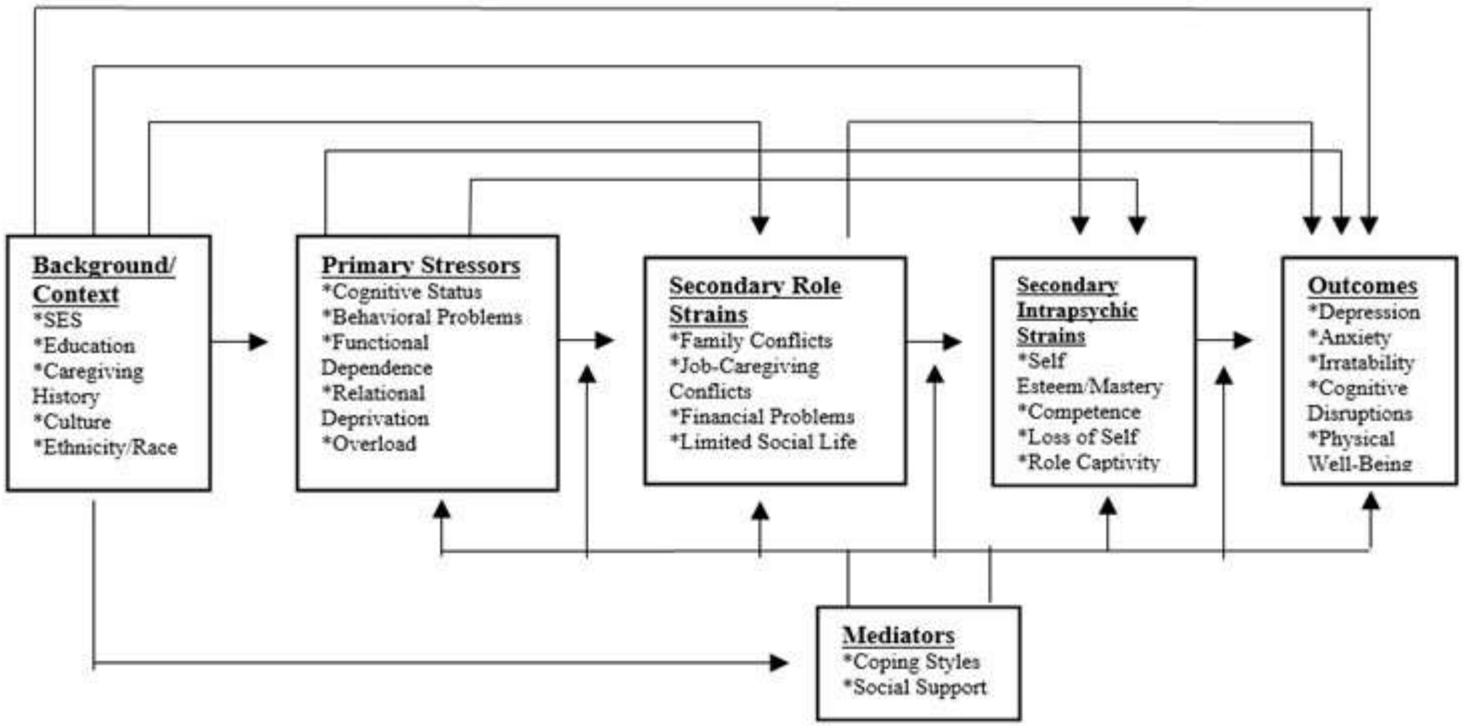


Figure 1. Stress Process Model (Pearlin et al., 1990)

The second prominent framework explaining caregiver stress among AD caregivers combined the stress process model with the appraisal models originated from the work of Lazarus in 1984 (Sörensen et al., 2006). Although they were structurally similar, one new component, appraisal, was added to this new model. Besides, the mediators component in Pearlin's model had been modified and named as exacerbating or ameliorating (moderator) factors (Figure 2). Appraisals referred to the caregivers' subjective evaluations of the caregiving demands, tasks and resources. If a caregiver perceived that his/her personal and environmental resources were insufficient to meet caregiving demands, he/she felt stuck in the caregiver role and the rates of morbidity and depression would show an increasing trend (Aneshensel, Pearlin, & Schuler, 1993; Pinquart & Sörensen, 2003; Williams, 2005). Besides, caregivers who thought that they had some control over the caregiving situation and who associated caregiving with more benign appraisals usually experienced lower psychological distress and higher quality of life (Pinquart & Sörensen, 2003; Sörensen et al., 2006).

This combined model also asserted that how stressors and appraisals related with each other to create adverse caregiving outcomes was partially determined by exacerbating or ameliorating factors. Exacerbating factors were comprised of personality vulnerabilities, pre-existing mental and medical problems, and dysfunctional coping strategies (Sörensen et al., 2006). Specifically, studies found that caregivers with depressive symptoms prior to AD diagnosis (Välimäki, Martikainen, Hallikainen, Väätäinen, & Koivisto, 2015), wishful coping (McClendon et al., 2004) and having more medical problems (Vitaliano & Scanlan, 2003) experienced increased levels of psychological distress and caregiver burden. Additionally, neuroticism was also reported as a risk factor for negative caregiving outcomes in AD context (Shurgot & Knight, 2005).

Although there were componential differences, both models aimed to understand and explain the complex nature of AD caregiving from a multidimensional standpoint (Pearlin et al., 1990; Sörensen et al., 2006). It was emphasized that there were various feedback loops among different components of the model. That is, changes in one level of the stress process model had a possible effect on another level underlying the interactional nature of various care recipient and caregiver related variables (Pearlin et al., 1990; Schulz & Martire, 2004; Sörensen et al., 2006). Researchers have recently started to focus more on caregiver related factors such as appraisals and moderator variables (e.g. coping styles, social support) since the associations between stressors and caregiving factors has been well-established in the literature (Conde-Sala et al., 2010; Schulz, R & Martire, 2004). Besides, these factors might have garnered more attention in the last decade since they were modifiable, thereby becoming important targets for possible intervention programs designed to alleviate caregiver and care recipient morbidity.

1.2.2. Negative Caregiving Outcomes

1.2.2.1. Caregiver Burden

The deleterious impacts of AD caregiving on family caregivers' health have been well-documented. Particularly, caregiver burden has garnered significant attention in the literature over 25 years. Rather than being a unitary phenomenon, caregiver burden was usually referred to as a complex structure with multiple components (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Savundranayagam, Montgomery, & Kosloski, 2011). It was best described as caregivers' subjective struggles arousing from emotional, physical, social and financial demands of AD caregiving (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Werner et al., 2012). It includes time restrictions due to extensive care responsibilities (e.g. reduced participation in leisure activities), distress resulting from patient's functional dependence, relational stress of reduced quality of caregiver-care recipient interaction, family struggles over care provision, financial problems and subjective assessment of overall stress associated with caregiving (Ankri, et al., 2005; Richardson, Lee, Berg-Weger, & Grossberg, 2013; Sörensen et al., 2006). Studies consistently revealed that AD caregivers experienced moderate to high levels of burden (Andrén & Elmståhl, 2008; Etters, Goodall, & Harrison, 2008; Sörensen et al., 2006). Particularly, AD caregivers felt stuck in the caregiving role

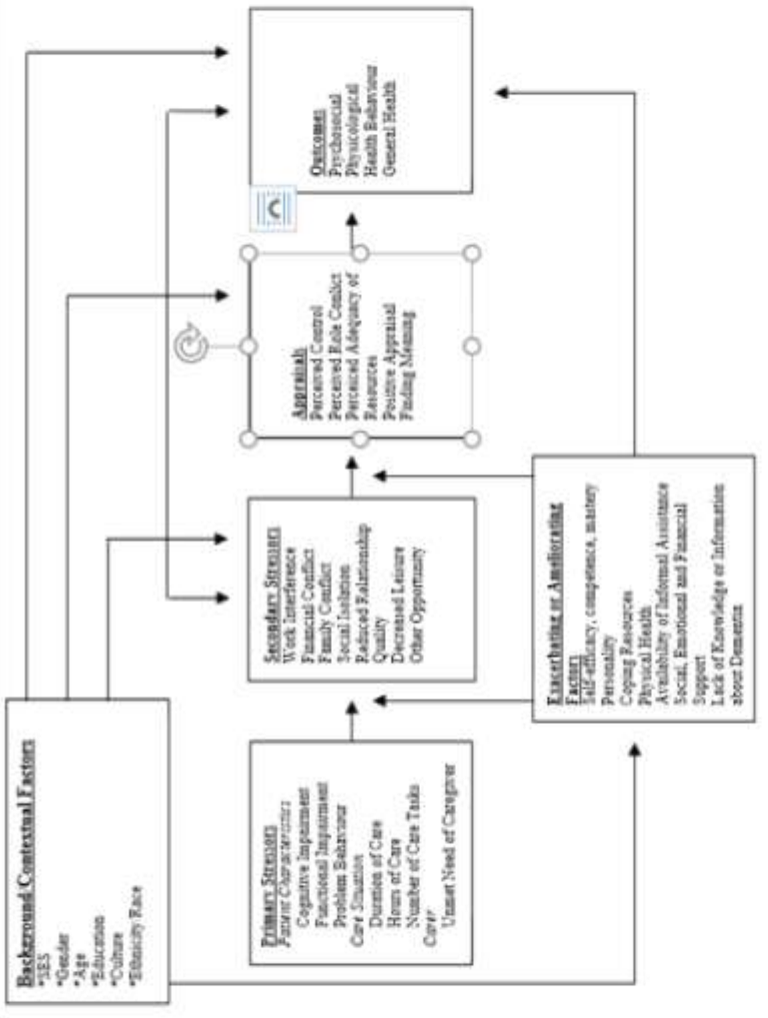


Figure 2. Model of Carer Stress and Burden (Sörensen et al., 2006)

and experienced distress of joggling multiple roles simultaneously (e.g. being a wife while still caring for the parent) (Brodaty & Hadzi-Pavlovic, 1990; Savundranayagam et al., 2011). They usually gave up their social life, had more absenteeism at work or missed the alternative job opportunities, and did not have time even to fulfill their own physical and psychological needs (Leong, Madjar, & Fiveash, 2010; Savundranayagam et al., 2011). Conceivably, caregivers with higher burden levels had poorer perceived health, increased psychological morbidity, lower sense of coherence and reduced quality of life (Andrén & Elmståhl, 2008; Conde-Sala et al., 2010; Savundranayagam et al., 2011). Besides, some researchers suggested that caregiver burden had also negative impacts on care recipient's well-being, as well. Specifically, patients with highly burdened caregivers were more likely to display increased behavioral symptoms and experience lower quality of life (Mittelman et al., 2006; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Savundranayagam et al., 2011).

1.2.2.2. Psychological Morbidity

Psychological morbidity that AD caregivers face could manifest itself through various psychiatric problems. Among these, depression is the most common psychopathology reported consistently across studies. It was found that up to half of the AD caregivers experience clinically significant levels of depressive symptoms during care provision (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Kim, Chang, Rose, & Kim, 2012; Martire & Hall, 2002; Schulz & Martire, 2004; Teri, Logsdon, Uomoto, & McCurry, 1997). Interestingly, caregivers’ depressive symptoms and emotional distress might even remain the same after nursing home placement (Mittelman et al., 2006) indicating that caregiver burden and objective caregiving stressors might not be solely responsible for the psychological distress that caregivers experienced. Although much less researched, quarter of AD caregivers had also anxiety symptoms which required clinical attention (Cooper, Balamurali, & Livingston, 2007; Joling et al., 2010). Additionally, informal caregivers usually had lower life satisfaction, poor quality of life, hostility, increased negative affect, and lower self-esteem (Kim et al., 2012; Schulz et al., 2002; Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006).

1.2.2.3. Physical Morbidity

AD caregiving has provided a great opportunity for researchers to examine the physiological impacts of being exposed to a chronic stressor (Allen et al., 2016). The median survival time for AD patients usually ranges from 4 to 10 years (AA,2016; NHS, 2016). Considering the majority of care is usually provided by informal caregivers during this period, AD carers are personally subjected to a variety of physical, psychological, financial, and social stressors over long periods of time. This persistent nature of stress associated with AD caregiving led researchers to examine the biological markers of chronic stress in AD context which have been associated with both short and long term physical ill-health consequences (Allen et al., 2016). The most robust finding about the link between AD caring and human physiology was the increased cortisol secretion among informal caregivers. Studies consistently reported that AD caregivers had increased cortisol levels both at a daily base and during overall caregiving period which made them more vulnerable to diabetes, cardiovascular problems, obesity and gastrointestinal problems (Allen et al., 2016; Bauer et al., 2000). Additionally, AD caregivers had compromised immune function (Bauer et al., 2000) and slow wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1996), although some studies presented inconclusive results (Allen et al., 2016). From a neurocognitive standpoint, it was also found that AD caregivers displayed poorer performance on executive functioning and attention tests (Allen et al., 2016; Oken, Fonareva, & Wahbeh, 2011). Nevertheless, the evidence was mixed regarding the performance of AD caregivers on short and long term memory tasks during care provision (Allen et al., 2016).

1.2.2.4. Anticipatory Grief

There has been an abundance of research on caregiver burden and distress while examining caregiving experiences in AD context. Nevertheless, some theorists have criticized this focus and claimed that pre-death grief experiences of dementia caregivers were usually overlooked by the researchers and mental health professionals (Mesuer & Marwit, 2001; Romero, Ott & Kelber, 2007). Pre-death grief responses of AD caregivers might have remained unnoticed for several reasons. Firstly, it could have been easily confused with caregiver depression since both constructs shared common symptoms such as profound sadness, guilt and despair (Sanders & Adams, 2005; Walker & Pomeroy, 1996). Besides, society’s misconception that grieving for a loved one who was still alive was inappropriate might have invalidated AD caregivers’ loss experiences (Boss, 2000; McEvoy, 2007; Wasow & Coons 1987). In fact, even caregivers themselves might push grief-related emotions into the background because of the extensive caregiving demands which required more immediate attention in their daily routines (Loos & Bowd, 2010).

Rando coined the term anticipatory grief (AG) for the first time to conceptualize grief responses that started long before the actual death of a chronically ill patient (Rando, 2000). It was described as mourning for the past losses (e.g. loss of the past relationship), present losses (e.g. ongoing cognitive deterioration) and future losses (e.g. hopes and plans with the loved one) in the face of an imminent death (Frank, 2008; Holley & Mast, 2009). AG is an inherent part of AD caregiving since caregivers bear witness cognitive and physical deterioration of their loved ones on a daily basis (Mace and Rabins 1981). Due to the unique neuropsychiatric symptoms, personality and identity of the patient become so changed that caregivers felt they had lost the person they knew in the past. They experienced intense grief reactions as the reciprocity, intimacy and closeness in the relationship declined through the disease trajectory (Rando, 2000; Sanders, & Corley 2008; Walker, Pomeroy, McNeil, & Franklin, 1994; Williams & Moretta, 1997). Caregivers reported that it was not the hands-on care tasks, but watching the psychological death of a loved one that caused much more emotional pain (Frank, 2008). Secondary losses associated with caregiving also intensified AD caregivers' grief reactions. Majority of caregivers stated that they had lost social interaction, their well-being and control over life events (Loos & Bowd, 2010; Sanders & Corley, 2003)

Boss (2000) introduced the concept of ambiguous loss in order to highlight the unique nature of AG in dementia context. Ambiguous loss was used to define unclear losses which had neither a clear beginning nor a definitive ending. It was specifically applicable to AD context because the losses associated with the disease process were full of uncertainties (Boss 2000; Doka, 2010). Although the person was physically present, s/he was not the same person cognitively and emotionally. Caregivers became confused as they were unsure of whether the person they knew were still there or not. Coupled with the uncertainties of disease progression, role confusions and family struggles aroused which also blocked family members' coping efforts. This constant state of ambiguity usually resulted in helplessness, despair, guilt, worry and isolation (Boss, 2000; Doka, 2010). Boss was first to speculate that caregiver depression that was examined so far might be more relevant to multiple ambiguous losses associated with AD, rather than the objective caregiver work-load (Boss, 2000). In fact, Walker and Pomeroy (1996), reported findings consistent to this hypothesis and revealed that more than half of the variance in caregiver depression could be explained by the anticipatory grief responses alone.

Although in its infancy, recent studies have started to investigate the concept of AG and associated variables among dementia caregivers. Findings revealed that AG prevalence ranged from 47 % to 71 % among dementia caregivers (Collins, Liken, King, & Kokinakis, 1993; Sanders & Corley, 2003). AG responses usually followed a curvilinear pattern reaching its peak after the initial diagnosis, declined and stabilized during 2-4 years, and again escalated towards the end stages of the disease (Ponder & Pomeroy, 1996). Grief responses became more evident specifically during cognitive transitions due to disease progression and institutionalization of the patient (Chan, Livingston, Jones, & Sampson, 2013; Mesuer & Marwit, 2001). Increased caregiver burden, decreased well-being, fewer positive appraisals of care provision and living with the care recipient prior to death were also associated with increased pre-death symptoms (Chan et al., 2013).

Several studies reported that pre-death grief among AD caregivers significantly and positively associated with caregiver depression (Sanders & Adams, 2005; Ott et al., 2007). In three studies, it was reported that a significant proportion of variance in caregiver depression, ranging from 12 % to 63 %, could be attributed to the pre-death grief symptoms (Sanders and Adams, 2005; Ott et al., 2007; Kiely et al., 2008; Walker & Pomeroy, 1996). These findings highlighted that what was assumed to be caregiver depression could also include symptoms of AG inherent in AD caregiving. Consequently, symptoms unique to AG process (e.g. yearning and longing for the past) were suggested to be investigated among AD caregivers in order to obtain a more comprehensive understanding of caregiver stress process.

1.2.3. Positive Caregiving Outcomes

There has been a vast majority of research on the negative consequences of AD caregiving. However, researchers have only recently started to look beyond the adverse AD caregiving impacts and investigate positive caregiving experiences, as well (Andrén & Elmståhl, 2008; de Labra et al., 2015). Positive and negative caring experiences were not simply the opposite sides of the same coin. Existence of negative sides did not preclude the occurrence of the former. Besides, they might have different predictors and implications, thereby giving pavement to the development of different intervention strategies (Andrén & Elmståhl, 2008; Cohen, Colantonio, & Vernich, 2002; de Labra et al., 2015; Pinquart & Sörensen, 2003). Examining positive caregiver experiences is of utmost importance because a non-negligible proportion of caregivers reported to show resilience in AD context (Cohen et al., 2002). Although these caregivers also reported distress and burden, the positive experiences seemed to play an important role in protecting them from psychological morbidity (Robertson, Duncan, & Rovine, 2007).

The recent empirical focus on positive caregiving experiences was compatible with a strength-based perspective of care provision. This framework stressed that caregivers had resources and values to deal with chronic caregiving conditions. It also implied that individuals had capacity to thrive under adverse life circumstances like AD caregiving (Peacock et al., 2010). Consistently, AD caregivers experienced personal gains in terms of joy from the intimate relation with the care recipient (Ar & Karanci, 2017; Cohen, Pushkar Gold, Shulman, & Zucchero, 1994; Harris, Adams, Zubatsky, & White, 2011), meaning making (Jeongim, 2014), feeling useful (Kramer, 1997), spiritual growth (Jeongim, 2014), and increased mastery and self-competence (Cohen et al., 1994). Caregivers with a good quality past relationship with the care-recipients, fulfilling caregiving duties voluntarily and having more personal times were reported to experience more positive aspects of caregiving (Lopez, Lopez-Arrieta, & Crespo, 2005). Additionally, caregivers having more positive caregiving experiences were found to have lower burden and depression (Cohen at al., 2002), increased well-being (Pinquart & Sörensen, 2003) and motivation to provide quality care (Cohen et al., 1994). These findings highlighted that positive and negative outcomes could coexist side by side in AD caregiving context. This co-existence necessitated the need to investigate prevalence and associates of caregiving gains to get a broader and more complete picture of AD caregiving experience.

1.3. Factors Associated with Caregiving Outcomes

1.3.1. Care Recipient and Disease Related Factors

1.3.1.1. Severity of the Disease

The extend of cognitive decline and associated functional dependence of care recipient on the caregiver were two objective stressors examined extensively in the AD caring literature. As memory losses became more dramatic, not only the type of tasks that caregivers provided assistance for became more complex but also the amount of assistance in daily living activities became much more extensive. Specifically, in the severe stages, caregivers had to fulfill almost all basic daily living needs of the patient such as assisting walking, eating, grooming and bathing. Additionally, they performed tasks of instrumental daily living such as house chores and paying bills which put them under additional burden and pressure (AA, 2016; AS, 2014). Still, there was not a consistent and conclusive relationship between severity of disease, functional impairment and caregiver distress. Several studies reported that caregiver burden, depression and grief escalated as the cognitive and functional impairment worsened over time (Conde-Sala et al. 2010; Kim et al., 2012; Mohamed et al., 2010; Pinquart & Sörensen, 2003; Raggi et al., 2015) Others, on the other hand, found no relationship among these variables (Andrén & Elmståhl, 2008; Ferrara et al., 2008). Upon these inconsistent findings, researchers posited that subjective appraisals and caregiver related factors might be more potent predictors of caregiver distress in AD context. This assumption has been reinforced by the more recent studies in which caregivers with similar objective disease related stressors experienced differential caregiver outcomes in the AD context (Schulz, & Martire, 2004).

Interestingly, there seems to be a positive relation between positive caregiving outcomes and disease severity, as well. Findings revealed that carers providing care for a patient with more severe dementia reported more caregiving gains (Andrén & Elmståhl, 2008; Kramer 1997). As the severity of the disease increased, the relation between caregiver and care recipient became more intense and intimate. This increased closeness could be one reason why caregivers reported more positive outcomes in the later stages of the disease (de Labra et al., 2015). Besides, behavioral disturbances usually decreased in the severe stages because patients become more immobile and bed-ridden. The relief arousing from decreased frequency of behavioral symptoms could also lead caregivers to focus more on the positive aspects of the care provision (Cummings, 2003; de Labra et al., 2015). Last but not the least, advanced disease stages usually signaled the impending death of the patient and evoked grief symptoms among caregivers (Boss, 2000). The upcoming physical separation might have resulted in a more empathetic perspective among caregivers thereby leading them to evaluate caregiving under a more positive light. Nevertheless, more research is needed to examine the relation between positive caregiving experiences and disease severity in this population.

1.3.1.2. Behavioral Symptoms

The most potent objective stressor predicting caregiver distress, physical morbidity and pre-death grief among AD caregivers was behavioral symptoms of the patients (Mohamed et al., 2010; Pinquart & Sörensen, 2003). Numerous studies revealed that increased behavioral disturbance (e.g. agitation, aggression, restlessness) was associated with increased caregiver burden, depression, anticipatory grief symptoms and poorer physical health (Austrom et al., 2014; (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Meuser & Marwit, 2001; Richardson et al., 2013; Savundranayagam at al., 2011; Sörensen et al., 2006; Välimäki et al., 2015). Behavioral disturbance was also a robust predictor of negative caregiver attitudes towards the patient and premature nursing home placement (McClendon et al., 2004; Mittelman et al., 2006). Behavioral problems were particularly challenging for AD caregivers because caregivers need to supervise the patient almost all the time in order not to hurt either themselves or others (Pearlin et al., 1990). Supervision of behavioral symptoms was also a physically demanding task on the behalf of caregivers leading to fatigue and exhaustion (AA, 2016; AS, 2014). Last but not the least, behavioral symptoms were the constant reminders of the loss of the person that caregivers knew and loved before diagnosis. Constantly witnessing these changes usually evoked profound sadness, helplessness and mourning responses among AD caregivers (Boss, 2000; Meuser & Marwit, 2001). To sum up, although other disease related factors such as disease severity and functional impairment did not have consistent effects and their effects could be buffered by other factors, behavioral symptoms seemed more resistant to subjective appraisals exerting pervasive impacts on morbidity for caregivers.

1.3.2. Caregiver Related Factors

1.3.2.1. Caregiver Gender

Numerous studies consistently reported that female caregivers were more vulnerable to negative caregiving outcomes when compared to their male counterparts. Female caregivers reported greater depression, burden, somatization, anger, lower quality of life, interpersonal conflict and poorer physical health during care provision (Ashley & Kleinpeter, 2008; Barber & Pasley, 1995; Bédard, Chambers, & Pedlar, 2000; Kim et al., 2012; Roche, Croot, MacCann, Cramer, & Diehl-Schmid, 2015; Papastavrou et al., 2011). This gender difference was generally attributed to the fact that female caregivers provided more intense care over longer periods of time (Pinquart & Sörensen, 2006) and had to handle more tasks associated with well-established gender roles (Connell, Janevic, & Gallant, 2001). The difference between female and male caregivers were also evident in their AG responses. Females were usually more expressive about the multiple losses they experienced. Their AG were usually manifested through despair, death anxiety, somatization and anger. Males, on the other hand, were more reluctant to accept and openly express their grief reactions while the AD patient was still alive (Gilliland & Fleming, 1998; Meuser & Marwit, 2001).

Previous studies of dementia caregiving have also suggested notable gender differences regarding the ways through which caregivers dealt with caregiving distress. Women sought for emotional support more readily than men (Ashley & Kleinpeter, 2008; Connell et al., 2001; Papastavrou et al., 2011). Nevertheless, men were more likely to utilize instrumental and formal support when compared to their women counterparts (Navaie-Waliser, Spriggs, & Feldman, 2002). Further, male caregivers usually displayed a task-focused orientation including making plans, developing alternative solutions and making practical arrangements while tackling disease-related issues (Geiger, Wilks, Lovelace, Chen, & Spivey, 2014; Navaie-Waliser et al., 2002).

As was pointed out in the literature, gender seems to be a decisive factor in shaping appraisals, coping and caregiving outcomes of dementia caregivers. However, there has been limited research on the mechanisms through which female and male caregivers differed in their caregiving experiences. Besides, dementia caregiving literature heavily focused on wives, daughters and daughter-in-laws' which might have overshadowed the distinct nature of male caregivers' experiences (Geiger et al., 2014). Therefore, more research seems necessary to capture the variability of husband, son and son-in-law caregivers' perceptions, coping styles and caregiving outcomes in dementia caregiving context.

1.3.2.2. Coping Strategies

The term coping has been used to refer to efforts spent to manage stressful situations. Although they aimed to alleviate distress, dysfunctional coping efforts might also intensify stress experience both in the short and in the long run (Lazarus & Folkman, 1984; Raggi, Tasca, Panerai, Neri, & Ferri, 2015). Dementia literature usually employed the general stress and coping framework developed by Lazarus and Folkman (1984) to investigate variability in caregivers' attempts to handle caregiving problems. In the original coping-stress model, coping styles were divided mainly into two categories, which were problem-focused and emotion-focused coping strategies. Later on, several researchers expanded this categorization and used broader factor structures (e.g. active coping, avoidance coping, dysfunctional coping) to measure variability in coping responses (Carver, Scheier, &Weintraub,1989; Powers, Gallagher-Thompson, & Kraemer, 2002). Due to this discrepancy in assessing and measuring coping styles, a careful consideration is necessary while interpreting findings regarding the relation between coping styles and mental health outcomes among dementia caregivers (Powers et al., 2002).

Studies examining the association of problem-focused coping with caregiving outcomes produced conflicting results. Several studies have revealed that problem-solving approach, logical analysis, making arrangements, seeking information and obtaining instrumental support were associated with lower levels of caregiver burden, depression and increased life satisfaction in dementia caregivers (Haley et al., 1996; Kneebone & Martin, 2003; Roche et al., 2015). Surprisingly, other studies reported negative relations or no significant relations at all (Li, Cooper, Bradley, Shulman, & Livingston, 2012). Problem-focused coping was generally effective in situations where individuals had control over the source of the stressful condition. The unpredictable and ambiguous nature of disease trajectory in dementia might hamper caregivers' active efforts to control and modify stressful caregiving experiences, which might explain the negative or non-significant associations between problem-focused coping and negative caregiving outcomes (Li et al.,2012).

As regards to emotional coping, wishfulness (e.g. wishing for the situation to be unreal), denial, blaming one-self for the situation, avoidance (e.g. overeating or substance use) and confrontation (e.g. venting anger toward patient) were all associated with compromised caregiving mental health (Ashley & Kleinpeter, 2008; Geiger et al., 2014; Papastavrou et al., 2011; Raggi et al., 2015). However, seeking for emotional support, positive reframing of the situation, meaning making, religious and spiritual support and acceptance-based efforts seemed to help caregivers to better cope with the disease and caregiving related realities, and were associated with positive aspects of caregiving (Jeongim, 2014; Kneebone & Martin, 2003; Li et al., 2012; Weisman de Mamani et al., 2014).

Although the differences of opinion still exist, there appears to be some agreement that coping responses had a notable influence on how dementia caregivers experience stress process of caregiving. AD caregiving process comprised of different phases giving rise to a variety of new stressors depending on the disease process. A coping strategy which was effective in the early stages might be ineffective or even harmful in advanced stages (Geiger et al., 2014; Kneebone & Martin, 2003). Investigating coping strategies was of utmost important since they were amenable to change with appropriate intervention strategies. Therefore, more research is necessary to understand which coping styles were adaptive at different stages of the disease, which factors impacted on the use of specific coping styles and how coping shaped the relation between caregiver strain and caregiving outcomes.

1.3.3. Other Factors

1.3.3.1. Type of Relationship

Whether the caregiver is an adult child or spouse of the patient seems to profoundly shape the caregiver stress process in AD. The pattern of psychological distress follows a curved line, in the shape of a reversed U, among adult child caregivers. The suffering was found to be in its mildest form after the initial diagnosis, reached the peak at moderate stages and became moderately intense at severe stages. In contrast, the psychological distress experienced by spousal caregivers gradually increased after the diagnosis, becoming most intense after the institutionalization (Marwit & Meuser, 2002). There were also differences on how adult off springs and spouses coped with the disease and caregiving process. While adult children were more likely to benefit from external and community services, spousal caregivers benefited most from emotional peer support (Lavoie et al., 2005). Additionally, spousal caregivers had a greater confidence in their caring abilities due to their age related experiences (Sorensen S, Pinquart M, & Duberstein, 2002)

The findings were inconsistent regarding which group was at a higher risk for psychological and physical morbidity. The most consistent and objective finding was that spousal caregivers had worse physical health during caregiving due to chronic and age-related medical conditions (Ott et al., 2007). However, results were contradictory regarding the negative psychological outcomes. Majority of research revealed that spouses tended to experience greater depression, burden and distress (Kim et al., 2012; Richardson et al., 2013; Sörensen et al., 2006; Välimäki et al., 2015; Waltrowicz, Ames, McKenzie, & Flicker, 1996). One study even reported that spousal caregivers were four times more likely to be diagnosed with depression and two times more likely to be prescribed with antidepressant medications than non-caregiving spouses (Joling et al. ,2010). Other researchers, on the other hand, reported that adult children were more possible prospects for depression, burden and general distress (Andren & Elmstahl, 2007; Conde-Sala et al.,2010). These researchers reasoned that multiple outside home roles that adult children handled, along with caregiving responsibilities made them feel more entrapped, thereby increasing their depression and burden (Conde-Sala et al.,2010).

The anticipatory grief and ambiguous loss experiences also differed between adult off springs and spouses (Marwit & Meuser, 2002). In the mild stages, adult children took an ambivalent position, recognizing the reality of the disease related changes and avoiding them at the same time. They usually tried to be task-oriented and sought for possible solutions. Rather than declining capacity, they spent an intentional effort to focus on strengths of the affected parent. This rational and intellectual position was replaced by intense raw emotions such as anger and frustration at the moderate stages of the disease. They felt intense grief over secondary losses such as loss of freedom and leisure activities. Their focus was usually on their own losses rather than patient related losses. Profound sadness became the dominant theme for adult off springs at the severe stages of the diseases. They yearned and longed for what has been lost and could never be the same again. They focused more on parental losses, loss of the past relationship and future opportunities with the care recipient. Interestingly, adult child caregivers, but not spouses, reported a lot of positive gains from caregiving and disease process (e.g. growing as a person, valuing intimate relationships) at severe stages of the AD. As for spousal caregivers, they did not deny or avoid the disease related changes at the mildest stages of the disease. They focused on more couple related losses (e.g. loss of companionship), rather than self-related ones. Compassion became the dominant emotion in the moderate stages where they viewed their affected spouse as “a beloved child” and tried to form a different but loving relationship. At the severe stages, however, compassion and empathy were replaced by anger and frustration in the face of impending death. They started to grieve for the self-related losses and felt confused about the prospect of being a widow in the near future.

1.3.3.2. Culture

Although Pearlin and his colleagues underlined the importance of culture in their original work, research on dementia caregiving had been mostly limited to Western caregivers' experiences for a long time (Dilworth-Anderson & Gibson, 2002; Janevic & Connell, 2001) Aranda and Knight (1997) were amongst the first to draw attention to the fact that non-Western caregivers might have different caregiving experiences as a function of culture relevant appraisals, coping strategies, and use of formal health care services.

An emerging literature has pointed out that African American and Asian dementia caregivers had lower levels of caregiver strain, depression and more positive caregiving outcomes (Chou, LaMontagne, & Hepworth, 1999; Cho, Ory, & Stevens, 2015; Connell et al., 2001; Haley et al., 1996; Ho et al., Holland et al., 2010; 2003; Ivey et al., 2012). These studies held the view that non-Western caregivers had a more positive appraisal of caregiving in dementia context than their Western counterparts. Since they were raised in cultures where devotion to family goals, respect to the elderly, family harmony and interdependence were valued, providing care for their elderly was an anticipated role in their lives. Consequently, they usually devoted financial, physical and psychological resources to provide good quality care for their loved ones (Fung, 1998; Gallagher-Thompson et al., 2000; Mahoney, Cloutterbuck, Neary, & Zhan, 2005; Min, 1995). Additionally, their spiritual and religious frameworks emphasizing finding good in painful situations and accepting what came from God seemed to help them find a higher meaning in the disease process and accept the unchangeable aspects of this illness (Lee & Sung, 1997; Napoles et al., 2010; Sethabouppha & Kane, 2005). They also seemed to find some respite from participating in public religious services during the disease process. Consistently, researchers found that African

American and Asian caregivers usually had a greater sense of mastery and competence over caregiving tasks (Connell et al., 2001; Ivey et al., 2012) Particularly, Black caregivers perceived behavioral and cognitive symptoms of the disease less stressful than White caregivers. While African Americans focused more on gains from the caregiving experience (Haley et al., 1996), White American caregivers focused on the deteriorating relationship with the care recipients and loss of freedom due to caregiving duties (Ivey et al., 2012, Janevic & Connell, 2001). Unlike the findings presented above, some researchers proposed that non-Western dementia caregivers might be at a particular risk for negative caregiving outcomes due their culture specific beliefs. In collectivistic cultures, social networks were usually expected to be activated under times of stress (Connell et al., 2001; Napoles et al., 2010; Sun et al., 2012). However, some findings showed that Asian caregivers did not receive more emotional and/ortangiblesupport as compared to their Western counterparts (Patterson, et al., 1998). Besides, they were more negatively influenced by this lack of support since they overvalued the extended kinship networks (Harper & Lund, 1990; Lai, 2009). Family disputes over care provision also place an extra burden on them due to resulting disharmony among close family members (Ho et al., 2003; Youn et al., 1999). Furthermore, underutilization of formal health care services might also pose a particular challenge for minority caregivers. Society’s belief that care provision was a family members’ obligation might lead them not to seek formal support when needed andmight delay nursing home placement (Janevic & Connell, 2001; Ho et al., 2003). This reluctance to use formal health services not only could result in exhaustion and burn-out on the part of informal caregivers, but also prevent care recipients from receiving proper medical care (Ar & Karanci, 2017).

Taken together, these findings suggested that cultural context in which informal caregiving was provided had a significant influence on caregiving outcomes for non-Western caregiver populations. Still, more research seems to be necessary to comprehend the meaning behind each culture specific appraisal and coping strategy, and resulting implications on dementia caregiving outcomes for minority caregivers.

1.3.3.3. Social Support

A considerable number of studies have been published on the relation between social support and dementia caregiving outcomes. Usually, both a direct protective and indirect buffering effect of social support on psychological well-being of caregivers was noted across studies   (Brodaty & Donkin, 2009; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Haley et al., Han et al., 2014; 1996; Heo, 2014). Nevertheless, the type of social support received and caregivers' perceptions regarding available support complicated the association and produced contradictory results (Brodaty & Donkin, 2009). Dementia caregivers did not encounter uniform stressors during the disease trajectory (Conde-Sala et al., 2010). Each stage of the disease posed qualitatively different challenges and necessitated different types of social support. To illustrate, while instrumental support (e.g. helping with house chores) and informational support (e.g. ways to handle behavioral disturbance) were more beneficial at the early stages where behavioral problems necessitated constant supervision, emotional support might be more useful in the advanced stages while caregivers' pre-death grief reactions are more intense (Conde-Sala et al., 2010). Furthermore, the effects of social support also varied depending on caregiver's gender (Connell et al., 2001, personality characteristics (Haley et al., 1996; Shurgot & Knight, 2005 and cultural context (Shurgot & Knight, 2005). Under some conditions, undesirable social support could bring more harm than benefit (Edwards & Cooper, 1988). Consequently, more studies investigating effects of different support types on different disease stages and in different cultural contexts seems important to establish more comprehensive intervention strategies.

1.4. The Scope and the Aims of the Thesis

Unpaid AD caregivers may become hidden patients who are vulnerable to a variety of physical and psychological ill health effects due to caregiving difficulties. This unpaid caregiving trend is much more common in under-developed or developing countries because of the financial restrictions and societal views on care provision. Turkey is also a developing country, dominantly influenced by Islamic values and collectivist norms. Informal caregiving of AD patients has become exponentially common over time as a result of the increasing incidence of AD and the cultural views encouraging familial care provision and the scarcity of alternative care institutions. However, there is limited formal services available to informal family caregivers in Turkey targeting unique needs of this population. In fact, informal caregiving provided substantial economic profits also to the society's budget. Therefore, social policies and formal health care services should be modified to protect caregivers' psychological and physical well-being while also ensuring optimal conditions of home care for care recipients' quality of life. In other words, intervention programs should be available to increase quality of informal caring without sacrificing caregivers' own needs. Besides, caregivers should also be encouraged to use formal care services including nursing home placement under necessary conditions through multi-component culture specific interventions. However, there has been limited research on the interrelations of disease, caregiver and contextual factors affecting both negative and positive outcomes of AD caregiving in Turkey (Atagün, Balaban, Atagün, Elagöz, & Yılmaz-Özpolat, 2014). Particularly, although well-established relations were proposed between disease related variables and caregiver outcomes, more research seems to be needed to explore the impacts of modifiable caregiver related factors in AD caregiving both in the world and in Turkey. Hence, the main aim of this study was to understand Turkish adult children caregivers' experiences of caring for a parent with AD.

1.5. Research Questions

To achieve this general aim, different data collection and analysis methods were employed, and two main studies were conducted. The first study used a qualitative approach in order to obtain a general understanding of culture-relevant caring experiences, coping strategies and caregiving outcomes in Turkey. A qualitative approach was purposefully employed to investigate the meaning behind each appraisal, coping style and caregiving outcome without enforcing any prejudgment on the caregivers' accounts. Hence, the research question for the qualitative part was determined as follows:

“How do Turkish adult children experience AD caregiving regarding appraisals, coping strategies and caregiving outcomes?”

The second study employed a quantitative methodology to examine how various contextual/background variables, primary stressors/disease-related variables, secondary stressors and moderator variables were associated with various caregiving outcomes. The predictor and outcome variables examined in this study was determined based the Caregiver Stress Model (Paerlin et al., 1990) and Model of Carer Stress and Burden (Sörensen et al., 2006), and also findings of the qualitative strand. Consistently, the main research question for the quantitative part formulated as follows:

“How do contextual/background variables (i.e. gender, education, SES, quality of past relationship with the care recipient), primary stressors (i.e. disease related factors such as stage of disease, time since onset, time since diagnosis, caregiving hours per week, length of caregiving, and co-residence), secondary stressors (i.e. subjective caregiver burden), and moderator variables (i.e. coping strategies and social support) affect depression, anxiety, grief and growth experiences of Turkish adult offspring of AD patients?”

CHAPTER 2

GENERAL METHODOLOGY

The current thesis aimed to understand the lived experiences of Turkish caregivers of parents with Alzheimer Disease (AD). This chapter was devoted to provide information on general methodology; and on general procedures applied specifically for each study conducted within the scope of the present thesis.

2.1. General Research Design

A multimethod research design was employed in this thesis in an attempt to answer the main research question of what are the unique and common experiences of Turkish caregivers of parents with AD. A qualitative and quantitative study were conducted in a sequential order. In multimethod research design, two or more interrelated studies employing different methodologies are performed within a comprehensive topic to address a general research question. The main assumption of this design is that merging qualitative and quantitative inquiries would provide a more comprehensive understanding of the phenomenon under investigation (Tassakkori & Teddle, 2003).

Multiple research design differs from mixed method research design in one major aspect. In mixed method designs, qualitative and quantitative strategies are used under a leading qualitative or quantitative orientation. Usually, either the qualitative or quantitative strategy is supplementary to the major methodological perspective, and is used to obtain clues that are investigated within the core methodology. In other words, the supplementary part does not have to follow all the assumptions of the respective methodology in terms of data collection and analysis being employed (Tassakkori & Teddle, 2003). Rather, a complimentary study is used to enhance findings of the dominant study which has followed all the methodological requirements (Cresswell, 2014; Tassakkori & Teddle, 2003). In multimethod design, by contrast, each research method is applied rigorously following all the assumptions of the respective methodology in terms of data collection and analysis to attain a comprehensive understanding. That is, although studies are interrelated and used to enhance understanding of the complete picture, each is self-contained and autonomous in terms of methodological requirements (Tassakkori & Teddle, 2003). In this regard, a multimethod approach was adopted in the current thesis to obtain in-depth knowledge regarding Turkish adult children's experiences of care provision to a parent with AD. Both of the studies met the basic assumptions of its own methodology; and later findings were analyzed and discussed together to provide a well-grounded understanding of Turkish adult children caregivers' experiences.

Among multimethod designs, QUAL→quan design was employed in this thesis, where the initial qualitative study was followed sequentially by the quantitative part. In this design, the main project is initially driven by a qualitative approach which is later followed by an autonomous quantitative study (Tassakkori & Teddle, 2003). A qualitative methodology was purposefully employed in the first study to unfold culturally relevant coping strategies, appraisals and caregiving outcomes among Turkish AD caregivers. It was thought that only administering standardized measures might fail to capture the diversity of caregivers' responses while describing the multifaceted nature of caregiver stress process. Later, the identified aspects in the qualitative part (i.e. religious/fatalistic coping and positive caregiving experiences) were used to shape the models tested in the quantitative study. Finally, findings from both the qualitative and quantitative studies were evaluated and integrated to interpret Turkish adult children's unique and common experiences while caring for an AD parent.

A multimethod research design was purposefully chosen as the most suitable method for this thesis for several theoretical and epistemological reasons. Firstly, although culture was proposed to be an important factor, AD caregiving beyond Western context has received scarce attention in the literature so far (Aranda & Knight, 1997; Sun, Ong, & Burnette, 2012). Few studies involving African

American and Asian caregivers revealed that even attributions of these caregivers for the AD symptoms significantly differed from those of Western caregivers (Hinton, Franz, & Friend, 2004; Zhan, 2014). Researchers emphasizing socio-cultural context of AD caregiving posited that values and norms regarding aging, gender roles, family rules, and interactional styles had profound influences on the appraisals, coping styles, and formal and informal help-seeking behaviors, thereby shaping negative and positive caregiving outcomes (Aranda & Knight, 1997; Dilworth-Anderson & Gibson, 2002; Minn, 1995; Sun et al., 2012). Since Western and non-Western contexts have distinct beliefs regarding these concepts (Triandis, Leung, Villareal, & Clack, 1985, Youn, Knight, Jeong, & Benton 1999), more research is needed to understand idiosyncratic experiences of AD caregivers from different cultural backgrounds. Additionally, culture is a concept more pertinent to subjective appraisals rather than the ultimate truth. This subjectivity necessitates the relative understanding of cultural dimensions from an interactional and active stand point (Aranda & Knight, 1997). Consequently, this thesis initially adopted a qualitative methodology to attain a well-grounded and in-depth understanding of Turkish AD caregivers' experiences based on their own accounts. Furthermore, studies investigating the effects of modifiable caregiver variables on caregiving outcomes are limited when compared to those examining the relations between care recipient factors and caregiving outcomes (Conde-Sala et al., 2010; Schulz, R & Martire, 2004). This lack of research is what drives this thesis to employ a quantitative methodology in a second study in an attempt to evaluate the association between identified caregiver related variables and caregiver outcomes.

2.2. General Procedure

Before application of any procedures, ethical permission was obtained from The Applied Ethics Research Center of Middle East Technical University, for each study separately. For the first study, which employed a qualitative methodology, admins of the three AD caregiver groups were contacted through the Facebook. These groups were informal support groups established by family AD caregivers to create an online space for sharing practical information and providing emotional support. In the initial contact, an informal debriefing was provided to the admins to get permission to make an announcement calling caregivers for participation in the current study. After verbal consent was obtained from the admins, an announcement stating the purpose and content of the study was posted on each group’s walls on Facebook (Appendix A). Caregivers in Ankara and İzmir who volunteered to take the semi-structured interviews were then reached through the Facebook. The time and place arrangements for the interviews were set up through Facebook messaging. Of 20 participants, 15 were interviewed at their homes because they did not have a chance to leave the home due to caregiving responsibilities. Before starting each interview, the rationale, the content and the process of the study were explained both verbally and in a written letter. Further, willingness for both participation and audio recording of the interviews was documented formally.

For the second study, which employed a quantitative methodology, the admins were reached through Facebook messaging again. For them to examine, the link disseminating the questions of the study were also provided before making the announcement. After permission was obtained from group admins, an announcement explaining the rationale and content of the study, and also notifying the link for questions were posted in each group again (Appendix B). For caregivers who volunteered to answer the online questions and who gave their e-mail to the researchers, an educational brochure was delivered through e-mail which contains information regarding common caregiving difficulties and ways to cope with caregiving stress (Appendix C).

CHAPTER 3

STUDY 1: LIVED EXPERIENCES OF TURKISH ADULTS CARİNG FOR A PARENT WİTH ALZHEIMER’S DISEASE

This chapter will present detailed information regarding research question, methodology and findings of the qualitative study conducted in the scope of the current thesis. The results of the quantitative study will also be discussed in relation to the current literature on AD caregiving outcomes. (Partial findings the current qualitative study were published in “Dementia: International Journal of Social Research and Practice”. See Ar & Karanci, 2017 for further information).

3.1. Introduction

There are major differences between Western and Eastern oriented cultures in terms of beliefs in aging, family norms and care provision; and it was claimed that these beliefs might shape caregiving process differentially across cultures (Janevic & Connell, 2001; Lai, 2009; Sun et al., 2012). Despite this, caregiving beyond Western context has become the focus of attention only recently in the current literature. Particularly, the research on appraisals, coping strategies and caregiving outcomes beyond Western context is still limited in number (Lee & Sung, 1997; Sun et al., 2012; Youn et al., 1999). Therefore, this study attempted to understand the lived experiences of Turkish AD caregivers regarding caregiver outcomes, coping strategies, and attitudes towards NHP. Particularly, it was aimed to provide a culturally relevant framework while understanding unique and common experiences of caregivers in Turkey; and to generate complimentary data for determining variables that would be tested in the quantitative strand.

3.1.1. Research Question of the Qualitative Study

How do Turkish adult children experience AD caregiving regarding appraisals, coping strategies and caregiving outcomes?

3.2. Method

3.2.1. Methodological Background

Interpretative Phenomenological Analysis (IPA) attempts to obtain a better understanding of a phenomenon as it displays itself in its natural environment. The approach was referred as phenomenological because it is asserted that a phenomenon is best understood from subjects' own personal perceptions and accounts (Smith, Osborn, & Jarman, 1999; Willig, 2008). IPA provides an in-depth description of lived experiences of subjects through language. Since the meaning of experience is conveyed through language, understanding a phenomenon inevitably involves an interpretative process (Giorgi & Giorgi, 2008). Likewise, meaning-making is a crucial component as the interpretative researcher tries to make sense of the concept under the influence of his/her own presumptions. Researcher's presumptions are challenged as the meaning evolves from participants' accounts, and these presumptions are used as tools to enhance understanding of the target phenomenon (Schleiermacher 1998; Willig, 2008). Consequently, the meaning conveyed is usually the sum of the participant's own descriptions, researcher's presuppositions and the interaction between the participant and the interpretative researcher (Smith et al., 1999).

IPA was preferred over other qualitative methods in this study because it is usually used to investigate phenomenon which is relatively less researched (Smith et al., 1999) and also takes into account the cultural context in which an experience is lived and expressed (Larkin, Watts, & Clifton, 2006). Further, it employs a bottom-up approach leaving room for the data to create and express itself (Willig, 2008). As there was scarcity of research on culture relevant appraisals, coping strategies and caregiving outcomes, IPA was chosen as the most suitable methodology in an attempt not to be restricted by any existing framework. Additionally, IPA's encouragement of an active interaction between the researcher and participants led to the use of this method (Jarman, Smith, & Walsh, 1997) since Turkish culture appreciates relatedness over a distant approach in interpersonal communication (Eraslan, Yakali-Çamoğlu, Harunzade, Ergun, & Dokur, 2012).

3.2.2. Participants

Twenty-three adult children were initially reached through 3 non-profit Facebook groups established for family AD caregivers. Two adult children were excluded from the study since their affected parent died before conducting the interviews. One participant was also not included since her schedule was busy during the research process. As a result, 20 adult children constituted the final sample. This sample size was determined to be sufficient as the saturation of categories was achieved and the data started to repeat itself.

Inclusion criteria for participation were (1) being an adult child of the patient, (2) being older than 18 years, (3) defining him/herself as an informal caregiver and (4) providing at least 4 hours of care per week. Furthermore, each patient was required to be officially diagnosed with AD by a neurologist or neuropsychiatrist.

The mean age for participants was 43.3, with ages ranging from 23 to 63 ($M = 43.3$, $SD = 11.53$). The majority of caregivers were daughters (n = 14), and more than half of them co-resided ($n = 14$) with the care-recipient. 15 % of the participants described their SES as low ($n = 3$), 55 % as medium ($n = 11$), 25 % as upper medium ($n = 5$), and 5 % as high ($n = 1$). 60 % participants had education beyond high school ($n = 12$), and more than half of them were unemployed ($n = 12$). Besides, all of the caregivers received help from another person including siblings, healthy parents or from a paid caretaker.

Adult children provided informal care for an average of 4.7 years ($SD = 3.8$). The mean hour for care provision per week was 110.90 hours ($SD = 71.92$). More than half of the patients were mothers of the adult children caregivers ($n = 12$). Information regarding care-recipients’ severity of disease was obtained through caregivers’ accounts. In that respect, while 45 % of care recipients had moderate dementia from AD (*n* = 9), 55 % had severe stage AD (*n* = 11). Table 1 presents the socio-demographic characteristics of the caregivers.

Table 1. Socio-demographic characteristics of the participants in the qualitative study

Variable	***f***	***%***	***M***	***SD***	***Range***
Gender	20				
Female	14	70			
Male	6	30			
Marital Status					
Single	8	40			
Married	6	30			
Divorced	6	30			
Education Level					
High School	8	40			
University	9	45			
Master's Degree	2	10			
Doctorate Degree	1	5			
Employment Status					
Employed	8	40			
Unemployed	12	60			
Monthly Income Level					
Low	3	15			
Medium	11	55			
Upper Medium	5	25			
High	1	5			
Time Since Diagnosis (years)			4.42	3.66	.40-14
Length of Caregiving (years)			4.67	3.79	.40-15
Caregiving per Week (hours)			110.9	71.91	4-168
Co-residence					
Yes	14	70			
No	6	30			

3.2.3. Ethical Permission

The procedures of the first study were approved by Human Ethics Committee of METU. Besides, verbal consent was obtained from group admins before contacting with the participants. The purpose of the study and the issue of confidentiality were explained to each participant verbally and in a written document. Participants were provided the chance to withdraw from the study on request on any time. Additional permission was also taken for the audio-recording. Consent both for participation and recording was obtained in a written format, subsequently. Besides, information revealing the identity of the participants was changed during the transcription and while giving quotations to demonstrate the results.

3.2.4. Procedure

Purposive sampling was applied while selecting the appropriate candidates for the interviews since it is the most preferred sampling strategy for IPA research. In purposive sampling, participants are selected intentionally according to the relevant criteria, which are developed based on research interest (Smith & Osborn, 2003; Willig, 2008). It aims to reach people sharing similar experience of a situation, event or fact, thereby creating a homogenous group (Willig, 2008). Herein, the homogenous group of participants refers to the people of similar experiences of a phenomenon under investigation (e.g. women suffering from fibromyalgia, female breast cancer patients with children).

Based upon the basic IPA principles, 10 open-ended questions were developed for the semi-structured interviews (Appendix D). Substantial attention was paid to form non-directive questions in order to allow caregivers to describe their own experiences without being restricted (Willig, 2008). Having obtained the permission from admins, an announcement for recruitment was posted on the walls of each Facebook groups. Arrangements of interviews were performed through Facebook messaging with caregivers fulfilling inclusion criteria. Interviews were mostly conducted in caregivers’ homes as they simultaneously had to care for their affected parents.

Having explained the purpose of the study and obtained written consent, each interview started with demographics and a general question to facilitate interaction with the caregivers (i.e. what are the first symptoms did you notice?). The duration of interviews ranged from 50 minutes to 90 minutes, with an average of 54 minutes.

3.2.5. Data Analysis

All interviews were audio-recorded, and later transcribed verbatim by the researcher (AR) consistent with the IPA principles. A computer program (Maxqda) was utilized while managing and analyzing the obtained data (Verbi Software, 2005). The researcher examined accounts repeatedly to become familiarized with the texture of the data before starting the analytic process. Further, notes about language, content and researcher’s observations were documented, which were later used to make sense of the participants’ accounts (Touroni & Coyle, 2002).

IPA necessitates an idiographic approach whereby each case is examined in detail before moving on to analyze the other one (Smith, 2004). Accordingly, analysis started with a throughout examination of the first case, and possible sub-ordinate and super-ordinate themes were formed on a list for this case alone. Later, these themes were compared with the transcribed accounts repeatedly to ensure the conceptualizations reflected the participants’ natural accounts. After the case examination of the first case, the same analytic process was applied for the second one and this analytic process was repeated for each individual case. Subsequently, cross-case comparisons were performed by the researcher until a master theme list was established.

To enhance credibility of the study, a research team was formed to contribute to the analytic process at different levels. Apart from the researcher (AR), a clinical psychologist who has expertise in qualitative research performed the analysis for 10 randomly selected cases. Upon the formation of super-ordinate and sub-ordinate themes independently, these two researchers met together to discuss conceptualizations of the recurrent themes. Finally, the thesis advisor (Karanci) audited the master theme list until it took its final form.

3.2.6. Reflexivity

Qualitative research acknowledges the subjective nature of data collection and data analysis. It does not aim to eliminate subjectivity. Rather, subjectivity is used as another source of data while interpreting the target phenomenon (Patton, 2002). According to IPA, researchers' own conceptions impact on research process in two ways: one is through the interaction with participants and the other is through the making sense of participants' natural accounts. Since it is inevitable for a researcher to become an active part of research process, *researcher's reflexivity* is a necessity while collecting, analyzing and presenting the data (Willig, 2008).

Researcher's reflexivity does not simply mean being aware of one's own "biases" during the research process; rather it encourages researchers to actively think about how they shape the research process and how the research process changes their perspectives on the subject matter (Willig, 2008). In that regard, the researcher (Ar) would provide background information about the researchers (Ar and Karanci) below:

"I am (Ar) a 28 years old female clinical psychologist and currently doing my PhD in Turkey. My religious background is Islam. Although I cannot describe myself as a devotee, I try to fulfill cultural rituals associated with Islam. I first encountered with a chronic disease at the age of 5, when my paternal grandfather was diagnosed with renal failure. He has gone through intensive medical treatment and most of the time I accompanied him and my grandmother during the dialysis sessions. Then in 2011, my maternal grandfather was diagnosed with moderate stage AD, and my mother started to provide care for him. During the first years of the disease, I experienced a double grief both for my grandfather and for my mother. It was a strange situation watching my strong and supportive grandfather becoming like a bad-tempered child. I also felt profound grief and sadness for my mother because she has lost all her freedom.

As a clinical psychologist, I always have an interest in the experiences of patients with chronic illnesses. Specifically, I have worked with breast cancer patients, children with cancer and relatives who have lost their loved ones due to chronic diseases. I believe that my personal and professional relatedness with AD and other chronic illnesses helped me establish a strong rapport with the participants during the interviews. In that regard, I think that I managed to have an insider's perspective to some extent. Apart from that, I use some religious and cultural phrases when appropriate (e.g. *geçmiş olsun, hayırlısı olsun)* because all of the participants verbalize such phrases during the interviews. I think that this cultural relatedness also provided some transparency and genuiness between me and the caregivers.

During the data analysis and auditing, what I realized by the comments of my supervisor was (Karanci) that I usually had a tendency to focus on the negative changes and losses. During our discussions, I acknowledged that AD caregivers see the silver linings of caregiving situation as well, and are not very much dissatisfied with their situation due to their religious beliefs and their affectionate relationships with the care recipients.

My thesis advisor, Prof. Dr. A. Nuray Karanci, is a senior clinical psychologist who has worked over many years with the families of patients with schizophrenia and trauma survivors. She has a special interest in the transformative power of negative life events and specifically on the phenomenon of post-traumatic growth. Thus, she has a special sensitivity to hearing positive changes as a result of struggling and coping with adversity."

3.3. Results

Six recurrent themes were identified across 20 cases which were (1) etiology of the disease, (2) changes and losses, (3) coping strategies, (4) factors helping or hindering caregiving process, (5) unique nature of the disease and (6) reluctance for institutionalization, respectively. For each super-ordinate theme, concrete quotations from caregivers' accounts were also provided. Additionally, Turkish idioms and cultural phrases were given in parentheses in order to provide accuracy in translation.

3.3.1. Etiology of the Disease

Caregivers believed that psychosocial factors lead to disease progression however biological and environmental risk factors (e.g. genetic transmission, head trauma, alcohol consumption) were also seldom addressed in their accounts, as well. They stated that negative familial experiences including adult children's tragic life experiences, domestic violence, and problematic parent-child relations triggered the disease formation. Some caregivers either blamed themselves or other family members for causing to the disease development:

> Let me tell you this way, my younger and older brothers were involved to some incidents, my mother was profoundly affected by them. Mom became very upset because of them, she secretly ate her heart (i.e. *içten içe kendini yiyip bitirdi*). My younger brother fell into a boiler at the workplace, his left arm was burned, mom was very upset. Those depression, troubles, stresses caused by them (his brothers) …I think this is the most important reason.

Adult children believed that some personality characteristics did also contribute to the development of AD. Being apprehensive, nervous, competitive and not being at peace with oneself were repeatedly mentioned in their accounts as prior personality characteristics responsible for the onset of the disease. It seems that caregivers were frustrated and disappointed as they believed their parents could have controlled the disease formation. For example, a 31-year-old female kindergarten teacher described her mother's situation as follows: "I think this is all psychological. She always found something to criticize, she was always on edges. She brought work to our home. She was never at peace. She caused this herself"

Particularly, adult off springs whose mothers were diagnosed with AD reported that being submissive, suppressing negative affect and prioritizing the needs of others could also lead to disease formation. These caregivers believed that "being nice and silent" in the past resulted in accumulation of stress over time, thereby increasing the risk for this disease. A 28-year-old son explained that: "My mother doesn't explain anything easily, she did not share anything with someone easily, she kept everything to herself (i.e. *herşeyi içine atardı*). That might have triggered the disease."

Although less emphasized, adult children caregivers also gave credit to physical and environmental risk factors in the formation of this disease. These factors included past head traumas, genetic transmission, being mentally inactive in the past and alcohol consumption.

3.3.2. Changes and Losses

Change of the relationship between the caregiver and affected parent was the first sub-category of changes and losses. Adult offspring initially expressed a deep sadness and grieving upon the loss of parental care, affection, support and mutual communication that they once received as a child from their parent. A 31-year-old female research assistant who provided care to her mother expressed that: “I will never have a mother-child relationship again (crying). I cannot communicate with her, cannot talk with her. You need your parent to share the most intimate things, but I do not have such a parent. I feel alone (crying).” Adult children also emphasized that lack of recognition as the most agonizing aspect of the disease. They stated that they felt shocked, disappointed, sad and lonely. For example, a 34-year-old son told that “Even I told him I –as your son- will go into jail tomorrow; he would remain unresponsive. He might say ‘come back immediately’ He does not see me as his son. Think that your father does not recognize you…Painful…”

Role reversals were also notified by almost all adult child caregivers as an indicator of the change in their relationship with the care recipient. They described their parents as a “little child” demanding constant care and attention. Adult offsprings defined themselves as “a mother, father or an older brother to their affected parent” providing nurturance and protection unconditionally. They also stated that they learned not to expect anything from their parents “since someone cannot expect anything from a child”. A 23-year-old daughter expressed those role-reversals as follows:

> I hide behind my mother always; she was very strong, authoritative. When my peers bullied me at school because I was fat, I called her to protect me. After she started to get sick, she became weaker and weaker. Now, she hides

> behind me if she is frightened, I protect her. Roles have changed. She is my little child now.

Another son gave a similar account and stated that “When someone asked me how many children do you have, I am answering three now. When I bought chocolate for my sons, I bought one for him (his father), too. It is easier this way”.
Interestingly, although adult children expressed sadness and disappointment due to the parental losses, they also described a new relationship pattern with their parents, which seems more affectionate, intimate and fulfilling than the past relation they had. They explained that their parents became more peaceful, tame and easy-going due to the disease-related personality changes. They were especially happy with the fact that their parents started to exhibit affectionate behaviors more frequently such as hugging and kissing. They expressed joy over their parents’ overly attached behaviors such as “only eating their meals from their hands” Caregivers also stated that this disease had given them a chance to have a more intimate and closer relationship with their parents. They shared more time with their affected parents and tried to seize the moment:

> Although we loved each other deeply, we had a troubled relationship. My father was very angry because I was married with someone he did not approve. I was also impatient and intolerant. He was always very impatient as a person, as well and never tried to understand me. He minimized my problems and we argued a lot. Now, we are a lot better than before (laughing). He is very compliant and easy-going. In the past, he became angry because I did not have breakfast with him. Now, we had every breakfast together. He opens his mouth and expects me to feed him like a child (laughing). I just like to see he is happy now. I am happy now, as well.

Change of the parent’s personality was the second sub-category which seems quite related with the change of relationship sub-category. Prior to the diagnosis, adult offsprings described their parents as “dominant, authoritative, distant, rigid and stubborn”. However, they usually described a positive personality change in their parents after the disease such as being more compliant, easy-going, friendly and calm:

> My mother was married with a man who deeply loved her. She was the queen of my father! She was used to getting attention from everyone. But she was also very authoritative. She was pressurizing even her own children. After the disease, she always says good things towards others, like thank you and may God bless you (i.e. *Allah razı olsun*). Now she is more much more positive towards everyone (laughing).

Never-ending losses was the third sub-category of the changes and losses. Caregivers expressed that witnessing their parents' losing their skills, abilities and identity day by day was heartbreaking, painful and wearing (i.e. *yıpratıcı*). They knew "the inevitable end" was approaching each day and there is nothing that they could do to change this situation. They felt as if their parents had been leaving this world a little each day as they lost contact with their environment progressively. They felt profoundly helpless in the face of a gradual deterioration. A 43-year-old daughter caring for her mother expressed that "It is not easy to watch deterioration of someone you love every day. You want to wake up from this nightmare, but you can't." Another daughter who was 58 years-old expressed similar feelings and described the situation as "as if mom is slowly slipping away from my hands and I can't do anything to prevent this". Gradual loss of functional and cognitive capacity (e.g. loss of ability of bathing/eating, profound memory lapses) coupled with the fading of past identity also resulted in yearning, sadness and longing among caregivers. They described the situation as if the actual death had already occurred while the patient was still alive:

> You are losing every day. It is something like death. You feel the pain constantly. For a moment, you become cheerful, but then everything fades away. She forgot all of her habits like eating, bathing, slowly. We lost her mentally and psychologically. Others said 'she looks at you, she still knows you', but this is not the case. Mom has already left us (i.e. *annem bizden çoktan gitti*).

Psychological changes were the fourth sub-category of changes and losses super-ordinate theme. Almost all caregivers stated that their physical and psychological well-being was significantly compromised due to extensive caring responsibilities. They stated to suffer from poor quality sleep, depression and anxiety symptoms. Their life was centered mainly around their parents' condition. A 49 years-old daughter caring for his father stated that "I have to arrange everything according to him. My mind is always busy. I have to follow him constantly whether he is awake, hungry, walking in the balcony…I cannot leave the house even for shopping”. Almost all the caregivers mentioned losing their freedom and not finding time for their social interests. They also believed that the loss of social life and freedom was a necessity to manage the caregiving responsibilities:

> Well… How can I tell? This disease literally said to the caregiver that ‘I am AD. You have to arrange your life in accordance with me. If you don’t, I will ruin you’. Now, I really know the meaning of every movement that my mother will make. I know she will go to the kitchen and jumble up all the tools when she gets up from the sofa. I get used to these. I gave up my own life to care for her because there is no other way. This disease dictates this.

Changes in close family dynamics due to conflicts arousing from sharing of caregiving responsibilities was also stressed out by the caregivers. Adult children resented and felt disappointed as they did not receive enough practical and social support from extended family members. They thought that they had no choice but to perform caring duties due to their relatives’ non-constructive attitudes. They complained about being left alone with their affected parents. Specifically married daughters mentioned that they started to have conflicts with their husbands as their husbands complained about the time they spent on the caregiver role:

> I broke up from my husband and there is nothing worse than this. At first, we together sought ways to solve the problem. However, my discomfort and my mind being always busy with my mother’s illness led my marriage to end. My husband couldn’t tolerate this. My siblings did not protect me (i.e. *kardeşlerim bana sahip çıkmadı*). Now, I took care of them (her mother and father), stayed with them. Thanks God they are receiving good care now (i.e. *çok şükür şimdi iyi bakılıyorlar*).

The final sub-category of the changes and losses theme was positive changes reported by the caregivers. Adult offsprings explained that they learned to be patient, tolerant and flexible towards people as they provided care to their parents. Indeed, they underlined that “there is no choice but being patient” since things became irreversibly harder each day. A 48-years-old daughter caring for his father expressed this positive change in herself as: “I was very impatient before. For example, I was very finical and intolerant. I was a free-spirit. I even did not drink water from my father’s glass. Now, I don’t care, I am relaxed, we are both happy”.

Caregiving process also enhanced self-efficacy beliefs among adult children caregivers. They realized that they could be achievers under difficult conditions since their coping skills were enhanced as a result of finding practical solutions for the patient related problems. To illustrate, a 40-years-old daughter stated that “In fact, I am not the kind of a person who could take care of someone. I was thinking like that before. I thought I was fragile physically and psychologically. But later, I see that I can manage difficult conditions like this”. Caregivers also stated to gain a new perspective of life. They believed this experience was “unique and transformative”. Disease and caregiving processthought them” life is not all about laughing and playing” (i.e. *hayat sadece gülmek oynamaktan ibaret değil*). They learned to “appreciate life” and “seize the moment” as they realized “anything can happen anytime to anyone”. They also stopped worrying about daily hassles as they came to face “the realities of life” with this disease.

3.3.3. Coping Strategies

Religious/fatalistic coping seems to help adult children cope with the realities of disease and caregiving process. They accepted “what is given by God” and described their current situation as a “mortal trial” (i.e. *imtihan*). They spent effort but left the rest to e God. They stated that “God gave malignity for a reason” and “there was benevolence in every malignancy” (i.e. *her şerde bir hayır vardır*). To exemplify, a 44-years-old daughter caring for his father stated that:

> I accept the situation and calm myself down by saying that ‘this was given by God, this is my trial in this world, things were supposed to happen this way’. I am not fussing around (i.e. *ortalığı velveleye vermiyorum*), I am not questioning. I just accept and look for what could be done right now. God knows the best.

Adult children caregivers also believed that “only Allah (God) could heal their parents”, if there was any solution. So, they prayed to God and performed salad (i.e. *namaz kılmak*) for him. They also read verses from Quran to find inner peace and to ease the symptoms of their parents:

> We had a strong faith in God, and I trusted my God whole-heartedly. It has been six months since I covered my head (i.e. *başını kapatmak*). I fondly

> fulfill all my religious duties, I perform ablution and namaz. When I feel suffocated and my mother's condition gets worse, I read my Quran. It benefits both me and my mother. She calms down and I feel relieved.

Şükür (i.e. expressing gratitude to God) was frequently mentioned in caregivers' accounts. Even adult children caring for a parent with severe stage AD felt gratitude towards God as their parents' condition could be much worse. They were grateful that their parents were not cognitively and physically as incapable as the other patients they heard of. To illustrate, a 63-years-old son providing care to his bed-ridden mother stated that "Thanks God (i.e. *Allah'a şükür*), she is not dependent on a breathing machine. Eventually, there are a lot of AD patients who have to spend rest of their life on a machine. My mother is at a better situation compared to them".

Problem-focused coping was also reported as an another way to handle disease-related problems. Caregivers tried to focus on what could be done to improve current situation, rather than dwelling on the unchangeable impacts of the disease. For example, a 40-years old daughter having a mother with severe stage AD conveyed that "I am trying to do my best. Instead of stressing difficulties, I think about 'what could I do?', and try to find the best solution". Caregivers also tried to develop practical solutions to physical impairments and behavioral problems of their parents (e.g. using a chair while bathing the parent; distracting attention when the patient insisted on something) to ease the caregiving process. Further, they searched for medical information related to the disease trajectory in order to be prepared for the disease-related changes and find appropriate solutions to patients' problems.

Accepting parents' disease-related limitations and handicaps was another coping strategy reported by adult children caregivers. Adult children caregivers thought that "dramatizing the situation" would only complicate this process. They tried to attribute personality and behavioral changes to disease progression. As they accepted the fact that their parents' actions were not intentional, their tolerance increased, as well. Although it was hard to accept initially, they knew the lost capabilities were irreversible and the situation would not change. To illustrate, a 37-

years old daughter explained that “you can’t be angry to a baby. AD patient is also a baby. Just think that ‘he would have never done this if he was healthy, then it is easier”.

Different forms of support were also used by caregivers as ways to facilitate physical and mental well-being during care provision. Caregivers benefited most from the instrumental support they received from their siblings, spouses and/or their non-dementing parents. One example for instrumental support was the physical help received from others while bathing, dressing and feeding the patient as these tasks require stamina from the caregivers. Besides, relatives’ taking parents’ responsibility for short durations during the day provided adult offsprings an opportunity for respite and fulfilling their own emotional and social needs. However, they also emphasized that although some help was available, the burden was still on their shoulders. A 57 years-old-daughter taking care of her mother explained the benefit of instrumental support as “This disease is not something you can handle alone. The fact that I had my sister, the fact that we share the burden… It helps a lot”. Similarly, a 26-years-old son told that:

> Since the onset of the disease, mom has not been getting along with my father. So, I am taking care of here. When I feel suffocated, I have a break for half an hour and my dad takes care of her during these times. I go for a walk. But, I take care of her for 24 hours a day.

Adult children also utilized emotional support as a resource for relief when they felt stuck in the caregiving role, and transitions related to the disease progression occurred. They usually shared their feelings with their children, close friends and, sometimes with their siblings and husbands. They believed that “things would be much more difficult” if these people did not support them psychologically.

As an other way to cope with caregiving stress, caregivers found different distractions including “solving puzzles”, “surfing on the internet”, “concentrating on their jobs”, “painting”, “watching series through internet”, “learning a foreign language” and “travelling without the patient”. These distractive activities helped “clear their minds” and “makes the intolerable situation more tolerable”. For example, a 40-years-old daughter caring for his demented mother told that “Since I pressurize and sacrifice myself a lot, I am trying to indulge myself more. As I thought ‘I shouldn’t lock myself to the house’, I started a painting course. When she sleeps, I am also trying to learn Italian myself. I try to reward myself in a way”.

Adult children caregivers also employed avoidant-coping strategies to cope with the feelings evoked by the disease progression. They felt anxious and afraid when they focused on “what the other day will bring” regarding disease-related decline. They intentionally refrained from thinking about the advanced stages of the disease and up-coming death. To illustrate, a 43-years-old female whose mother had advanced stage AD expressed that “I avoid taking her to the doctor in fear that if the doctor says ‘the disease has progressed’. I know she is not good, but I don’t want to know. I don’t want to think about the last stages”. Similarly, a 26-years old son said that “We will see. But thinking about what we will become in the future makes me nervous. I try not to think about it”. A 62-years-old daughter with a moderately demented mother even stated that she wished to die before her (her mother) as she did not want to experience the very last stages of the disease.

3.3.4. Factors Helping or Hindering Caregiving Process

Several personality features seem to ease dealing with the cognitive and behavioral symptoms of the patient, and extensive caregiving demands. Adult children caregivers consistently reported that being a patient, compassionate (i.e. *merhametli*), helpful, responsible, and non-complaining person increased their tolerance towards the patient. They described AD as a disease requesting persistent care irrespective of caregivers’ own emotional and physical well-being. This process was also complicated by the behavioral symptoms (e.g. agitation, obstinacy) developed in response to the disease progression. Caregivers admitted that, “from time to time”, they felt angry, frustrated and resented as their parents shouted repeatedly or refused to eat. According to their accounts, handling these symptoms effectively necessitated “a strong psychology” on behalf of the caregiver. In that sense, they believed their personality features helped them regulate their negative emotions towards the patient, and provided them physical and emotional endurance over long periods of time. To illustrate, a 38-years-old son explained that:

> Being a tolerant and patient person helped me a lot while taking care of her (his mother), because she might ask a question ten times. She might demand anything at any time. For example, you want to sleep, but she wants to eat. You have to take care of her whenever she wants something. You don't have your own schedule. You should adapt to her.

Another 48-years-old caregiver gave a similar account on how her "agreeable" personality helped her to provide good quality care for her father:

> He is sick and I have to take care of him. Although I am a very patient and compatible person, there were times he tested my tolerance hardly. Eventually, I am a human being and I also have some personal borders. As I treated him with anger, I felt guilty then. Thanks God, I have always been a patient person throughout my life. I tried to be gentle towards him, my patience helps me tolerate his behaviors. I calm myself down. As I persist and be nice towards him, he accepts what I want eventually.

Further, caregivers believed that being domestic and less socially active simplified this process as they were usually home-bound due to the extensive caregiving responsibilities. They felt they alienated from the "outside world" as they could not participate in outdoor activities. They sometimes could not find time even to read newspapers or watch the news during a day. To illustrate, a 63 years-old son told that "Since I am a domestic person, I get used to it more easily. However, my wife was spending most of her time outside the house before this disease. It was more difficult for her to get accustomed to the situation".

Another factor aiding caregivers to provide care in a more empathetic and tolerant manner was the quality of the past relationship with the care receiver. Adult off springs stated that having a mutually responsive and loving relationship before the disease helped them endure through long-lasting caregiving demands. A good past relationship also provided motivation to assume the caregiver role:

> Initially, my love towards mom helped me a lot. I was the youngest child and I did not have any responsibility until then. Not having a goal in my life and my love towards her led me to take her responsibility. I believed in

> myself that I could achieve this. I do not have heart to hurt her. I have an indescribable love towards her. That is what gives me strength to carry on.

By contrast, caregivers having a conflictual relationship with the affected parent in the past experienced anger towards the patient and rebelled at having to be a caregiver. A 40-years-old daughter explained this situation as follows:

> That is very hard for me. My mother never treated us with love, there is no love between us. Therefore, I think as if I was taking care of a stranger. My mother was not a person who deserved to be taken care of, she didn't fulfill her motherhood duties towards me. She was behaving as if I had been the child of another person. So, I am angry at her. So, I cannot say 'poor mom'. Looking at the past, I am asking myself continuously 'why I am here?'

3.3.5. Unique Pathology of the Disease

Caregivers reported that unique pathology of AD made the caregiving and disease process itself unique, as well. Caregivers reported that cognitive changes associated with the disease had a distinct nature when compared to other diseases like cancer. Some caregivers thought that parents' not having an awareness of their current situation due to the cognitive decline is a chance for them. Caregivers found comfort in the fact that their parents are not suffering at a conscious level. They believed that AD is a "lesser evil" (i.e. *kötünün iyisi*) when compared to other diseases like cancer, in which patients are aware of their terminal situation. For example, a 38-years-old son told that "This disease is like a puzzle. In fact, I know this disease will end with tears, the end is death. But at least, he (his father) is not aware of his suffering, like in cancer, there is a process in this". Similarly, a 57-years-old daughter caring for her mother expressed that:

> This is a bizarre disease. How can I say? I see her becoming like a child each day and I can assure myself that 'she is not in pain'. That is what comforts me. If she suffers from another disease…That would make us suffer more. Her inability to understand comforted us.

By contrast, other caregivers believed that parents' not being aware of the situation and not being able to communicate with them caused an enduring sadness, and made the process exponentially painful. They also commented that this disease is much more painful than cancer as the death process is gradual. To illustrate, a 26-years-old son told that:

> This is such a disease I even do not wish for my enemy. I have never thought that my mother would be in such a situation. Sometimes I wish she had cancer in that she could at least be mentally capable, understand what is going on, we could communicate, she could understand what I say. But now she is unable.

Behavioral problems displayed by the patients also posed a specific challenge for the adult children caregivers of AD. These problematic behaviors evoked conflicting emotions like sadness, anger, guilt and frustration on behalf of the caregivers. They described the

situation of not being able to sooth their parents as a state of complete helplessness. A 26-years-old expressed that:

> Words are not sufficient to tell you what we have been through. Lately, I took her (his mother) to the hospital. She caused quite a stir in the bus (i.e. *Otobüsü ayağa kaldırdı*). Then we entered the hospital, a temper tantrum began. Believe me, I just could not manage to get her into the hospital. I chased her around the hospital until my uncle came. She calmed down a little when he came. Managing this disease is very difficult. You should experience it in order to understand.

3.3.6. Reluctance for Nursing Home Placement (NHP)

Turkish adult off springs usually opposed the idea of placing their affected parent in a nursing home facility. They evaluated NHP as an “immoral” and “unethical act”, and perceived this decision as an “issue of conscience”. They considered NHP as being equal to abandoning the patient in his/her own while the children of these patients were still alive and healthy. To illustrate, a 37-years-old daughter responded to the question of “Have you ever considered placing your father in an institution?” as follows:

> I have never thought about it and I will never think about it. I do not find it ethical. My grandmother had also AD and my mother took care of her till death. You think him as a baby and teach him to live. You cannot throw away the person in his most difficult times as if he was nothing, this is not moral. It is a matter of conscience, as well.

Adult children caregivers did not consider NHP as an option also because they believed that it was their responsibility to provide care for their demented parents. Their parents provided love, nurturance and protection to them while they were children. Hence, they believed it was their turn to meet the physical and emotional needs of the affected parent. In other words, caregivers provided care as a means to reciprocate the love once they received as a child from their parents. In that regard, a 50-years-old daughter expressed her motivation for the continuation of home care as follows:

> I think in this way, for example I was putting on her (her mother's) socks yesterday. I thought 'once we were children, we did not know that whether we were cold, and she put on our socks'. This always comes to my mind, I feel the love, now I am doing the same to her as a child.

Caregivers also provided care as a way to show respect towards their parents, and to pay their moral debt as a child. For example, a 55-years-old daughter providing care to her mother stated that "If I do not provide care to my own mother, shame on me as a child. Likewise, a 26-years old son told that "Looking after my parents, obeying them is very important for me. They have a different place in my heart. I have never been disrespectful towards them. Putting her there is not appropriate for me."

Another reason why caregivers did not prefer NHP was caregivers' putting themselves in their parents' shoes as they (caregivers) were parents themselves. They had children, as well and they did not want to be "thrown away" by their own children. They showed empathy towards them by imagining themselves in need of intense caregiving in the future. For example, a 48-years-old daughter caring for his father believed that "there is no guarantee that I won't be in his position one day". Alike, a 34-years-old son caring for his father told that "One day I will be old, as well and I also have two children. Such a disease could also happen to me. If my children put me in a nursing home, I wouldn't like it".

Adult offsprings also showed reluctance towards NHP as they evaluated conditions of nursing home facilities in Turkey as poor. They were negatively influenced by the media representations of such facilities, in which elder people were neglected, and even abused by nursing home staff. Some also had negative experiences with these staff personally in the past. For example, a 31-years-old daughter expressed her unwillingness to place her father into a nursing home as follows:

> In fact, I thought about this option a lot. I was not completely opposed to this idea…But you hear a lot of things and you watch TV, they (nursing home staff) show violence towards them, or they make patients sleep all day. I don't know, you cannot trust them under these conditions. Now, we do not think about this option anymore.

Finally, few caregivers explained that their relatives and neighbors might despise them if they put their affected parents into a facility. They believed Turkey is not a country that could tolerate such an act of an adult child. For example, a 58-years-old daughter taking care of his father complained about the neighborhood pressure she felt as "We are not European, family ties end there around the age of 15-16, that is not the case here. My relatives will not understand this".

3.4. Discussion

This study was set out with the aim of exploring Turkish adult children's experiences of caring for a parent with AD. Although, studies examined ethnic, racial and cultural differences in AD caregiving among African Americans, Hispanics, Latinos and Asians, they usually sampled minority caregivers living in the USA (Haley, Gitlin, & Wisniewski, 2004; Hilgeman et al., 2009; Schulz & Martire, 2004, Sun et al., 2012). Accordingly, the differential patterns revealed by these studies might also be accounted by the acculturation process and minority status (Ho et al., 2003; Youn et al., 1999). Thereby, there is a gap in the literature regarding research exploring AD caregiving process beyond Western contexts. To our knowledge, the current study is one the few studies examining caregiving appraisals, coping strategies and caregiver outcomes beyond Europe and USA. Six super-ordinate themes were identified from the data obtained from semi-structured interviews conducted with 20 Turkish adult children caregivers: (1) etiology of the disease, (2) changes and losses, (3) coping strategies, (4) factors helping or hindering caregiving process, (5) unique pathology of the disease and (6) reluctance to NHP.

3.4.1. Etiology of the Disease

The current study found that Turkish adult children caregivers favored psychological factors in the development of AD although they also seldomly mentioned the role of biological and environmental factors. This finding is in accord with the former studies highlighting that minority caregivers uttered “folk terms” (e.g. pressure, being worrisome, evil’s business) more frequently while describing illness perceptions, whereas White-Americans made more emphasis on medical explanations (Chi-Chan, 2011; Gilbert, Bhundia, Mitra, McEwan, Irons, & Sanghera, 2007). One interesting finding of this study was that adult of springs strongly believed that stress caused by past family conflicts had a major role in the etiology of the disease. Their parents suffered agony from adult children’s tragic life experiences (e.g. accidents, divorce, imprisonment, death), domestic violence and conflictual relationships with adult children, which in turn resulted in disease formation. A possible explanation for this finding might be the importance given to family harmony in cultures where collectivistic values are more dominant (Triandis & Suh, 2002). In collectivistic cultures, respecting group values, maintaining in-group harmony and interdependence are appreciated over the individual goals and achievements. Consistently, protecting family harmony and integrity is an important goal in these contexts (Jones, 1995; Triandis, Leung, Villareal, & Clack, 1985; Youn et al, 1999). Therefore, Turkish adult children might think that their parents experienced a unique and profound burden due to the negative experiences they had with family members. Further, Turkish caregivers either blamed their siblings, healthy parents or themselves for being responsible for disease development. One possible implication of blaming others for causation might be the fact that caregivers refrain from seeking social and tangible support from family members. Alternatively, blaming themselves might increase the feelings of guilt that may result in self-sacrificing care behaviors and unwillingness to use formal help on the behalf of caregivers as devotion to family is an already valued behavior in our culture.

Another finding related with the etiology of the disease category was the caregivers' belief upon the role of past personality features in disease causation. Turkish adult children believed that being competitive, worrisome and tense could lead to accumulation of stress over time, consequentially resulting in AD. A possible explanation for this finding might be related with the conceptualization of negative personality attributes in Islam. Islamic beliefs presented being worrisome as a trait inflicted by evil to dissuade God's serves from the right path, which results in negative experiences in one's life. Further, being covetous and competitive were conceptualized as the traits of the essence (i.e. *nefis*) that should be controlled as a faithful Muslim to promote positive life outcomes (Seyyar, 2010). Consequently, Turkish caregivers might associate negative attributes of patients' past personality with the disease experience. Yet, this perspective might carry the danger of stigmatizing the affected parent. Besides, it might also reinforce caregivers' belief that parents could have prevented disease development by changing these traits.

Additionally, caregivers caring for their mothers emphasized that being emotionally suppressive and displaying self-sacrificing attitudes might be related with disease formation. Eastern cultures promote non-complaining attitudes (e.g. emotional suppression, being submissive) among women in order to settle down the conflicts and disagreements in family context (Jones, 1995). Hence, this culturally appreciated attitudes described as responsible for the disease formation might take the responsibility away from the care recipients, and could account for the affection and compassion shown by caregivers towards their affected parents.

3.4.2. Changes and Losses

Caregivers expressed sadness, disappointment and yearning upon the loss of mutual communication, parental protection and loss of their status as the child of the affected parent. They longed for the past identity of the care recipients and past relationship quality, and suffered from negative psychosocial outcomes due to disease and caregiving process. Turkish caregivers also emphasized that they had lost their freedom to engage in recreational activities due to profound caregiving responsibilities. These findings were in line with the previous studies indicating that such changes and subsequent losses were evident across caregivers of different race, ethnicity and cultural background (Ablitt, Jones & Muers, 200; Connell et al., 2001; Frank, 2007; Harris et al., 2011; Mesuer & Marwit, 2001; Romero, Ott & Kelber, 2007).

Nevertheless, what is surprising was that Turkish offsprings evaluated disease-related personality and relationship changes in a positive light, after they ventilated on the losses. It seems that caregivers' child-like state evoked affection and compassion among Turkish caregivers. Besides, they reported to establish a different, but more intimate relationship with care recipients during the caregiving process. Positive changes in caregivers were also noted consistently reinforcing the interpretation that Turkish adult offsprings perceived this process as a learning experience and derived satisfaction from their role. These results seem to be consistent with other research findings which found that positive caregiving experiences were more noticeable among non-Western caregivers (Connell et al., 2001; Hebbert & Schulz, 2006; Heo, 2014; Ivey et al., 2012). Particularly, while Western caregivers' emphasis was more on negative feelings, reduced relationship quality and restricted social activities (Ivey et al., 2012, Janevic & Connell, 2001), minority caregivers pronounced gains more frequently (e.g. deriving satisfaction from care, increased mastery, newly established intimate relationship with the patient) from disease and caregiving process more (Haley et al., 1996). This notable difference between Western and non-Western caregivers might be accounted by the fact that caregiving is a socially and culturally valued practice in some non-Western contexts (Ho, et al., 2003; Lai, 2009). Accordingly, such values might provide minority caregivers a stronger justification and motivation for AD caregiving (Dilworth-Anderson & Gibson, 2002). Coupled with the cultural rewards associated with care provision to a family member, Turkish caregivers might be perceiving the silver linings of this experience more readily. Another explanation for this difference might be related with the previous findings revealing that non-Western caregivers might have a greater social support system easing the caregiving burden (Gupta & Pillai, 2000). Finally, some religious beliefs of non-Western caregivers might facilitate acceptance of the situation and lead caregivers to reframe stressful caregiving process as a positive experience (Heo, 2014).

3.4.3. Coping Strategies

One of the most notable finding was related with the role religious/fatalistic coping played on the adaptation of caregivers to the disease and caregiving process. It was evident that the Islamic teaching, every unfortunate event harbors opportunities and benevolence, seem to have helped caregivers to evaluate disease-related changes in a positive way. Although they tried their best at caregiving, they left the rest to the God's hands and hoped for the best outcome. *Şükür* (i.e. expression of gratitude to God) was also frequently mentioned in their accounts. Rather than rebelling against the situation, they accepted the situation as it was, which seem to ease adaptation to the unchangeable aspects of the disease trajectory. Further, Turkish caregivers performed religious rituals like salad and reading Quran as a way to relieve caregiving burden and stress. The positive impact of religious/fatalistic coping on AD caregiving process seems to in line with the previous research (Heo, 2014; Lim, Griva, Goh, Chionh, &Yap, 2010). For example, the spiritual doctrine of benefit finding in unfortunate situations lead African American caregivers to obtain more satisfaction from caregiving (Lee & Sung, 1997). They also accepted disease-related changes more readily and had increased self-competence when compared to Western AD caregivers (Napoles et al., 2010). Likewise, Buddhism seem to help Chinese caregivers adapt to the caregiving process more easily and removed feelings of guilt and self-blame away from them (Sethabouppha & Kane, 2005). Consistent with these findings, the Islamic teachings of fate, *tevekkül*, *şükür* and benefit-finding in unfortunate events might have facilitated the acknowledgement of disease process as it was and positive re-appraisals of their current situation. Nevertheless, a note to caution is due here as studies investigating the use and impacts of coping strategies across different cultural groups is very limited.

Besides, some religious teachings might also result in negative caregiving outcomes, as well. Since Islamic teachings discourage rebelling against a given incidence, caregivers might have inhibited or refrained from expressing their negative emotions, which might lead them to feel guilty, helpless and stuck in the caregiving role. They might exhibit extreme self-sacrificing care behaviors in the fear of being despised by God. Further, the belief that 'healing could only be given by God' might prevent caregivers from seeking professional help required for their patients.

On the question of coping strategies, Turkish offsprings reported to have benefited from both tangible and emotional support they received from their siblings, spouses and friends. This finding was in agreement with the previous findings about the protective role of social support on AD caregivers' well-being (Brodaty & Donkin, 2009; Clyburn et al., 2000; Haley et al., Han et al., 2014; 1996; Heo, 2014). Further, this pattern was also parallel to those observed in studies about caregivers of different cultural backgrounds. Researchers reported that Asian American and African American caregivers had more active support systems, which was associated with less burden and more positive caregiving outcomes (Gupta & Pillai, 2000; Lai, 2009). Still, this finding should be interpreted with caution as resentment and relationship burden were also evident in Turkish caregivers' descriptions due to the family conflicts resulting from sharing of the care responsibilities and lack of support. As family ties are important in determining daily life practices in collectivistic cultures, problematic family relations and satisfaction with familial support might be particularly burdensome for these caregivers (Harper & Lund, 1990; Lai, 2009). Further, assuming that caregivers from collectivistic cultures have more mobilized support systems might mislead social policy makers and mental health professionals. Such an assumption might result in insufficient service delivery to this population who already tended to refrain from using formal care services (Ho et al., 2003).

Turkish adult children also reported to use problem-focused coping strategies in order to cope with difficulties encountered during care provision. In fact, findings regarding the role of problem focused coping on AD caregiving process have produced inconsistent results. While generally positive effects were noted in the literature (Haley et al., 1996; Kneebone & Martin, 2003; Roche et al., 2015), some findings revealed that problem-focused coping strategies were ineffective in dementia context as the AD is full of uncertainties and the changes are irreversible (Li et al., 2012). Yet, Turkish adult children caregivers described problem-focused coping as a functional and adaptive strategy. This positive effect could be explained by the fact that Turkish caregivers seem not to be fixated on the unchangeable aspects or try to reverse the disease-related decline. Rather, they developed alternative practical solutions to daily caregiving issues.

Another finding revealed under the theme of coping strategies was the positive effects of acceptance-based coping style on caregiver mental health. Accepting care recipients’ disease related decline and associating behavioral problems with disease progression seem to regulate anger, frustration and sadness upon the symptoms of the disease. Rather than dwelling on the irreversible losses, Turkish caregivers tried to remain calm and plan for the future challenges. This finding seem to confirm the already established association between the use of acceptance coping style and positive caregiving outcomes (Geiger et al., 2014; Li et al., 2012). This positive relation could be explained by the unique pathology of the AD. Cognitive, physical and psychosocial deterioration in AD is gradual, and the losses associated with disease progression are usually irreversible (AA, 2016; Brodaty & Donkin, 2009; Smith et al., 2001). Hence, accepting the current limitations might lead the caregivers to regulate negative emotions, and provide room for focusing on the modifiable aspects of caregiving process.

Finally, both distraction and avoidance coping styles were reported by Turkish adult children as ways to handle disease and caregiving-related stress. Caregivers either physically or psychologically separated from the intense caregiving demands by engaging in some social and recreational activities. These activities seem to provide respite for the caregivers as it is very frustrating to be exposed to caregiving stressors continuously. Caregivers also avoided thinking about the losses associated with the advanced stages of the disease as these stages signaled the profound impairment and impending death. Although avoiding the future deterioration of the parent might provide a short lived relief for caregivers, it might also hamper the instrumental and psychological preparation process for the last stages of the disease. Besides, avoiding and processing impending death might also deter the anticipatory grief process, thereby increasing the risk of intense grief responses after the actual death of the patient.

3.4.4. Factors Helping or Hampering Caregiver Process

Another important finding of the current study was that being agreeable, affectionate, tolerant and conscientious as a caregiver was perceived as facilitating the caregiving process on the behalf of both the caregiver and care recipient. Turkish adult children reported that these personality traits not only increased their tolerance towards the patients, but also provided an intrinsic motivation to remain in the caregiver role. It was also evident that these personality characteristics enhanced quality of care provided to the affected parent. By contrast, caregivers who were impatient and socially active experienced difficulties in adaptation to the disease and caregiving process. This finding was plausible in that AD caregiving necessitates an intense supervision over a variety of tasks for extended time periods (AA, 2016; Brodaty & Donkin, 2009; Smith et al., 2001). Caregiving demands constantly change as the neurological damage becomes more severe (AA, 2016). In that regard, a personality organization enhancing empathy, compassion and tolerance towards patients would be a valuable internal resource while dealing with patients' symptoms and caregiving demands. On the other hand, an impatient and socially active personality structure might lead caregivers to feel frustrated and angry in their role, which might also decrease their motivation to provide quality care. It can therefore be assumed that assessment procedures might be helpful to mental health professionals in identifying AD caregivers at risk based on evaluation of personality traits. Nevertheless, this suggestion should be approached with caution as these results are only preliminary.

The results of the current study also indicated that the quality of the past relationship between the caregiver and affected parent might influence caregivers' motivation for caregiving and their feelings about the patient. Caregivers having an affectionate relationship with the care recipient in the past seem to provide care in an empathetic and compassionate manner. Their care motivation also seems to derive from the strong bond they established before the disease. By contrast, caregivers who described their past relation as unresponsive and unsatisfying seem to feel angry and resentful towards the patients. Besides, they also questioned their caregiver role and seem to have a lower motivation for care provision. These results seem to be consistent with the other research findings which found that a well-established past relationship with the patient improved caregivers' well-being regarding depression, burden and positive caregiving experiences (Fauth et al., 2012; Quinn, Clare, & Woods, 2008; Williamson & Shaffer, 2001; Williamson & Schulz, 1990). However, how the past relation quality influences the current interaction with the care recipient and whether a positive current bond could be established even in the case of poor quality of relationship in the past still needs further investigation. Additionally, past relationship quality might also have different impacts on anticipatory grief process. Preliminary findings suggested that if the bond between the patient and care recipient has been stable before the diagnosis, caregivers experience more intense pre-death grief reactions as the separation approaches (Lindgren et al., 1999).

3.4.5. Unique Pathology of the Disease

Turkish adult children caregivers reported that AD has a distinct characteristic as a chronic disease due to its peculiar cognitive and behavioral symptoms. Caregivers had a tendency to compare AD with other chronic diseases like cancer to underlie the unique nature of the disease. Interestingly, some caregivers were at ease knowing that their parents were not aware of the profound impairment they have experienced. They would prefer AD over cancer, since in the latter the cognitive faculties are intact and patients are suffering at a conscious level. By contrast, other caregivers expressed deep agony over their parents' inability to meaningfully communicate with the environment. These caregivers would prefer cancer over AD as they could still have a mutual relationship with the care recipient in the former. In fact, this result partially supports the earlier findings indicating that lack of mutual processing due to the cognitive impairment gave AD caregiving a unique texture (Austrom et al., 1990; Harris et al., 2011; Meuser & Marwit, 2001). These findings revealed that lack of cognitive awareness lead to a specific burden on behalf of the caregivers. What is surprising was that some Turkish caregivers in the current study felt comfortable as cognitive impairment allows patients to be free from the psychological pain of deterioration. This finding, although preliminary, suggested that caregivers might have different appraisals of cognitive symptoms. One symptom which might be counted as painful and burdensome in one situation could be regarded as less stressful or even advantageous in another context. Hence, it is important for interventions to be designed considering caregivers' both common and unique understandings of the disease-related symptoms.

Another important finding was related to the behavioral problems exhibited by the care recipients. Turkish adult children described behavioral symptoms as a particular challenge, upon which they alternate between helplessness, frustration, guilt and grief. This finding was also consistent with the current literature stating that neuropsychiatric symptoms (e.g. agitation, apathy, depression, aggression, delusions) not only harden the caregiving process but also lead to feelings of anger and grief among caregivers (Ankri et al., 2005; Frank, 2008; Savundranayagam at al., 2011).

These findings highlighted the specific nature of AD caregiving resulting from unique disease pathology. It can therefore be suggested that informal AD caregivers might need additional components in intervention programs, which aim to assess meanings attached to the disease symptoms and to develop skills in handling neuropsychiatric symptoms across different situations.

3.4.6. Reluctance for NHP

One clinically and socially significant finding of the current study was the barriers reported by Turkish caregivers to prefer NHP as an option. Turkish adult children conceptualized NHP as abandoning and giving up on the affected parent. They personally felt responsible for care provision, through which they fulfilled their duties towards the ones who raised them as a child. They also wanted to be role models for their own children in order to ensure the continuation of intergenerational care process. This unwillingness to use NHP is likely to be related to the cultural context in which Turkish caregivers have been raised. Care provision to an elder is usually a culturally normative practice in Eastern contexts (Janevic & Connell, 2001; Ho et al., 2003). Children from these backgrounds are raised under the influence of values like familism and filial piety (Jones, 1995). They are taught to show respect towards their parents and encouraged to spend psycho-social resources for the sake of familial bonds. In those cultures, family harmony and cohesiveness are more important than the individual goals and achievements (Ho, et al., 2003; Lai, 2009; Sun et al., 2003). Consistently, dementia caregivers usually provide care to their affected parents out of a sense of moral and cultural obligation (Mahoney et al., 2005; Min, 1995). Society values and reinforces the sacrifices they make for the elderly (Jones, 1995). As a result, care provision for a parent is an anticipated role in their lives (Ho et al., 2003). Indeed, this normative nature of informal care provision might partially explain the lack of formal service use among non-Western caregivers and also the scarcity and low quality of such facilities, as well. Consistently, Turkish caregivers also evaluated NHP as an inappropriate act and felt obliged to care for their demented parents at home. Some of the Turkish caregivers also felt neighborhood pressure, fearing that they may be despised by them, which seem to discourage them seeking for such an alternative.

It is somewhat surprising that affection and compassion were also evident in the accounts of Turkish offsprings. They described a satisfactory relationship with patients as their maternal side connected with the child like status of the patients. They seem to have a positive regard for, and showed empathy towards their demented parents. In fact, such a pattern might be point out that the sole motivation of Turkish caregivers to provide care is not only a moral one. Rather, their affectionate relationships might also explain their willingness to continue informal caregiving at home. In fact, to our knowledge, this pattern has not been previously reported in the literature. While Western caregivers provided informal care to their relatives out of affection, sense of duty was a more influential factor in non-Western caregivers' motivations (Lee & Sung, 1997). Nevertheless, a more hybrid motivation seems to exist for Turkish caregivers including aspects of both filial obligation and affection. This hybrid motivation could also explain the positive appraisals and experiences of Turkish adult children caregivers in this study.

Turkish offsprings also reported an external barrier preventing them from placing their loved one in a formal institution. They were unsatisfied with the conditions of such facilities in Turkey and scared that their parents would be neglected and maltreated in such facilities. They were both affected by the negative social representations and their personal experiences with nursing staff. Besides, none of the informal caregivers reported to have received any formal help either offered by the government or a volunteer public organizations. Such accounts might either indicate a lack of such formal services or ineffective delivery of such services in Turkey.

3.4.7. Conclusions and Implications

The main goal of the current study was to understand the experiences of Turkish adult children in caring for a parent with AD. This study has shown that Turkish children caregivers did not only experience caregiver burden, but also perceived the silver linings of the caregiving situation. They employed both common and culturally relevant coping strategies to deal with disease and caregiving related difficulties. It seems that they remained in the caregiver role not only out of a sense of duty, but also out of affection and compassion, as well. Further, Turkish values highlighting the importance family bonds and harmony seem to be a cultural barrier preventing caregivers from placing their loved ones in an institution. Taken together, these results suggest that Turkish caregivers might have some unique needs during caregiving process, as their views on aging, family interactions and help-seeking behaviors are different from those of the Western AD caregivers. Nevertheless, claiming that their cultural values only have a protective or hindering function on AD caregiving would be an oversimplification. While Islamic religious/fatalistic coping, positive appraisals and compassion might decrease their burden, the same values might also prevent them from seeking out appropriate care both for themselves and their affected parents. These values might also lead to extreme self-sacrificing tendencies during care provision, which could result in long term ill health effects and lower quality of life for both the caregivers and the affected parent. Therefore, more studies should be conducted to understand (1) common and unique needs of AD caregivers from different cultural backgrounds, and (2) how the interaction between cultural values and stressors impact on various caregiving outcomes.

The findings of the current study, while preliminary, has important clinical implications. Firstly, results suggested that Turkish adult children might have some individualized needs while caring for a demented parent. Based on the findings, it might be suggested that intervention programs should be sensitive to the cultural context in which AD care is provided. Accordingly, multicomponent interventions are suggested to be developed not only aiming to decrease caregiver distress but also to facilitate strengths and positive caregiving outcomes. Besides, these interventions should also take into account culturally relevant coping strategies to boost caregivers' well-being and improve quality of informal care. Secondly, culturally sensitive interventions are necessary to remove barriers for NHP. In that regard, challenging dysfunctional appraisals of institutionalization and providing formal care services which give importance to cultural values of Turkish caregivers might be beneficial. To illustrate, conditions of nursing facilities might be arranged so that caregivers are allowed to be more actively involved in the caregiving process. However, currently most formal care is still being provided by nursing staff. Last but not the least, governments and social policy makers should be more active in improving the conditions of such facilities to encourage more common use of formal health services.

3.4.8. Limitations

An important limitation of the current study is that it mainly included informal family caregivers. Accordingly, more research is required to understand the dynamics of Turkish families who had already placed their loved ones in an institution. Secondly, although Turkey has a pre-dominantly collectivistic texture, it has also undergone a radical transformation over the years, and some individualistic components are also influential in daily life experiences. Further, within and between cultural heterogeneity also exist across different regions of the country. Hence, further investigation is needed to reveal experiences of caregivers from different regions of Turkey, and to understand the effects of individualistic elements on caregiving experiences. Finally, although it is not within the scope of this study, effects of gender, gender roles and providing care to a same-sex or opposite-sex parent should be investigated in future studies as specific roles were assigned to the caregivers depending on their gender.

CHAPTER 4

STUDY 2: FACTORS ASSOCIATED WITH DEPRESSION, ANXIETY, GRIEF AND GROWTH IN THE ADULT CHILDREN CAREGIVERS OF ALZHEIMER'S DISEASE

This chapter will present the research questions, methodology and findings of the quantitative study conducted in the scope of the current thesis aiming to explore factors associated with depression, anxiety, grief and growth in the caregivers of Alzheimer patients. The results of the quantitative study will also be discussed in relation to the current literature on AD caregiving outcomes.

4.1. Introduction

Findings of the qualitative study revealed three important aspects that are likely to influence the main outcome variables of the quantitative research. Firstly, it was inferred that Turkish adult children not only suffered from burden, depression and anxiety, but also perceived the silver linings of the disease and the caregiving process. They reported positive changes both in themselves (i.e. increased self-efficacy and a new perspective on life), and their relationship with the care recipient after the disease onset. Based on this finding, positive caregiving outcomes were integrated to the quantitative phase of the current thesis as another caregiver outcome since only examining negative caregiving outcomes might run the risk of providing an incomplete picture of the AD caregiving experiences of Turkish offspring. Secondly, both primary (i.e. loss of parent's old identity, loss of a parental figure, the progressive deterioration of cognitive and physical abilities) and secondary (i.e. loss of caregivers' freedom, loss of caregivers' well-being) losses were evident in Turkish offspring's accounts. Hence, AD caregiver grief was also added to the quantitative phase as another caregiver outcome to provide a more comprehensive understanding for the Turkish adult children's AD caregiving experiences. As there isn't any AD caregiver grief inventory available in the

Turkish literature, examining the psychometric properties of Marwit-Meuser Caregiver Grief Inventory-Short Form (MMCGI-SF) was set as another aim of the quantitative part of the present thesis, which later were also examined in relation to various disease and caregiver-related factors. Thirdly, it was inferred from the qualitative findings that religious/fatalistic coping was an effective way to handle disease and caregiving related changes as it facilitated acceptance and positive reframing of the situation. Additionally, social support seems to enhance caregivers' resources through instrumental and emotional help received from others. However, resentment was also evident in caregivers' accounts as they were unsatisfied with the help offered by their extended family members. Accordingly, both a coping instrument including religious/fatalistic coping as a sub-factor (Ways of Coping Inventory, Karanci & Erkam, 2007) and an instrument measuring perceived social support were utilized in the quantitative study to understand how these factors influence the relation between caregiver burden and various caregiving outcomes among Turkish offspring.

Along with the findings of the qualitative study, the quantitative phase of the current thesis was also shaped by Pearlin and his colleagues' (1990) "Stress Process Model", and "Model of Carer Stress and Burden" developed by Sörensen et al. (2006). Based on the conceptualizations of the models, four variable domains were established, which are contextual/background factors, primary stressors/disease-related variables, secondary stressors, moderator variables, and caregiver outcomes. See Table 2 for a detailed presentation of the variable domains utilized in the quantitative study.

4.2. Research Questions of the Quantitative Study

Based on the findings of the qualitative findings and AD caregiver models in the current literature, three research questions were formed for the quantitative study:

1. How do contextual/background variables (i.e. gender, education, SES, quality of past relationship with the care recipient), primary stressors (i.e. disease related factors such as stage of disease, time since onset, time since diagnosis, caregiving hours per week, length of caregiving, and co-residence), secondary stressors (i.e. subjective caregiver burden), and

moderator variables (i.e. coping strategies and social support) affect depression, anxiety, grief and growth experiences of Turkish adult offspring of AD patients?

2. Does coping strategies moderate the relationship between caregiver burden and caregiving outcomes?
3. Does perceived social support moderate the relationship between caregiver burden and caregiving outcomes?

4.3. Hypothesis of the Quantitative Study

It was hypothesized that contextual/background variables (i.e. gender, education, SES, quality of past relationship with the care recipient), primary stressors (i.e. disease related factors such as stage of disease, time since onset, time since diagnosis, caregiving per week, length of caregiving, and co-residence), secondary stressors (i.e. caregiver burden), and moderator variables (i.e. coping strategies and social support) would be significantly associated with depression, anxiety, grief and growth experiences of Turkish adult offsprings of AD patients. Additionally, coping strategies (i.e. fatalistic coping, problem-focused coping, optimistic/seeking social support coping, and helplessness coping/self-blame) and perceived social support would moderate the relationship between secondary stressors (i.e. subjective burden) and caregiving outcomes (i.e. depression, anxiety, grief, and growth).

4.4. Method

4.4.1. Participants

The sample of the quantitative study was composed of 190 Turkish adult children caring for a parent with AD. Participants were recruited from three informal support groups on Facebook (i.e. Alzheimerlı Hasta ile Yaşayanlar, Alzheimerlı Hastalar and Alzheimer Hastalığı). The eligibility criteria for participation were (1) being an adult child of a patient with AD, (2) defining oneself as an informal caregiver, (3) giving some assistance in daily and instrumental living activities and (4) providing at least four hours of caregiving per week. The mean age of the participants was 51.41 (*SD* = 8.68), ranging from 26 to 77. The gender proportion of the study was

Table 2. Variables Used in the Quantitative Study

Contextual/ Background Variables*	**Primary Stressors/ Disease-Related Variables**	**Secondary Stressors**	**Moderators**	**Caregiver Outcomes**
Age	Stage of Disease	Caregiver Burden	***Coping Strategies***	***Negative Caregiver Outcomes***
Gender	Time Since the Onset (years)		Fatalistic Coping	Depression
Education	Time Since the Diagnosis (years)		Problem-Solving Coping	Anxiety
SES	Caregiving per Week (hours)		Optimistic/Seeking Social Support	Grief
Marital Status**	Lenght of Caregiving (years)		Helplessness Coping	***Positive Caregiver Outcomes***
Quality of Past Relationship	Co-Residence		***Perceived Social Support***	Growth
	Help from Others**			

*These variables represent the socio-demographic characteristics of the caregivers.

**These variables were only used for descriptive purposes but not included in the main analyses.

consistent with the existing literature indicating that the majority of AD caregivers were female relatives of the AD patient (AA, 2016; Brodaty & Donkin, 2009). Eighty-nine percent of the sample were female (*N* = 170), while 11 % was male (*N* = 20). More than half of the caregivers had education beyond high school (*N* = 109, 54.7 %). Almost half of the caregivers reported their income level as equal or more than 2500 TL (*N* = 85, 44.7 %), 11.6 % as 2000-2449 TL (*N*= 22), 20.5 % as 1500-1999 TL (*N*= 39), 14.7 % as 1001-1499 TL (*N* = 28), and 8.4 % as below 1000 TL (*N*= 16). More than half of the caregivers were married (*N* = 109, 57.4 %), 17.4 % of the participants were single (*N* = 33), 9.5 % were divorced (*N* = 18) and 15.8 % were either divorced, widowed or cohabiting with a partner (*N* = 48). Thirty-eight percent of the participants were employed (*N* = 73) at the time of the study, while 7.89 % of them were retired (*N* = 15) and 53.68 % of them were unemployed (*N* = 102).

Seventy-eight percent of the adult children (*N* = 144) provided care for their mother, while 24.2 % provided care for their demented fathers (*N* = 146). They provided care for 5.23 years on average (*SD* = 3.46), and the mean of score for hours spent on caregiving per week was 103.57 (*SD* = 65.92). More than half of the caregivers co-resided with the care recipients (*N* = 129, 67.9 %), and majority of them (*N* = 136, 71.6 %) received some form of instrumental help from siblings, healthy parents, husbands and paid care takers.

All information on disease-related characteristics were obtained through caregivers' own reports. Accordingly, half of the care recipients had severe, 39.5 % of them moderate (*N* = 75) and 10.5 % of them had mild dementia from AD (*N* = 20). Besides, all care recipients had received a formal diagnosis of AD either from a neurologist or neuropsychiatrist. Table 3 below illustrates the socio-demographic characteristics of caregivers and disease-related information of care recipients.

Table 3. Socio-demographic characteristics of caregivers and disease-related characteristics of care recipients

Variable	***f***	***%***	***M***	***SD***	***Range***
Gender	190				
Female	170	89.5			
Male	20	10.5			
Age			51.41	8.68	26-77
Marital Status					
Single	33	17.4			
Married	109	57.4			
Divorced	18	9.5			
Widower	9	4.7			
Cohabitating	15	7.9			
Other	6	3.2			
Education Level					
Primary School	5	2.6			
Secondary School	13	6.8			
High School	63	33.2			
University	92	48.4			
Master's Degree	10	5.3			
Doctorate Degree	7	3.7			
Employment Status					
Employed	73	38.43			
Retired	15	7.89			
Unemployed	102	53.68			
Household Income Level					
Equal to or Below 1000 TL	18	8.4			
1001-1499 TL	28	14.7			
1500-1999 TL	39	20.5			
2000-2499 TL	22	11.6			
Equal to or Higher than 2500 TL	85	44.7			
Time Since Diagnosis (years)			5.6	3.48	1-19
Length of Caregiving (years)			5.23	3.46	1-15
Caregiving per Week (hours)			103.57	65.91	4-168
Co-residence					
Yes	129	67.9			
No	61	32.1			

Table 3 (cont'd). Socio-demographic characteristics of caregivers and disease-related characteristics of care recipients

Type of Relationship		
Mother	144	75.8
Father	46	24.2
Stage of Disease		
Mild	20	10.5
Moderate	75	39.5
Severe	95	50

4.4.2. Instruments

4.4.2.1. Demographic Information Form

A demographic information form was constructed by the researchers, composing of 15 questions. The form included questions regarding caregiver's age, gender, educational attainment (response options: illiterate, literate, primary school, secondary school, high school, university, master's degree, and doctorate degree), monthly income (response options: equal or below to the 1000 TL, 1001-1499 TL, 1500-1999 TL, 2000-2499 TL, and equal to or higher than 2500 TL), employment status (response options: employed, retired and unemployed), marital status (response options: single, married, divorced, widowed, cohabitating and other), duration of caregiving provided by the caregiver per week (in terms of hours), length of caregiving provided by caregiver since the diagnosis of the disease (in terms of years), help provided by others, and co-residence with the care recipient. The form also included questions regarding disease-related characteristics of the patients such as the stage of the disease (response options: mild, moderate and severe), time since the onset of the disease (in terms of years), time since the diagnosis of the disease (in terms of years) and type of the relationship with the caregiver (response option: mother and father). See Appendix F for the demographic information form.

4.4.2.2. Marwit-Meuser Caregiver Grief Inventory-Short Form (MMCGI-SF)

The Marwit-Meuser Caregiver Grief Inventory (MMCGI) was originally developed through a two-step project. In the first phase of the study, 16 focus groups were conducted with spousal and adult children caregivers of patients with dementia. Then grief narratives were formed taking into consideration both the type of the relationship between the caregiver and care recipient (whether a spousal or parental relationship exists between the caregiver and care recipient) and the stage of the patients' disease (Meuser & Marwit, 2001). In the second phase of the study, 184 items tapping grief related issues were generated by Marwit and Meuser (2002) initially. While some items were formed from direct or modified caregivers' quotations reported during focus groups, other items were generated covering grief-related issues uttered throughout the focus group discussions. After that, a series of statistical tests were performed to obtain a manageable item count to measure pre-death grief symptoms among dementia caregivers. Based on principal component analyses, examination of skewness of single items, and inspection of partial and error residual matrices, the final MMCGI included 50 items with three sub-factors. The factors were labeled as (1) personal sacrifice burden, (2) heartfelt sadness and longing, and (3) worry and felt isolation, respectively. The first factor, personal sacrifice burden, aimed to measure personal sacrifices that caregivers had to make for the caregiver role and associated secondary losses due to caregiving demands. This factor included 18 items in the original long version of the inventory. Sample items are "*I feel this constant sense of responsibility, and it just never leaves*" (item 17) and "*I feel I am losing my freedom*" (item 3). The second factor, heartfelt sadness and longing, which was also referred as the "true grief factor" aimed to measure the sadness over what have been lost due to disease development in terms of loss of patient's identity and past quality of the relationship, and the longing for the past life with the care recipient prior to disease. This factor included 15 items in the original long version of the inventory. Sample items are "*I have this empty, sick feeling knowing that my loved one has gone*" (item 9) and "*I long for what was, what we had and shared in the past*" (item 18). The third factor, worry and felt isolation included 17 items and aimed to measure anxiety related to the uncertainty of the disease progression and isolation due to disease and caregiving process. Sample items are "*I spent a lot of time worrying about the bad things to come*" (item 12) and "*My friends simply don't understand what I'm going through*" (item

16). All items of the instrument were responded on a 5 point Likert Type scale, 1 representing “*strongly disagree*”, 2 representing “*disagree*”, 3 representing “*somewhat agree*”, 4 representing “*agree*” and 5 representing “*strongly agree*”.

The internal consistency of the total MMCGI was high, with an alpha value of .96. Alpha coefficients were .93 for personal sacrifice burden, .91 for heartfelt sadness and longing, and .90 for worry and felt isolation subscales. The construct validity of the MMCGI was originally established through examination of convergent and divergent validity scores. In terms of convergent validity, the correlation of total MMCGI with Beck Depression Inventory (BDI) was .76, while it was .71 with Geriatric Depression Scale. As for the correlations between BDI and subscales of MMCGI, it was .72 for personal sacrifice burden, .59 for heartfelt sadness and longing, and .66 for worry and felt isolation relation. Marwit and Meuser (2002) claimed that the modest correlations with depression scales were plausible as dementia caregiver grief included unique symptoms when compared to depression such as yearning and longing for the losses associated with disease-related changes. As an another indicator of convergent validity, the correlation between total MMCGI and Anticipatory Grief Scale (AGS) was reported as.80, as well. The correlation of total MMCGI with Caregiver Strain Index (CSI) was .66, while personal sacrifice burden had the highest correlation with CSI, as both indices commonly measures the burden and stress resulting directly from caregiving demands.

Regarding divergent validity, the correlation between total MMCGI and Caregiver Well-Being Scale was -.66. An inverse relationship was also found between total MMCGI scores and Family Subscale of Perceived Social Support Scale as expected, although the association was weaker. (r = -.36).

Although the long version of MMCGI is a psychometrically sound instrument measuring multidimensional pre-death grief responses of AD caregivers, a shorter version of the scale was developed by Marwit and Meuser (2005) to eliminate issues with time constraints and problems with filling a lengthy instrument. The examination of inter item correlation matrices of within and between factors yielded a final 18 items, where 6 items loaded under each one of the three subscales of MMCGI. Items 1,2,10, 16,17,18 comprised the personal sacrifice burden subscale, items 4, 8, 9, 11, 12, 15 comprised the heartfelt sadness and longing subscale, and items 3, 5, 6, 7, 13, 14 comprised the worry and felt isolation subscale. The internal consistency for the three subscales was good for a short version of an original scale. The alpha coefficient was .83 for personal sacrifice burden, and .80 for both heartfelt sadness/longing, and worry/felt isolation subscales. As a first step of establishing concurrent validity, correlations were computed between the scores obtained from MMCGI and MMCGI-SF based on a sample of 292 participants. Computed correlations were promising in that the correlation between personal sacrifice burden subscale from MMCGI and MMCGI-SF was .92, the correlation between heartfelt sadness and longing subscale from MMCGI and MMCGI-SF was .93, and the correlation between worry and felt isolation subscale from MMCGI and MMCGI-SF was .93, respectively. The correlation values found in respect to other standardized values (i.e. depression, CSI, and Family Subscale of Perceived Social Support Scale) were also similar to those found in the original longer version of the MMCG-SF. The correlation between total MMCGI-SF and BDI was modest (*r* = 70) indicating caregiver grief and depression shared both common and unique symptoms. The correlation values of BDI with personal sacrifice burden was .61, .51 with heartfelt sadness and longing, and .60 for worry and felt isolation. As expected, the correlation between CSI and personal sacrifice burden was higher (*r* = .69) than those between CSI and heartfelt sadness and longing (*r* = .38), and those between CSI and worry and felt isolation (*r* = .46). These findings indicated that the factor structure and psychometric properties of MMCGI-SF was similar to those found in the original MMCGI. MMCGI-SF is specifically encouraged to be used in studies where a pack of inventories was distributed to participants as a quick way to assess pre-death grief experiences of informal dementia caregivers.

The psychometric properties of the Turkish version of the MMCGI-SF will be established under the scope of the current thesis, and relevant findings will be presented in the result section. (See Appendix G).

4.4.2.3. Beck Depression Inventory (BDI)

BDI was originally developed by Beck and his colleagues in 1961. The scale consists of 21 items and each item is responded on a 4-point scale format. Each single item presents four depressive symptom of increasing intensity. Response options range from 0 to 3. Higher scores on each item and total instrument indicate greater depressive symptoms. The instrument aimed to measure affective, cognitive, motivational and psycho-motor aspects of depression. The scores range from 0 to 63 (Beck et al., 1961). BDI was adapted to Turkish by Hisli (1989). The internal consistency of the scale was found to be .80, whereas the split half reliability was reported as .74. Concurrent validity was established by computing correlations among BDI and MMPI-D subscale, and the correlation between the scales was reported as .50 (Hisli 1989). In the current study, BDI was used to establish concurrent validity of MMCGI-SF and to measure depressive symptoms of Turkish offspring of AD patients. The internal consistency of the scale was .88 for the present study (See Appendix H).

4.4.2.4. Zarit Burden Inventory (ZBI)

Zarit Burden Inventory was developed by Zarit and his colleagues (1980) to assess subjective emotional and social burden resulting from direct and indirect caregiving demands. The scale consists of 22 items that are answered on a 5 point Likert type scale. Response options range from 1 (never) to 5 (always). Higher scores on each item and on total scale indicate greater perceived burden and distress. Sample items are "*Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work"* (item 3) and *"Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?"* (item 14).

The scale was adapted to Turkish by Özlü, Yıldız and Aker in 2009. Three items were excluded from the Turkish version as those items' factor loadings were found to be below .50 in the initial factor analysis. The Cronbach alpha value for the Turkish version of the ZBI was .83. Regarding concurrent validity, the correlation between total ZBI scores and Maslach Burnout Inventory was reported as .61. ZBI was used to test concurrent validity of MMCGI-SF and burden scores of adult children caregivers. The Cronbach alpha of ZBI for the current study was .91 (See Appendix I).

4.4.2.5. The Caregiver Well-Being Scale

The Caregiver Well-Being Scale was developed by Berg-Weger and his colleagues in 2000. The scale was developed to measure the extent to which caregivers are able to meet their own basic and daily living needs while assuming the caregiver role. The scale consists of two factors, which are basic needs and activities of daily living subscales, respectively. The basic needs subscale is comprised of 22 items and aims to measure how much caregivers meet their physical and emotional needs during performing their caregiving role. Sample items of this subscale are "*eating a well-balanced diet*" (item 1) and "*expressing love*" (item 7). The activities of daily living activities subscale consist of 24 items and aims to measure to what extend caregivers fulfill their needs for daily and leisure activities. Sample items of this subscale are *"washing and caring for clothing"* (item 8) and *"starting a new interest or hobby"* (item 12).

All of the questions in the Caregiver Well-Being Scale was responded on a 5-point Likert type scale. Response options range from 1 (never) to 5 (always). The Turkish adaptation of the scale was performed by Demirtepe-Saygılı and Bozo (2009). The Cronbach alpha value for the Basic Needs subscale of the Turkish version was .93, while test re-test reliability was reported as .79. Regarding divergent validity, the correlation coefficient between Basic Needs subscale and depression was reported as -.71. Further, Basic Needs subscale had a correlation coefficient of .55 with general well-being scores indicating good convergent validity. As for Activities of Daily Living subscale, the internal reliability coefficient was reported as .89 while test re-test reliability was found to be .86. One item (i.e. *getting yard work done*) was excluded from the Activities of Daily Living subscale as it substantially lowered the internal consistency of the subscale. Similar to Basic Needs subscale, Activities of Daily Living subscale had a correlation coefficient of -.69 with depression, and .54 with general well-being scores. In the current study, Caregiver Well-Being Scale total scores were used to established divergent validity with MMCGI-SF. The internal reliability coefficient of the scale was .93 in the present study (See Appendix J).

4.4.2.6. Multidimensional Scale of Perceived Social Support (MSPSS)

MSPSS was originally developed by Zimet and his colleagues in 1988. The instrument consists of 12 items, and each item is answered on a 7 point Likert type scale. Response options range from 1 (disagree very strongly) to 7 (agree very strongly). The scale has 3 subscales, which are support from family, support from friends and support from significant others. Higher scores on items indicate greater level of perceived social support.

The psychometric properties of MSPSS in Turkey was initially established by Eker and Arkar in 1995, and later on by Eker, Akar and Yaldız in 2001. Regarding construct validity, a positive correlation was reported between MSPSS total and Perceived Social Support-Family subscale (PSS-Fa) (r = .61) and between MSPSS total and Perceived Social Support-Friends Subscale (PSS-Fr) (r = .59). Negative associations were also found between total MSPSS scores and UCLA Loneliness Scale (r = -.63); and between MSPSS total scores and Symptom Checklist scores (r = -.58) indicating good divergent validity.

The scale was applied across different populations to test psychometric properties including university students, kidney disease patients and psychiatric inpatients and outpatients (Eker et al., 2001). The Cronbach alphas for the total scale obtained from these studies ranged from .85 to .91.

MSPSS was used in the current study in order to establish divergent validity of MMCGI-SF and to measure total perceived social support levels of AD caregivers. The Cronbach alpha value of the total scale was .90 in the present study (See Appendix K).

4.4.2.7. State-Trait Anxiety Inventory-State Form (STAI-S)

STAI is a self-report instrument developed by Spielberger and his colleagues (1970). The scale consists of two sub-scales, which are state anxiety and trait anxiety form, respectively. Both sub-scales include 20 items, and each item is responded on a 4 point Likert type scale. Response options range from 1(almost never) to 4 (almost always). State form of STAI aims to measure a temporary emotional state of being worrisome and nervous in response to stress. Sample items for the state anxiety subscale are "*I am tense*" (item 3) and "*I am worried*" (item 17). By contrast, trait form of STAI aims to measure a general predisposition to anxiety. A sample item for the trait anxiety subscale is "*I worry too much over something that really doesn't matter*" (item 9).

The Turkish adaptation of STAI was performed by Öner and Le Compte (1985). The internal consistency coefficients were found to be ranging from .83 to .87 for the state form of STAI, while coefficients values were reported between .94 and .97 for the trait form of the scale. The correlations between various anxiety scales and state anxiety form also ranged from .52 and .80 indicating good convergent validity. In this study, only STAI-S was used in order to establish construct validity of the MMCGI-SF and to determine anxiety levels of the caregivers. The Cronbach alpha value of the STAI-S was .94 for the current study (See Appendix L).

4.4.2.8. Post Traumatic Growth Inventory (PTGI)

Post Traumatic Growth Inventory (PTGI) was originally developed by Tedeschi and Calhoun in 1996 to evaluate positive transformations occurring in the aftermath of the traumatic events. It has five subscales which are (1) new possibilities (consisting of 5 items), (2) relating to others (consistent of 7 items), personal strength (consisting of 4 items), spiritual change (consisting of 2 items) and appreciation of life (consisting of 3 items). The scale has 21 items, and each item is responded on a 6 point Likert type scale. Response options range from 0 (I did not experience this change) to 5 (I experienced this change to a very great degree). Sample items for the scale are "*I established a new path for my life*" (item 7) and "*New opportunities are available which wouldn't have been otherwise*" (item 14).

The Turkish adaptation of PTGI was initially performed by Kilic (2004) using a 5 point Likert Type format. The internal reliability coefficient was reported as .91, while split half reliability was .84 for both parts of the scale. Regarding construct validity, significant negative correlations were established between PTGI scores and different psychopathology measures. In order to develop a more veridical version, Dirik and Karanci (2008) translated PTGI into Turkish with a 6 point Likert type format and obtained a high internal consistency value for the total scale (α = .94). Later on, Karanci and her colleagues also confirmed the original five factor structure of PTGI (2009). The internal consistency of the total scale was reported as .93, while it was .80 for new possibilities, .83 for relating to others, .81 for personal strength, .72 for spiritual change, and .65 for appreciation of life subscales.

In the current study, total PTGI scores were used in order to assess positive changes of caregivers after the diagnosis of AD and during the caregiving process. As there is not any available instrument in Turkey assessing positive transformations resulting from AD caregiving, PTGI was utilized to assess positive outcomes of AD caregiving. Dirik and Karanci's (2008) translated version was used to reach this aim. The Cronbach alpha value for the total PTGI was .92 in the present study (See Appendix M).

4.4.2.9. Ways of Coping Inventory (WCI)

Ways of Coping Inventory (WCI) was originally developed by Lazarus and Folkman (1980) in an attempt to measure coping strategies individuals employ in response to stressful life events. Although the initial version consisted of 68 items measuring emotion-focused and problem focused coping strategies, the modified version was composed of 66 items (Folkman & Lazarus, 1985). Each item is responded on a 4 point Likert type scale, and response options range from 1 (not used) to 4 (used a great deal). The 66 item version includes 8 factors, which were categorized into three main domains, namely, (1) problem-focused coping, (2) emotion focused coping and (3) social support coping, respectively.

Turkish adaptation of the WCI was performed by Siva in 1991. Eight items were added to the original scale in order to cover religious and spiritual coping styles used frequently by Turkish population. Further, a 5 point Likert type response format was applied in Turkish adaptation. Factor analyses revealed a seven factor structure, which are (1) planned behavior, (2) fatalism, (3) mood regulation, (4) being reserved, (5) acceptance, (6) maturation, and (7) helplessness-seeking help, respectively. The Cronbach alpha value was reported to be .91 for the total scale. Turkish version of WCI was modified on a sample of earthquake survivors by Karanci and her colleagues in 1999. Thirteen items were excluded from the scale due to statistical and content-related concerns. Further, a 3 point Likert type response format was applied in order to facilitate responding. Principal components factor analysis with varimax rotation yielded a five factor solution of the scale. These factors are (1) problem-solving/optimistic coping ($\alpha = .75$), (2) fatalistic coping ($\alpha = .78$), (3) helplessness approach ($\alpha = .69$), (4) social support ($\alpha = .59$), and (5) escape ($\alpha = .51$), respectively. The Cronbach alpha of the total scale was found to be .76, as well.

In Karanci and Erkam’s study (2007), the item count of the scale was further reduced to 42 through including items only having a loading higher than .40 to the corresponding factor. Principal components factor analysis with varimax rotation yielded a four factor structure explaining 47.2 % variance. Factors are (1) fatalistic coping (e.g. “*I believe that God knows the best*”), (2) optimistic/seeking social support (e.g. “*I accept sympathy and understanding from someone*”), (3) problem-solving coping (e.g. “*I make a plan of action and follow it*”), and (4) helplessness coping (e.g. “*I wish that I can change what has happened or how I feel*”). The Cronbach alpha value for the fatalistic coping was .90 for the fatalistic coping, .76 for optimistic/seeking social support, .81 for problem-solving coping, and .78 for helplessness coping. Items 1, 2, 9, 10, 14, 15, 16, 20, 24, 29, 30, 33, 34, 37 comprises of fatalistic coping subscale; items 3, 4, 6, 7, 8, 21, 23, 27, 42 comprises of optimistic/seeking social support; items 5, 19, 22, 25, 28, 31, 38, 39, 41 comprises of problem-solving coping; and items 12, 17, 26, 35, 36, 40 comprises of helplessness coping, respectively.

Karanci and Erkam’s (2007) adaptation of WCI was used in the current study to assess coping styles employed by Turkish caregivers to handle disease and caregiving related stressors. The Cronbach alpha value for the total scale was .72 in the present study. The internal consistency values were .70 for the fatalistic coping, .64 for the optimistic/seeking social support coping, .82 for problem-solving coping and .72 for helplessness coping (See Appendix N).

4.4.2.10. The Perceived Partner Responsiveness Scale (PPR)

The Perceived Partner Responsiveness Scale (PPR) was originally developed by Reis (2003) in order to assess an individual’s perceived responsiveness in romantic, family and friendship relationships. The scale consists of 18 items and each item is responded on a 9 point Likert type scale ranging from 1 (almost never) to 9 (almost always). PPR aims to measure to what extend a relationship satisfied their core emotional needs such as validation and care). A sample item is “s/he appreciates my abilities and ideas” (item 15).

The Turkish adaptation of PPR was performed by Taşfiliz and her colleagues (2016). The Cronbach alpha values were .91 for partners, .96 for family members and .94 for friends. PPR was used in the current study to assess the quality of past relationship between the caregiver and care recipient prior to disease development. Hence, wording of the instructions were modified and caregivers were requested to answer each item by thinking their past relationship quality with the affected parent. The Cronbach alpha value of the scale was .97 in the present study (See Appendix O).

4.4.3. Procedure

Before application of any procedures, ethical permission was obtained from The Applied Ethics Research Center of Middle East Technical University. To initiate the adaptation process of MMCGI-SF, the original scale was translated into Turkish by 2 professors and 1 Ph.D. student, all of whom had experience in clinical psychology and were fluent both in Turkish and English. Later on, these translations were sent to two bilingual Ph.D. students to rate each Turkish translation for reflecting the meaning in the original item and make suggestions on the wording of the items. Feedbacks received from these two graduate students were later examined by Ar and Karanci together to determine the most appropriate and sensible translations for each item. This tentative Turkish version was sent to an instructor from Department of Basic English in METU for back translation purpose. Having compared the back translation with the original version, the final Turkish version agreed upon by Ar and Karanci was examined by a Turkish literature teacher for grammar and wording.

The instruments were uploaded on a data management program called Qualtrics, which were later disseminated through the internet. Written permission was obtained from the admins of three informal caregiver platform on Facebook. Upon permission of admins, an announcement calling for taking part in the study was posted on the walls of Facebook groups with a link providing the pack of questionnaires (APPENDIX B). Each caregiver willing to fill the questionnaires were offered a brochure including information on caregiving problems and possible coping strategies (APPENDIX C). As the current study only included adult children caregivers, an announcement informing group members that the brochure could also be sent to non-participants upon request was also posted through Facebook. To establish test re-test reliability, participants were contacted again through Facebook again after a 2-months interval, and participant match was done through nicknames provided by the caregivers at the initial assessment.

4.4.4. Data Analysis

In order to examine the factor structure of MMCGI-SF, a confirmatory factor analysis (CFA) was conducted on a sample of 190 adult children caregivers by means of EQS. To establish internal consistency reliability and construct validity of the total MMCGI-SF and its subscales, Cronbach alpha values were calculated with IBM SPSS v20.0 Computer Software (SPSS Inc., 2011). Further, convergent and divergent validity of MMCGI-SF was tested through calculation of Pearson conduct correlation values of the scale with other measures (i.e. BDI, ZBI, STAI-S, The Caregiver Well-Being Scale, and MSPSS).

Predictors of negative (i.e. depression, anxiety, grief and growth) and positive (i.e. growth) caregiving outcomes were examined through conducting four hierarchical regression analyses using IBM SPSS v20.0. Further, moderator roles of coping strategies and perceived social support was tested for each outcome variable separately using MODPROCESS macro (Hayes, &Preacher, 2008).

4.4.5. Data Cleaning

Prior to performing any statistical analyses, the current data was examined with respect to data entry, missing values, fit of distributions and assumptions of multivariate analysis. No missing values were detected on responded items since forced response option was applied while disseminating data through Qualtrics. Forced response did not allow participants to continue with the next page unless they fill out all the questions of the previous inventory. Linearity assumptions were also checked through inspection of skewness/kurtosis and bivariate associations between measures of the study. Multicollinearity between interest variables was ruled out as well, for none of the correlation values exceeded .90 among scales except for the inter-correlations between subscales of the MMCGI-SF.

4.5. Results

4.5.1. Psychometric Properties of Turkish Version of Marwit-Meuser Caregiver Grief Inventory-Short Form (MMCGI-SF)

4.5.1.1. Factor Structure of Turkish Version of Marwit-Meuser Caregiver Grief Inventory-Short Form (MMCGI-SF)

In order to examine whether the factor structure of MMCGI-SF in the current sample was equivalent to the structure reported by Meuser and Marwit in 2005, a Confirmatory Factor Analysis (CFA) was conducted by means of EQS 6.1 on a sample of 190 adult children caregivers. A maximum likelihood (ML) estimation was employed as it is appropriate for both continuous and normally distributed data

(Tabachnick, & Fidell, 2001). Although the skewness and kurtosis values are supposed to be equal to zero for data to be normally distributed, a value between -2 and +2 has also been accepted as an indicator of normal distribution (Chou & Bentler, 1995; Mindrila, 2010). Consistently, no item was excluded from the current analysis as the skewness and kurtosis values of each item were within the accepted levels.

MMCGI-SF composed of a three latent variable structure, which are (1) personal sacrifice burden, (2) heartfelt sadness and longing, and (3) worry and felt-isolation, respectively. To examine the match between the structure of the original scale and the structure that emerged from the current data, various fit indices were utilized. Based on the recommendations of Schwizer (2010), values of chi-square (χ 2), the root mean square error of approximation (RMSEA), the Bentler comparative fit index (CFI), and the standardized root mean square (SRMR) were determined as the minimum set of statistics to evaluate the current factor structure of MMCGI-SF (Tabachnick, & Fidell, 2001).

Chi-square (χ *2*) value is usually expected to be small and non-significant for a model to be regarded as acceptable. However, this assumption is criticized as the Chi-square (χ *2*) value is very sensitive to the sample size, and other fit indices could also be better indicators of a model fit (Schweizer, 2010; Tabachnick, & Fidell, 2001). Therefore, a relative chi-square value (χ *2*) is generally calculated through dividing chi-square (χ *2*) value to degrees of freedom (*df*), and a ratio below 3:1 is usually regarded as an acceptable fit. As for CFI, values between 1.00 and .95 indicate an excellent fit, while values ranging from .90 to .95 are regarded as an acceptable fit. Finally, the SRMR value is expected to be lower than .10 for a good model fit (Tabachnick, & Fidell, 2001).

Three latent variables were identified for the current study, each corresponding to the three subscales of MMCGI-SF, and each latent variable was allowed to correlate with each other. The initial model produced a relatively poor data fit statistics (χ *2*(132) = 411.416, *p* < .000, RMSEA = .10, CFI = .84, GFI = .79). Based on the suggestions of modification indices, error covariance was added between the two indicators of Worrying and Felt-Isolation (items 7 and 14), between the two indicators of Personal Sacrifice Burden (items 1 and 2), and between the two indicators of Heartfelt Sadness and Longing (items 11 and 12), respectively. Each item pair suggested to covary were examined to determine whether adding correlations between these item pairs were theoretically sensible or not. Examining meanings of these items suggested that the addition of error covariance for each suggested pair was appropriate due to the overlap between the meanings. (e.g. item 7 is " my friends simply don't understand what I'm going through/*arkadaşlarım neler yaşadığımı anlamıyorlar*" and item 14 is " the people closest to me do not understand what I'm going through/*bana en yakın insanlar neler yaşadığımı anlamıyorlar*"; item 1 is "I've had to give up a great deal to be a caregiver/*ona bakabilmek için pek çok şeyden vazgeçmek zorunda kaldım*" and item 2 is "I feel I am losing my freedom/*ona bakmaktan dolayı özgürlüğümü kaybettiğimi hissediyorum*"; and item 11 is "It hurts to put her/him to bed at night and realize that she/he is gone/*onu geceleri yatağa yatırmak ve onun eskisi gibi olmadığını fark etmek canımı acıtıyor*" and item 12 is "I feel very sad about what this disease has done/*bu hastalığın hasta olan ebeveynime yaptıkları beni çok üzüyor*"). All of the suggested modifications were run separately for each pair, and adding error covariance between the suggested items significantly improved the model. ($\chi\ 2_{dif}(1) = 61.63$, $p < .001$, χ 2dif (1) = 24.15, $p < .001$ and $\chi\ 2_{dif}(1) = 22.15$, $p < .001$, respectively). (See Table 4 for the items and factor loadings obtained from CFA). Thus, all of the suggested correlations were added to the current model as they were statistically and theoretically sensible. After correlations were allowed between paired items, the model significantly fitted the original factor structure of MMCGI-SF better ($\chi\ 2(129) = 303.681$, $p < .000$, RMSEA = .08, CFI = .90, GFI = .85). The chisquare/df ratio (303.681/129 = 2.35) was also below the 3:1 rule, suggesting an acceptable fit for the current model. See Table 4 for the items and factor loadings of MMCGI-SF.

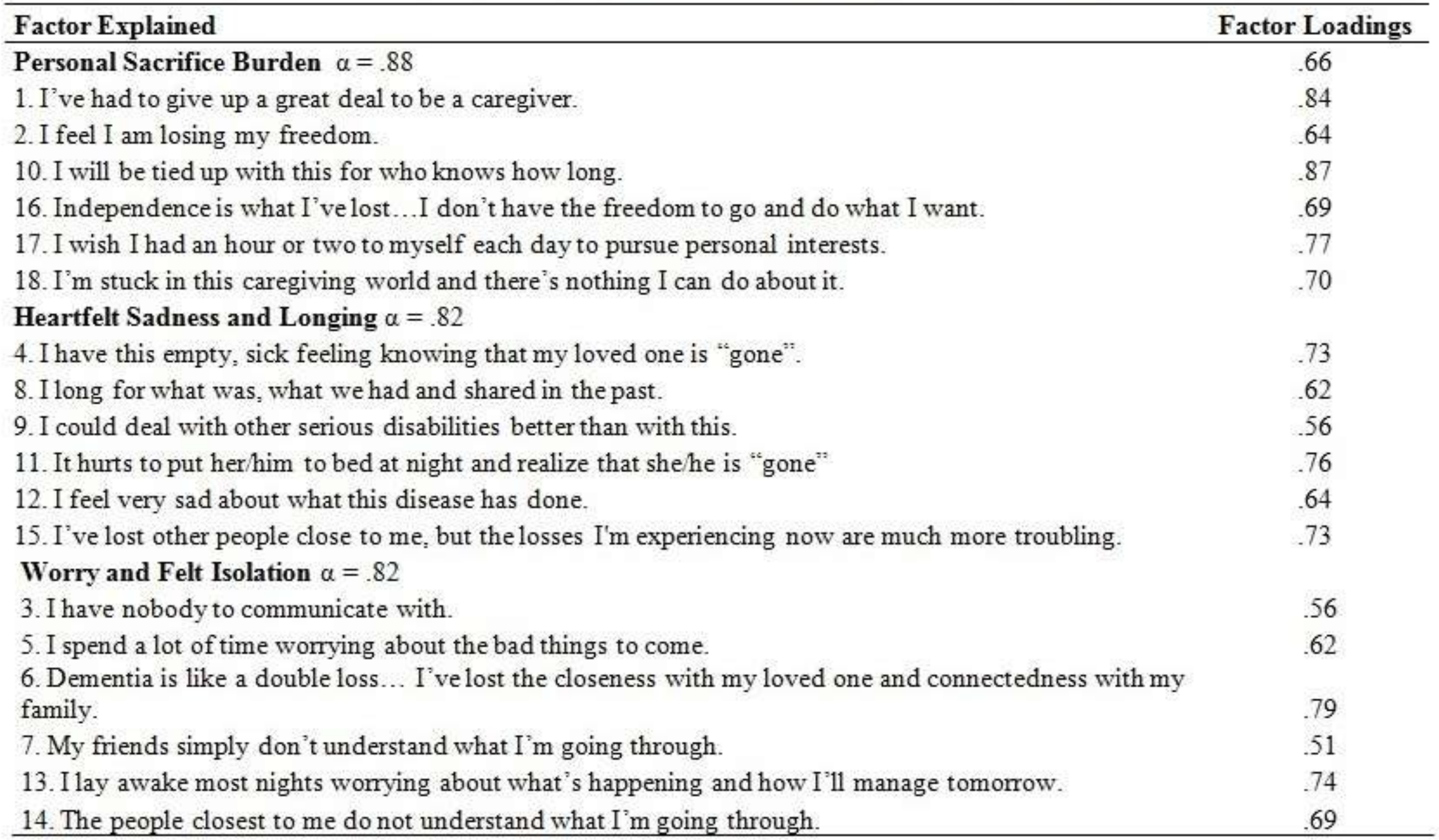
4.5.1.2. Internal Consistency of the MMCGI-SF

Cronbach alpha values were calculated in order to investigate internal consistency of the overall measure, and each of the three subscales. The total MMCGI-SF was found to have high internal consistency (α = .92). The corrected inter-item correlations ranged from .44 to .74 and Cronbach alpha value did not increase higher than .92 if any of the items were deleted from the measurement. Likewise, personal sacrifice burden (α = .88), heartfelt sadness and longing (α = .82), and worry and felt isolation (α = .82) subscales also exhibited high internal consistencies, as well. The corrected inter-item correlations ranged from .56 to .80 for the personal sacrifice burden, from .47 to .70 for heartfelt sadness and longing, and from .48 to .71 for worry and felt isolation. As was the case with the total MMCGI-SF, deletion of any item from corresponding subscales did not contribute to an increase in the Cronbach alpha values of the factors. Means, SDs and correlations among three subscales are presented in Table 5.

4.5.1.3. Concurrent Validity of MMCGI-SF

In order to examine concurrent validity of the scale, correlational analyses were conducted among MMCGI-SF, BDI (Beck Depression Inventory), ZBI (Zarit Burden Interview), and STAI-S (State-Trait Anxiety Inventory-State Form). As consistent with the psychometric properties of the long version of MMCGI and MMCGI-SF, the correlation of total MMCGI-SF with BDI was found to be moderate (r = .52). Consistently, the correlation between BDI scores and each of the three subscales (i.e. personal sacrifice burden, heartfelt sadness and longing, and worry and felt-isolation) ranged from moderate to moderate-to-low (r = .40, $p <$ .001; r = .39, $p < .001$; r = .56, $p < .001$, respectively). This modest relation of MMCGI and its subscales with depression was expected theoretically as grief and depression were proposed to be conceptually different phenomena although both share some common symptoms as well (e.g. sadness, hopelessness).

Table 4. Items and Factor Loadings of MMCGI-SF obtained from CFA performed among 190 Turkish adult children caregivers



Factor Explained	**Factor Loadings**
Personal Sacrifice Burden α = .88	.66
1. I've had to give up a great deal to be a caregiver.	.84
2. I feel I am losing my freedom.	.64
10. I will be tied up with this for who knows how long.	.87
16. Independence is what I've lost…I don't have the freedom to go and do what I want.	.69
17. I wish I had an hour or two to myself each day to pursue personal interests.	.77
18. I'm stuck in this caregiving world and there's nothing I can do about it.	.70
Heartfelt Sadness and Longing α = .82	
4. I have this empty, sick feeling knowing that my loved one is "gone".	.73
8. I long for what was, what we had and shared in the past.	.62
9. I could deal with other serious disabilities better than with this.	.56
11. It hurts to put her/him to bed at night and realize that she/he is "gone"	.76
12. I feel very sad about what this disease has done.	.64
15. I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	.73
Worry and Felt Isolation α = .82	
3. I have nobody to communicate with.	.56
5. I spend a lot of time worrying about the bad things to come.	.62
6. Dementia is like a double loss… I've lost the closeness with my loved one and connectedness with my family.	.79
7. My friends simply don't understand what I'm going through.	.51
13. I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	.74
14. The people closest to me do not understand what I'm going through.	.69

The correlation between total MMCGI-SF and ZBI scores were found to be .78 indicating a strong positive relation (*p* < .001). As expected, the correlation of Personal Sacrifice Burden with ZBI (r = .76, *p* < .001) was higher than that of Heartfelt Sadness/Longing (r = .56, p < .001) and Worry/Felt isolation (r = .71, *p* < .001) as the items of personal sacrifice burden measure secondary losses associated with caregiving demands, that are directly related with caregiver burden.

The correlation of MMCGI total with STAI-S was .48 (*p* < .001) indicating a modest relationship between AD caregiver grief and anxiety symptoms. As anticipated, the correlation between STAI-S and Worry/Felt Isolation subscale was slightly higher (r = .48, *p* < .001) than that of the other two subscales as one aim of the Worry and Felt Isolation subscale is to assess the anxiety associated with the unexpected course of the disease and caregiving process.

4.5.1.4. Divergent Validity of MMCGI-SF

In order to examine divergent validity of the scale, correlational analyses were conducted among MMCGI-SF, MSPSS (Multidimensional Scale of Perceived Social Support) and Caregiver Well-Being Scale. A significant negative correlation was found between MMCGI-SF and MMSPS although the association was weaker (r = -.15, *p* < .001). As for the subscales, only the correlation of Worry/Felt Isolation with MSPSS was found to be significant (r = -.26, *p* < .001). Finally, the correlation between total MMCGI-SF and Caregiver Well-Being scores were negative (r = -.38, *p* < .001), as well. The correlation of Caregiver Well-Being scores was -.35 with Personal Sacrifice Burden (*p* < .001), -.21 with Heartfelt Sadness and Longing (*p* < .001) and -.41 with Worry and Felt Isolation (*p* < .001). Table 5 gives detailed information about means, SDs and correlations among MMCGI-SF, BDI, ZBI, STAI-S, MSPSS and Caregiver Well-Being Scale.

4.5.2. Main Findings of the Study

4.5.2.1. Descriptive Statistics for the Study Variables

Means, SDs and minimum-maximum score ranges were calculated in order to investigate descriptive features of the study variables, namely, MMCGI-SF, ZBI, MSPSS, WCI, PTGI, PPR, BDI, and STAI-S. Table 6 provides detailed information on the descriptive characteristics of the study variables.

4.5.2.2. Correlations among Study Variables

Pearson correlation analyses were performed to examine the bivariate associations among the study variables (see Table 7). As can be seen from the table 7, one of the main outcome variables, depression, was positively associated with total grief score (r =.52, *p* < .01), caregiver burden (r =.47, *p* < .01), helplessness coping (r =.62, p < .01), and anxiety (r =.62, *p* < .01). Conversely, depression was negatively associated with social support (r = -.26, *p* < .01), total coping score (r = -.15, *p* < .01)., coping optimistic/seeking social support (r = -.53, p < .01), problem-focused coping (r = -.49, p < .01), caregiver well-being (r = -.58, *p* < .01) , growth (r = -.31, p < .01), and quality of past relationship (r = -.20, *p* < .01).

Another outcome variable, caregiver grief (measured by MMCGI-SF), was found to be positively correlated with caregiver burden (*r* =.78, *p* < .01), fatalistic coping (r =. 17, *p* < .001), helplessness coping (*r* = .57, *p* < .01), depression (*r* = .52, *p* < .01), and anxiety symptoms (*r* = .48, *p* < .01). By contrast, grief was negatively correlated with) perceived social support (*r* = -.15, *p* < .05), optimistic/seeking social support (*r* = -.28, *p* < .01), problem-focused coping (*r* = -.27, *p* < .01), caregiver well-being (*r* = -.38, p < .01), and quality of past relationship (*r* = -.15, *p* < .05).

The third outcome variable, growth, was found to be positive correlated with total coping score (*r* = .15, *p* < .05), optimistic/seeking social support (*r* = .37, *p* < .001), problem-focused coping (*r* = .17, *p* < .05), while negatively correlated with helplessness coping (*r* = -.21, *p* < .001), depression (*r* = -.31, *p* < .001), and anxiety (*r* = - .28, *p* < .001).

Table 5. Means, Standard Deviations, and Correlations between Study Variables

	1	2	3	4	5	6	7	8	9
1. MMCGI-SF Total	1	.87**	.84**	.90**	.52**	.78**	-.48**	-.15*	-.38**
2. Personal Sacrifice Burden			.57**	.68**	.40**	.76**	.39**	-.094	-.35**
3. Heartfelt Sadness and Longing				.67**	.56**	.56**	.39**	-.04	-.21**
4. Worry and Felt Isolation					.56**	.71**	.48**	-.26**	-.41**
5. BDI						.47**	.62**	-.29**	-.57**
6. ZBI							.48**	-.12	-.31**
7. STAI-S								-.22	-.47**
8. MMSPS									.34**
9. Caregiver Well-Being									1
Mean	64.08	21.84	23.38	18.87	14.98	57.18	43.49	48.08	148.61
SD	13.54	5.55	4.68	5.26	9.04	14.59	11.11	22.43	24.97

*$p < .05$
** $p < .001$

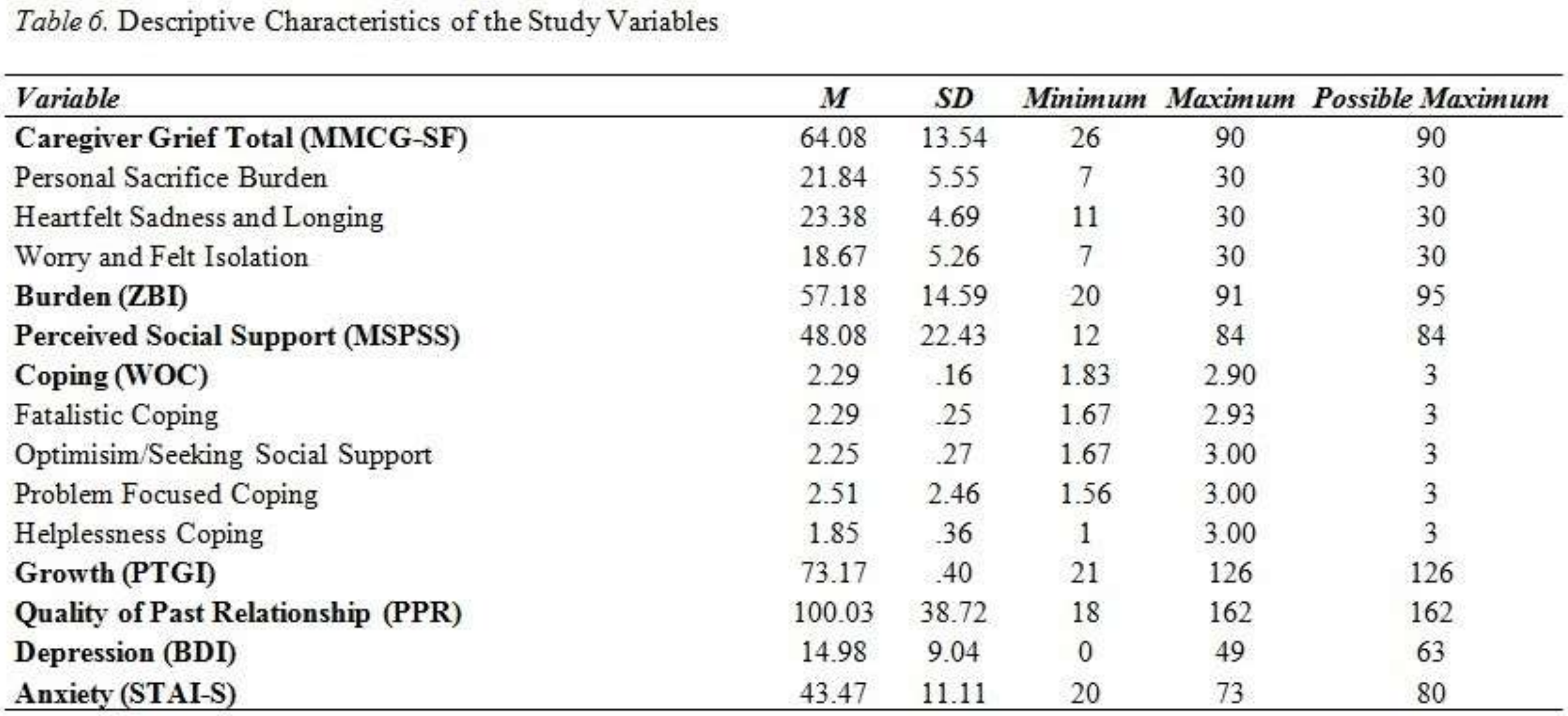


Table 6. Descriptive Characteristics of the Study Variables

Variable	*M*	*SD*	*Minimum*	*Maximum*	*Possible Maximum*
Caregiver Grief Total (MMCG-SF)	64.08	13.54	26	90	90
Personal Sacrifice Burden	21.84	5.55	7	30	30
Heartfelt Sadness and Longing	23.38	4.69	11	30	30
Worry and Felt Isolation	18.67	5.26	7	30	30
Burden (ZBI)	57.18	14.59	20	91	95
Perceived Social Support (MSPSS)	48.08	22.43	12	84	84
Coping (WOC)	2.29	.16	1.83	2.90	3
Fatalistic Coping	2.29	.25	1.67	2.93	3
Optimisim/Seeking Social Support	2.25	.27	1.67	3.00	3
Problem Focused Coping	2.51	2.46	1.56	3.00	3
Helplessness Coping	1.85	.36	1	3.00	3
Growth (PTGI)	73.17	.40	21	126	126
Quality of Past Relationship (PPR)	100.03	38.72	18	162	162
Depression (BDI)	14.98	9.04	0	49	63
Anxiety (STAI-S)	43.47	11.11	20	73	80

Table 7. Bivariate Correlations among Study Variables

	1	2	3	4	5	6	7	8	9	10	11
1. Age	1										
2. Gender	-.15	1									
3. Education	.03	.01	1								
4. Income	.10	.03	.33**	1							
5. Stage of Disease	.03	.00	.08	-.02	1						
6. Time Since Onset of the Disease	.02	-.01	.10	-.02	.47**	1					
7. Time Since Diagnosis	.00	-.04	.05	-.01	.42**	.86**	1				
8. Length of Caregiving	.08	-.06	-.01	-.07	.33**	.62**	.66**	1			
9. Caregiving per Week	.09	-.04	-.17	-.13	.11	-.04	-.08	-.05	1		
10. Co-residence	-.05	.02	.05	.16**	-.05	-.01	.03	.01	-.57	1	
11. Help from Others	.09	-.18*	-.27**	-.21**	-.32**	-.23**	-.18*	-.13	.31**	-.28**	1

* $p < .05$
** $p < .001$

Table 7 (cont'd). Bivariate Correlations among Study Variables

	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
1. Age	.04	.16*	-.06	-.01	.05	.05	-.03	-.08	-.00	.00	.04	.10	.03	-.06	-.06	.01
2. Gender	-.15*	-.13	-.20	-.07	-.12	.01	-.09	-.10	-.09	.02	-.04	-.02	-.14	.07	-.05	-.00
3. Education	-.01	-.01	-.02	-.00	.03	.12	.00	-.16*	.08	.12	-.04	.03	-.02	.10	-.09	.03
4. Income	-.03	-.06	.04	-.04	-.08	.10	-.09	-.19*	.03	.05	-.05	.18*	.00	.11	-.11	-.07
5. Stage of Disease	.13	.06	.19**	.10	.08	-.03	.09	.06	.02	.09	.04	-.03	.10	.11	.05	.06
6. Time Since Onset of the Disease	.00	.02	-.04	.01	-.03	-.07	.01	-.01	.04	.07	-.06	.03	.01	.03	.02	-.04
7. Time Since Diagnosis	-.02	-.03	-.01	-.02	-.06	-.01	.02	.01	.02	.06	-.04	.08	-.01	-.01	.07	-.02
8. Length of Caregiving	.05	.06	.04	.04	.03	-.06	.06	.10	.03	-.01	.02	.08	.03	.01	.10	-.03
9. Caregiving per Week	.12	.18*	.03	.11	.07	-.06	.01	.04	.01	.01	-.07	-.12	.05	-.01	.00	-.03
10. Co-residence	-.19**	-.28**	-.04	-.17*	-.23**	.12	-.11	-.11	-.05	.01	-.03	.14	-.03	.00	-.06	-.01
11. Help from Others	.08	.15*	-.07	.11	.13	-.07	.03	.07	-.06	-.06	.08	-.09	-.12	-.15*	.09	.05

* $p < .05$

** $p < .001$

Table 7 (cont'd). Bivariate Correlations among Study Variables

	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
12. Caregiver Grief Total	1															
13. Personal Sacrifice Burden	.87**	1														
14. Heartfelt Sadness and Longing	.84**	.57**	1													
15. Worry and Felt Isolation	.90**	.67**	.67**	1												
16. Caregiver Burden	.78**	.56**	.71**	.71**	1											
17. Social Support	-.15*	-.04	.26**	-.12	-.12	1										
18. Coping Total	.01	.18*	.05	.03	.12	.12	1									
19. Fatalistic Coping	.17*	.21**	.12*	.08	.02	.69**	.69**	1								
20. Optimistic/Seeking Social Support	-.28**	-.18*	-.30**	-.32**	.14	.64**	.14	.14	1							
21. Problem-Solving Coping	-.27**	-.13	-.31**	-.29**	.16*	.58**	-.02	.69**	.69**	1						
22. Helplesness Coping/Self-Blame	.57**	.49**	.55**	.55**	-.13	.17*	.20**	-.38**	-.39**	-.39**	1					
23. Caregiver Well-Being	-.38**	-.21**	-.41**	-.31**	.34**	.25**	.02	.48**	.47**	-.43**	-.43**	1				
24. Growth	-.01	-.05	-.07	-.11	.11	.15*	.07	.27**	.17*	-.21**	-.35**	.35**	1			
25. Quality of Past Relationship	-.15*	.06	-.17*	-.27**	.22**	.10	-.03	.22**	.23**	-.22**	.23**	.10	.10	1		
26. Depression	.52**	.39**	.56**	.47**	-.26**	-.15*	.09	-.53**	-.49**	.62**	-.57**	-.31**	-.20**	-.20**	1	
27. Anxiety	.48**	.39**	.48**	.48**	-.22**	-.15*	.07	-.52**	-.45**	.59**	-.47**	-.28**	-.23**	.62**	.62**	1

* $p < .05$
** $p < .001$

4.5.2.3. Main Analyses: Variables Associated with Negative and Positive Caregiving Outcomes

In the current study, it was hypothesized that certain background/contextual variables (i.e. age, gender, education, income, quality of past relationship), primary stressors/disease-related factors (i.e. stage of disease, time since onset of the disease, time since diagnosis, caregiving per week, length of caregiving, co-residence), secondary stressors (i.e. caregiver burden), moderator variables (e.g. coping styles, social support) would be associated with caregiver depression, anxiety, grief, and growth. Four hierarchical regression analyses were conducted to determine the predictors of caregiver outcomes (i.e. depression, anxiety, grief, and growth), and to investigate whether addition of aforementioned variables in sequential orders would explain a unique variance in caregiver outcomes beyond previously entered variables of the study. For all regression analyses, four sets of independent variables (IVs) were entered into the equation once at a time. The first set of IVs were composed of background/contextual variables. This set included age, gender, education, income and quality of past relationship between the caregiver and care-recipients. The second set of IVs corresponded to primary stressors/disease-related stressors. This set included stage of disease, time since onset of the disease, time since diagnosis, caregiving per week, length of caregiving and co-residence. The third set included subjective caregiver burden to investigate effect of secondary stressors on caregiver outcomes. The final set of IVs were moderating variables. Coping strategies (i.e. fatalistic coping, problem-focused coping and helplessness, optimistic/seeking social support coping and perceived social support were entered in this final step. List of variable sets entered in hierarchical regression analyses were presented in Table 8.

4.5.2.4. Variables Associated with Depression

The first hierarchical regression analysis was performed in order to identify factors associated with depression. Results indicated that 54 % of the variance (*adjusted* R^2 = .50) in depression scores was explained by some of the variables entered into the equation through four different steps.

Table 8. List of variables in the four steps of the regression analyses

Steps	**Predictors**
Step 1: Background/Contextual Variables	Age
	Gender (1: female, 2: male)
	Education
	Income
	Quality of Past Relationship
Step 2: Primary Stressors/Disease-Related Factors	Stage of Disease
	Time Since Onset of the Disease
	Time Since Diagnosis of the Disease
	Caregiving per Week
	Lenght of Caregiving
	Co-residence (1:yes, 2:no)
Step 3: Secondary Stressors	Subjective Caregiver Burden
Step 4: Moderator Variables	Fatalistic Coping
	Problem-Solving Coping
	Optimistic/Seeking Social Support
	Helplessness Coping
	Perceived Social Support

Findings suggested that contextual/background variables entered in the first step and primary stressors/disease-related variables entered in the second step did not explain a significant amount of variance in caregivers' depressive scores. By contrast, the third step including caregiver burden explained 19 % of the total variance in depressive symptoms of AD caregivers (*Fchange* [1,177] = 45.42, $p <$ .001). Adding caregiver burden to the model improved explained total variance from 8 % to 27 %. Specifically, increased caregiver burden was associated with higher depressive symptoms in this step (β = .48, *t*[189] = 6.74, $p < .01$). Entering coping styles and perceived social support in the final step lead to a significant increment in the R^2 and explained a unique 28 % variance in the model (*Fchange* [5,172] = 20.82, $p < .00$). Whereas optimistic/seeking social support (β = -.26, *t* [172] = -3.33, $p < .001$) and perceived social support (β = -.13, *t*[172] = -2.35, $p <$ .05) were negatively associated with depressive symptoms; helplessness coping (β =

.14, *t*[172] = 5.81, *p* < .01) was positively associated with depression scores of the caregivers. When all the variables were entered in the final model, the association between caregiver burden and depressive symptoms were still significant (*β* = .48, *t*[172] = 2.03, *p* < .05). See Table 9 for the predictors of depression.

Table 9. Factors Associated with Depression

	Fchange	t value	df	β	ΔR2
Outcome Variable: Depression					
Step 1: Background/Contextual Variables	2.13 (n.s.)		5, 184		.06
Age		-.92		-.07	
Gender		-.51		-.04	
Education		-.58		-.04	
Income		-.89		-.07	
Quality of Past Relationship		-2.29		-.19	
Step 2: Primary Stressors/Disease-Related Factors	.73 (n.s.)		6, 178		.02
Stage of Disease		.84		.07	
Time Since Onset of the Disease		-1.04		-.15	
Time Since Diagnosis of the Disease		.66		.10	
Caregiving per Week		-.68		-.06	
Lenght of Caregiving		1.07		.11	
Co-residence		-1.01		-.09	
Step 3: Secondary Stressors	45.41**		1, 177		.19
Subjective Caregiver Burden		6.74		.48	
Step 4: Moderator Variables	20.82**		5, 172		.28
Fatalistic Coping		.24		-.01	
Problem-Solving Coping		-1.35		-.10	
Optimistic/Seeking Social Support		-3.33**		-.26	
Helplessness Coping		5.81**		.39	
Perceived Social Support		-2.35*		-.13	

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

4.5.2.5. Variables Associated with Anxiety

The second hierarchical regression analysis was performed in order to identify factors associated with anxiety. Results indicated that 50 % of the variance (adjusted R^2 = .45) in anxiety scores was explained by some of the variables entered into the equation through four different steps.

Findings suggested that contextual/background variables entered in the first step explained 6 % variance in anxiety scores of caregivers (F_{change} [5,184] = 2.28, $p < .05$). Among contextual/background variables, only quality of past relationship was negatively associated with anxiety scores ($\beta = -.23$, $t[184] = -3.14$, $p < .05$). Conversely, the second step including primary stressors/disease-related variables did not explain a significant amount of variance in anxiety scores. Adding caregiver burden to the model improved explained total variance from 7 % to 26 % (*Fchange* [1,177] = 43.86, $p < .01$). Specifically, higher caregiver burden was associated with increased anxiety scores in this step ($\beta = .80$, $t[177] = 15.83$, $p < .01$).

Table 10. Factors Associated with Anxiety

	Fchange	t value	df	β	ΔR^2
Outcome Variable: Anxiety					
Step 1: Background/Contextual Variables	2.27*		5, 184		.06
Age		0.04		.00	
Gender		0.18		.01	
Education		0.94		.07	
Income		-0,91		-,07	
Quality of Past Relationship		-3.13**		-,23	
Step 2: Primary Stressors/Disease-Related Factors	.60 (n.s.)		6, 178		.02
Stage of Disease		1.68		.14	
Time Since Onset of the Disease		-.71		-.11	
Time Since Diagnosis of the Disease		.14		.02	
Caregiving per Week		-.85		-.08	
Lenght of Caregiving		-.36		-.04	
Co-residence		-.49		-.04	
Step 3: Secondary Stressors	43.86**		1, 177		.18
Subjective Caregiver Burden		6.62		.47	
Step 4: Moderator Variables	16.12**		5, 172		.24
Fatalistic Coping		.76		-.01	
Problem-Solving Coping		.76		-.06	
Optimistic/Seeking Social Support		-3.47**		-.28	
Helplessness Coping		4.85**		.34	
Perceived Social Support		-1.99*		-.11	

* $p < .05$, ** $p < .01$

Entering coping styles and social support in the final step lead to a significant increment in the R^2 and explained a unique 24 % variance in the model (*Fchange* [5,172] = 16.12, $p < .00$). Among other variables, helplessness coping was positively associated with anxiety scores of caregivers ($\beta = .35$, $t[172] = 4.85$, $p < .01$). By contrast, optimistic/seeking social support ($\beta = -.28$, $t[172] = -3.47$, $p < .01$) and perceived social support ($\beta = .-11$, $t[172] = -1.99$, $p < .05$). were negatively associated with anxiety symptoms. When all the variables were entered in the final model, only the association between caregiver burden and anxiety scores was still significant ($\beta = .16$, $t[172] = 2.24$, $p < .05$). See Table 10 for the predictors of anxiety.

4.5.2.6. Variables Associated with Caregiver Grief

The third hierarchical regression analysis was performed in order to identify factors associated with caregiver grief. Results indicated that 67 % of the variance (adjusted $R^2 = .64$) in grief scores was explained by some of the variables entered into the equation through four different steps.

Findings suggested that contextual/background variables entered in the first step did not explain a significant amount of variance in caregivers' grief scores. By contrast, the second step including primary stressors/disease-related variables explained 11 % of the total variance in grief symptoms of AD caregivers (*Fchange* [6,178] = 2.29, $p < .05$). In this step, stage of disease was positively associated with caregivers' grief scores ($\beta = .18$, $t[178] = 2.17$, $p < .05$).

Adding caregiver burden to the model improved explained total variance from 6 % to 61 %. Specifically, higher caregiver burden was associated with higher grief symptoms in this step ($\beta = .80$, $t[177] = 15.83$, $p < .01$).

Entering coping styles and social support in the final step lead to a significant increment in the R^2 and explained a unique 4 % variance in the model (*Fchange* [5,172] = 4.16, $p < .00$). Among other variables, only helplessness coping was positively associated with caregiver grief scores ($\beta = .19$, $t[172] = 3.28$, $p < .01$). When all the variables were entered in the final model, only the association between caregiver burden and grief scores was still significant ($\beta = .68$, $t[172] = 11.92$, $p < .05$). See Table 11 for the predictors of grief.

Table 11. Factors Associated with Grief

	Fchange	t value	df	β	ΔR2
Outcome Variable: Grief					
Step 1: Background/Contextual Variables	1.61 (n.s.)		5, 184		.04
Age		.34		.03	
Gender		-1.91		-.14	
Education		.09		.01	
Income		-.15		-.01	
Quality of Past Relationship		-1.86		-.14	
Step 2: Primary Stressors/Disease-Related Factors	2.29*		6, 178		.04
Stage of Disease		2,17*		.18	
Time Since Onset of the Disease		-.03		-.00	
Time Since Diagnosis of the Disease		-1.09		-.16	
Caregiving per Week		-.20		-.02	
Lenght of Caregiving		1.08		.10	
Co-residence		-2.21*		-.19	
Step 3: Secondary Stressors	250.81**		1, 177		.52
Subjective Caregiver Burden		15.84		.80	
Step 4: Moderator Variables	4.16**		5, 172		.04
Fatalistic Coping		1.67		.08	
Problem-Solving Coping		-.08		-.01	
Optimistic/Seeking Social Support		-.10		-.01	
Helplessness Coping		3.28**		.19	
Perceived Social Support		-.47		-.07	

* $p < .05$, ** $p < .01$

4.5.2.7. Variables Associated with Growth

The forth hierarchical regression analysis was performed in order to identify factors associated with growth. Results indicated that 13 % of the variance (adjusted R^2 = .05) in growth was explained by some of the variables entered into the equation through four different steps.

Findings suggested that only entering coping styles and social support in the final step lead to a significant increment in the R2 and explained a unique 7 % variance in the model (F_{change} [5,172] = .05, $p < .00$). Among other variables, only optimistic/seeking social support ($\beta = .23$, $t[172] = 2.19$, $p < .05$) was positively associated with caregiver growth. See Table 12 for the predictors of growth.

Table 12. Factors Associated with Growth

	Fchange	t value	df	β	ΔR2
Outcome Variable: Growth					
Step 1: Background/Contextual Variables	1.19 (n.s.)		5, 184		.03
Age		.40		.03	
Gender		-1.96		-.14	
Education		-.37		-03	
Income		.00		.00	
Quality of Past Relationship		1.50		.11	
Step 2: Primary Stressors/Disease-Related Factors	.40 (n.s.)		6, 178		.01
Stage of Disease		1.28		.11	
Time Since Onset of the Disease		.16		.02	
Time Since Diagnosis of the Disease		-.65		-.10	
Caregiving per Week		.24		.02	
Lenght of Caregiving		.40		.04	
Co-residence		-.11		-.01	
Step 3: Secondary Stressors	3.26 (n.s.)		1, 177		.02
Subjective Caregiver Burden		-1.80		-.15	
Step 4: Moderator Variables	2.73*		5, 172		.07
Fatalistic Coping		.51		.04	
Problem-Solving Coping		-.67		-.07	
Optimistic/Seeking Social Support		2,19*		.23	
Helplessness Coping		-1.77		.08	
Perceived Social Support		.99		.32	

* $p < .05$, ** $p < .01$

See Table 13 for the summary of all hierarchical regression analyses.

4.5.3. Moderation Analyses

The moderator roles of coping strategies (i.e. fatalistic coping, optimistic/seeking social support, problem-solving coping and helplessness coping) and perceived social support on caregiver outcomes (i.e. depression, anxiety, grief and growth) were investigated through conducting a set of moderation analyses. Hayes and Matthes (2009) macro was used in order to perform moderation analyses. Prior to analyses, Z-scores were calculated for each independent and moderator variable; and the moderation analyses were performed for each caregiver outcome separately. Among a series of analyses performed to examine moderator roles of coping

Table 13. Summary of all the hierarchical regression analyses

	Depression	Anxiety	Grief	Growth
Step 1: Background/Contextual Variables				
Age	ns	ns	ns	ns
Gender	ns	ns	ns	ns
Education	ns	ns	ns	ns
Income	ns	ns	ns	ns
Quality of Past Relationship	ns	sign.	ns	ns
Step 2: Primary Stressors/Disease-Related Factors				
Stage of Disease	ns	ns	sign.	ns
Time Since Onset of the Disease	ns	ns	ns	ns
Time Since Diagnosis of the Disease	ns	ns	ns	ns
Caregiving per Week	ns	ns	ns	ns
Lenght of Caregiving	ns	ns	ns	ns
Co-residence	ns	ns	sign.	ns
Step 3: Secondary Stressors				
Subjective Caregiver Burden	sign.	sign.	sign.	ns.
Step 4: Moderator Variables				
Fatalistic Coping	ns.	ns.	ns.	ns.
Problem-Solving Coping	ns.	ns.	ns.	ns.
Optimistic/Seeking Social Support	sign.	sign.	ns.	sign.
Helplessness Coping	sign.	sign.	sign.	ns.
Perceived Social Support	sign.	sign.	ns.	ns.

strategies and social support on subjective burden and each outcome variable, only four of the moderation models were found to be significant. A visual representation of each significant model is also provided below through plotting regression lines based on obtained observed scores.

4.5.3.1. Moderator Role of Problem-Focused Coping on the Relationship between Caregiver Burden and Depression

The model examining effect of problem-focused coping on the relationship between caregiver burden and depression was found to be significant (R^2= .38, F (3, 186) = 37.38, p < .001). The interaction was also significant (B = -.03, SE = -0.01, p <

.05). Johnson and Neyman (1936) method was employed in order to explain the relationship between caregiver burden (IV) and depression (DV) for different scores of problem-focused coping (M). It was shown that as the scores of problem-focused coping got higher than the critical value (1.3053), the relationship between the caregiver burden and depression became non-significant. When the scores of problem-focused coping got lower than the critical value (1.3053) the relationship between the caregiver burden and depression became significant (*B* = 1.6919, *SE* =.8576, *p* =.050, 95% CI [0, 3.3838]). This finding indicated that higher levels of problem-focused coping buffered the negative effect of caregiver burden on depression symptoms, decreasing the intensity of detrimentals effect of burden on caregiver depression. In other words, the results of the moderation analyses revealed that when caregivers used problem-solving coping strategies less, caregiver depression tended to increase at higher levels of caregiver burden. Nevertheless, higher levels of problem-focused coping did not have a moderating effect on the relationship between caregiver burden and depression.

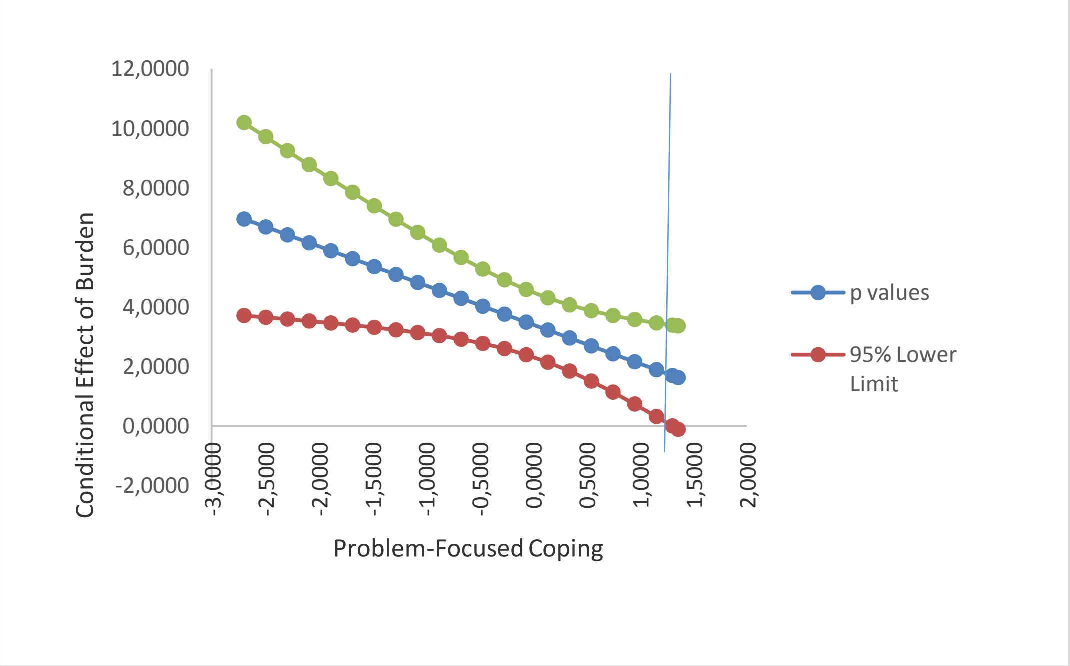


Figure3. Relationship between Caregiver Burden and Depression for Different Scores of Problem-Focused Coping with the Confidence Interval Values

Note: Critical Value is 1.3053

4.5.3.2. Moderator Role of Perceived Social Support on the Relationship between Caregiver Burden and Depression

The model examining effect of social support on the relationship between caregiver burden and depression was found to be significant ($R^2 = .29$, $F(3, 186) = 24.96$, $p < .001$). The interaction was also significant ($B = -1.35$, $SE = 0.56$, $p < .05$). Johnson and Neyman (1936) method was employed in order to explain the relationship between caregiver burden (IV) and depression (DV) for different scores of social support (M). It was shown that within the observed range of social support scores (M), the relationship between caregiver burden and depression did not become non-significant. Inspection of change in the slopes between burden and depression as a function of social support indicated that the negative effect of caregiver burden on depressive symptoms became less intense as the level of perceived social support increased. By contrast, the negative effect of burden on depression intensified as the level of perceived social support decreased. In other words, when caregivers perceived greater social support from others, caregiver depression tended to decrease at higher values of caregiver burden. By contrast, when the perceived social support level was lower, caregiver depression tended to increase at higher values of caregiver burden (See Figure 4).

4.5.3.3. Moderator Role of Social Support on the Relationship between Caregiver Burden and Anxiety

The model examining effect of social support on the relationship between caregiver burden and anxiety was found to be significant (R2 = .29, F(3, 186) = 24.96, p < .001). The interaction was also significant (B = -1.35, SE = 0.56, p < .05). Johnson and Neyman (1936) method was employed in order to explain the relationship between caregiver burden (IV) and anxiety (DV) for different scores of social support (M). It was shown that within the observed range of social support scores, the relationship between caregiver burden and anxiety did not become non-significant. Inspection of change in the slopes between burden and depression scores as a function of social support indicated that the negative effect of caregiver burden on anxiety symptoms became less intense as the level of perceived social

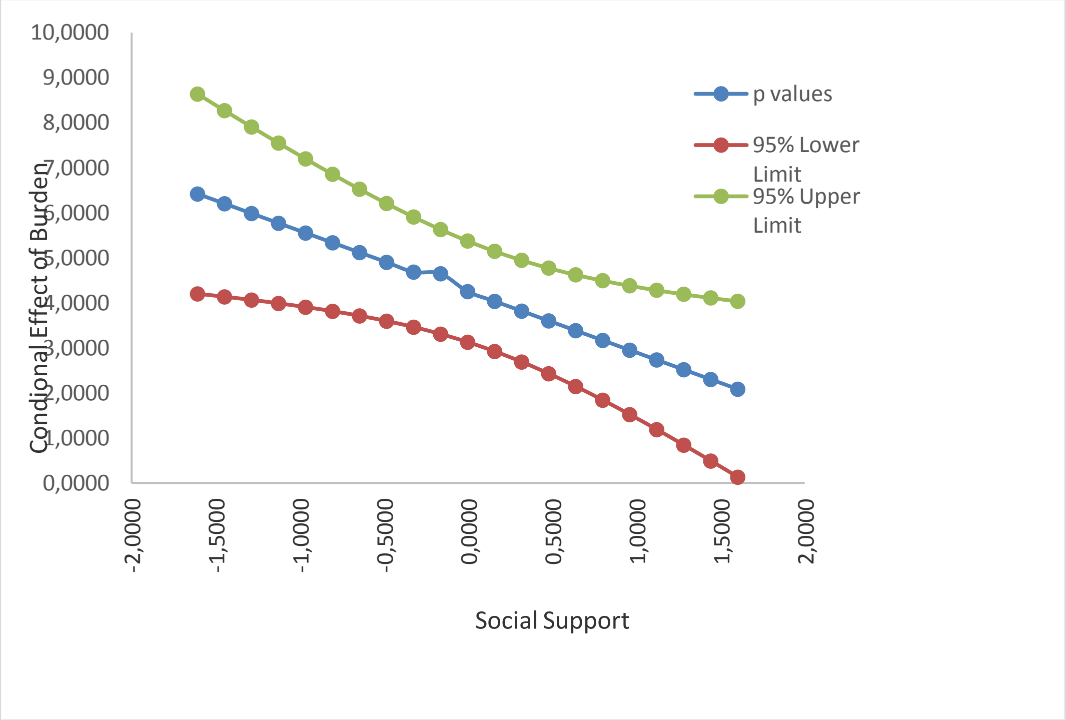


Figure 4. Relationship between Caregiver Burden and Depression for Different Scores of Perceived Social Support with the Confidence Interval Values

support increased. By contrast, the negative effect of burden on anxiety symptoms intensified as the level of perceived social support decreased. In other words, when caregivers perceived greater social support from others, anxiety tended to decrease at higher values of caregiver burden. By contrast, when the perceived social support levels were lower, caregiver anxiety tended to increase at higher values of caregiver burden. (See Figure 5).

4.5.3.4. Moderator Role of Social Support on the Relationship between Caregiver Burden and Growth

The model examining effect of social support on the relationship between caregiver burden and growth was found to be significant ($R^2 = .09$, $F(3, 186) = 6.09$, $p < .001$). The interaction was also significant ($B = 5.61$, $SE = 1.52$, $p < .001$). Johnson and Neyman (1936) method was employed in order to explain the relationship between caregiver burden (IV) and growth (DV) for different scores of social support (M). It was shown that as the scores of social support became lower than the critical value (-.0247) or became higher than the critical value (1.3777) the

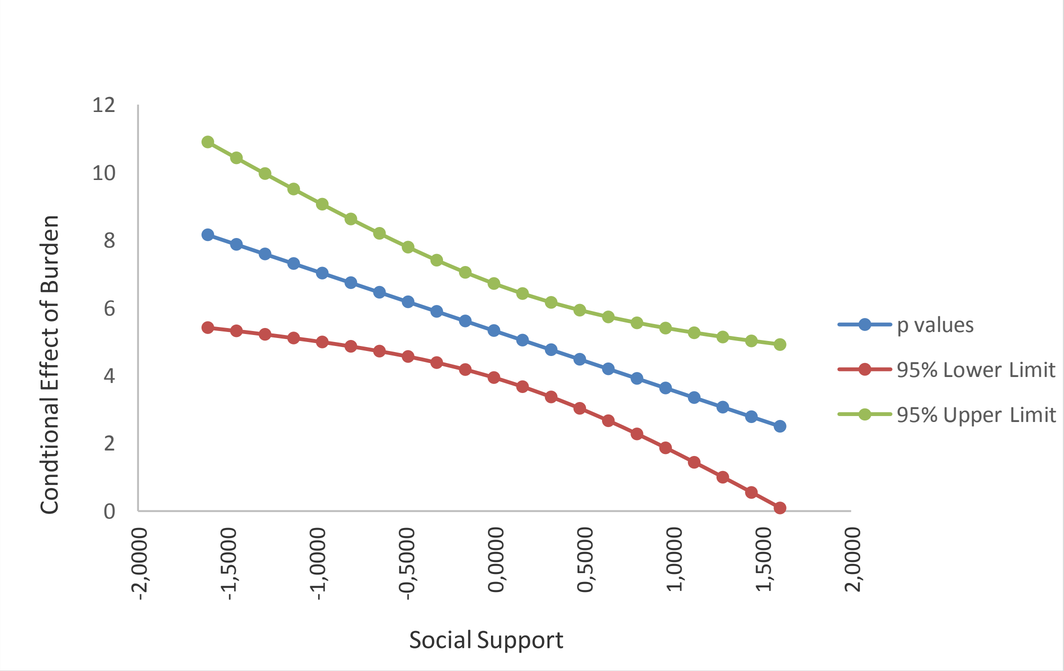


Figure 5. Relationship between Caregiver Burden and Anxiety for Different Scores of Perceived Social Support with the Confidence Interval Values

relationship between the caregiver burden and growth became significant. When the scores of social support became lower than the critical value (-.0247), the negative relation between caregiver burden and growth became accentuated, meaning that caregiver burden had a more negative impact on growth scores when the perceived social support became lower. Interestingly, as the scores of social support became higher than the critical value (1.3777), the positive association between caregiver burden and growth became stronger meaning that increased caregiver burden was associated with greater levels of growth among caregivers in the presence of higher levels of perceived social support. Nevertheless, moderate levels of social support (between the critical values of -.0247 and 1.3777) did not have a buffering effect on this relation (See Figure 6).

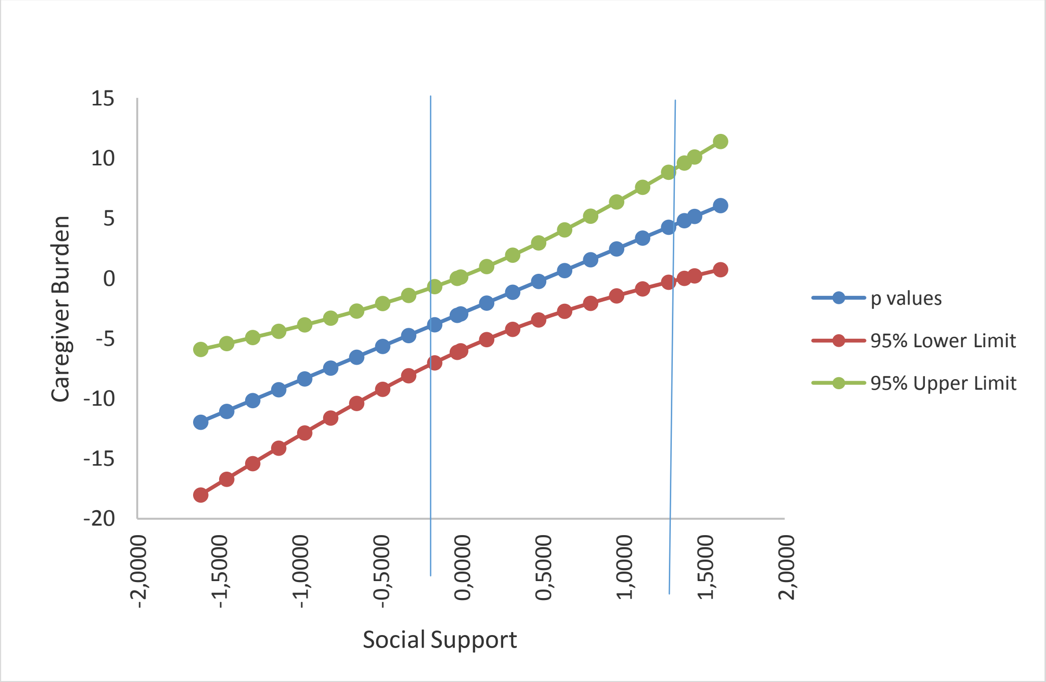


Figure 6. Relationship between Caregiver Burden and Growth for Different Scores of Perceived Social Support with the Confidence Interval Values

Note: Critical Values are -.0247 and 1.3777

4.6. Discussion

The quantitative part of the current thesis was conducted for three main purposes. The initial objective was to establish the psychometric properties of the Marwit-Meuser Caregiver Grief Inventory-SF (MMCGI-SF) which aims to measure grief responses of informal AD caregivers prior to the actual death of the patient. For this purpose, a CFA was initially performed on a sample of 190 adult children caregivers. Later on, the scale was validated against a series of instruments (i.e. BDI, ZBI, STAI-S, Caregiver Well-Being Scale and MSPSS). The second purpose of the quantitative strand was to examine different predictors of negative (i.e. depression, anxiety and grief) and positive (i.e. growth) caregiver outcomes. For this purpose, variables constituting different sets were constructed based on the "Caregiver Stress Model" (Pearlin et al., 1990) and "Model of Carer Stress and Burden" (Sörensen et al., 2006). In that respect, the predictive roles of contextual/background variables (i.e. age, gender, education, household income and quality of past relation with the care recipient), primary stressors/disease-related variables (i.e. stage of disease, time since onset, time since diagnosis, caregiving per week, length of caregiving and co-residence), secondary stressors (i.e. subjective caregiver burden) and moderators (i.e. coping styles and perceived social support) on caregiver outcomes (i.e. depression, anxiety, grief and growth) were investigated through four hierarchical regression analyses. The third and final purpose of the quantitative part was to investigate the moderator roles of coping strategies (i.e. fatalistic coping, problem-solving coping, optimistic/seeking social support coping and helplessness coping) and perceived social support on the relationship between subjective caregiver burden and caregiver outcomes (i.e. depression, anxiety, grief and growth). For this purpose, Hayes and Preacher's (2008) MODPROCESS macro was used for each outcome variable.

Psychometric Properties of MMCGI-SF

The present study revealed that MMCGI-SF had psychometric soundness for Turkish adult children caregivers of AD. On the whole, findings confirmed the original factor structure of thescale (Marwit & Meuser, 2005), and revealed that MMCGI-SF is a reliable tool for assessing distinctive pre-death grief symptoms among Turkish informal AD caregivers.

Anticipatory Grief Scale (AGS) was the only supposedly related measure to assess anticipatory grief responses of AD caregivers (Theut, Jordan, Ross, and Stephen, 1991) until the development of the original MMCGI. Nevertheless, AGS was not a robust measure as it was not empirically derived, and validated only against a single instrument (Marwit & Meuser, 2002; Marwit & Meuser, 2005). Besides, items of AGS did not include differential aspects of dementia grief such as the ongoing primary and secondary losses associated with cognitive deterioration (Marwit & Meuser, 2002). Hence, in an attempt to create a valid instrument to measure the qualitatively different nature of dementia caregiving, Meuser and Marwit (2001) conducted 16 focus groups with informal dementia caregivers in order to identify themes related to the anticipatory grief processes. Based on the information obtained from the focus groups, 184 grief-related statements were constructed by the researchers. Some of these statements were direct accounts of the caregivers, while some others were modified statements tapping the loss and grief related issues uttered during focus group discussions. Through factor analytic techniques, the item count of the scale was reduced to 50, and this final version was validated against BDI, Geriatric Depression Scale, AGS, Caregiver Strain Index, Caregiver Well Being Scale and Family Subscale of Perceived Social Support Scale (Marwit & Meuser, 2002). Having found MMCGI was a reliable and valid tool, these researchers developed a shorter form of the scale (MMCGI-SF) to ease the implementation of the instrument in large-scale research, and they further reduced the item count to 18 through inter-correlation matrix techniques to determine which items best represented the full content of the MMCGI. They employed the same scales used in the original validation of MMCGI and found that the 18-item MMCGI-SF was also a useful tool to evaluate grief responses of dementia caregivers (Marwit & Meuser, 2005).

The results of the CFA conducted within the scope of the present study revealed that the Turkish version of the MMCGI-SF also had a 3-factor structure, as was the case in MMCGI and MMCGI-SF (Marwit & Meuser, 2002; Marwit & Meuser, 2005). Expectedly, the first factor, personal sacrifice burden, had a strong correlation with ZBI, although the correlations between ZBI scores and other two factors (i.e. heartfelt sadness and longing, and worry and felt-isolation) were smaller. This higher correlation between personal sacrifice burden and caregiver burden/strain was also evident in the original validation studies of MMCGI and MMCGI-SF, respectively (Marwit & Meuser, 2002; Marwit & Meuser, 2005). A possible explanation for this stronger association between personal sacrifice burden and ZBI scores might be related to the fact that this factor aims to measure secondary personal losses of caregivers (e.g. loss of freedom, loss of well-being) directly resulting from assuming the informal caregiver role.

Interestingly, the correlation between factor 3 (worry and felt isolation) and ZBI scores was stronger in the current study than those found in the earlier research (Marwit & Meuser, 2002; Marwit & Meuser, 2005). While the correlation between factor 3 and caregiver burden was .71 in the present study, it was reported as .46

and .51 in the earlier studies. This difference might be explained by how Turkish caregivers understand and responded to items of Worry and Felt Isolation subscale. This subscale particularly covered anxiety and worry resulting from the uncertainty of the disease trajectory, which was claimed to be intensified with the social isolation from others. In fact, withdrawal from social relations due to caregiving responsibilities might also be understood as a secondary loss by the Turkish caregivers as it was another sacrifice that they have to make to continue intense care providing duties. Besides, isolation from others might create a unique stressor for Turkish caregivers as collectivistic cultures emphasize social relatedness and harmony in times of stress (Kağıtçıbaşı, 1994; Lai, 2009) Accordingly, Turkish caregivers might associate loss of social relations with caregiver burden more readily and directly in their interpretation of items, which might explain the greater correlation between worry and self-isolation subscale and ZBI scores in this sample.

Furthermore, consistent with the prior findings, worry and felt isolation subscale was negatively correlated with perceived social support scores (measured by MSPSS). In fact, worry and self-isolation had the greatest correlation coefficient with the MSPSS scores when compared to the correlations of total MMCGI-SF, personal sacrifice burden and heartfelt sadness and longing; and perceived social support scores (Marwit & Meuser, 2002; Marwit & Meuser, 2005).

The correlations of MMCGI-SF, and all three subscales with depression (measured by BDI) were also similar to those found in the earlier validation studies of the scale (Marwit & Meuser, 2002; Marwit & Meuser, 2005). The lowest correlation was found between factor 2 (heartfelt sadness and longing) and depression scores as was the case in the previous findings. In fact, heartfelt sadness and longing subscale captures the sadness, longing and yearning over the losses associated with disease and caregiving process. It refers to a more affectionate and intrapsychic state associated with past, present and future losses. In that respect, this subscale is conceptually more similar to traditional grief definitions highlighted in the current literature (Marwit & Meuser, 2002). Consistently, the moderate to low correlation between factor 2 and depression scores are theoretically sensible as the two concepts are qualitatively different from each other although both share some symptoms and expressions (e.g. sadness, hopelessness). The literature differentiating caregiver grief from depression claimed that these two mental states have different symptoms and etiologies that warranted differential treatment (Boelen & van den Bout, 2005). While depression is a more pervasive affective state associated with low self-worth and loss of hope, grief is usually evoked in response to a particular loss situation. Besides, separation anxiety, longing for and yearning pertains more to a grief related state rather than to depression (Jacobs, Mazure, & Prigerson, 2000; Shear, Frank, Houch, & Reynolds, 2005). Nevertheless, although heartfelt sadness and longing subscale is more akin to conventional grief reactions, none of the studies, including ours, has validated the scale against an empirically valid pre-death grief instrument. This shortcoming is usually explained by the lack of such a measure aiming to assess this unique form of grief among dementia caregivers (Marwit & Meuser, 2002; Marwit & Meuser, 2005).

To our knowledge, the psychometric properties of MMCGI and MMCGI-SF were also examined among Puerta Rican (Alvelo, Cancio-Gonzalez, & Collazo, 2016) and African American caregivers (McLennon, Bakas, Habermann, & Meuser, 2014), and the results regarding the use of MMCGI as a tool of assessing pre-death grief among dementia caregivers seems promising. The current study provided further support for the empirical use of this instrument, as well. Still, the results should be interpreted with caution. The main aim of the present study was not to examine cross-cultural differences in terms of grief responses in dementia context. Rather, the current findings merely indicated that MMCGI-SF has satisfactory psychometric properties in assessing pre-death grief responses of Turkish adult children caregivers of AD. Besides, the lack of an empirically sound anticipatory grief instrument to establish the construct validity of MMCGI-SF was another problem while examining the psychometric properties of the scale across different contexts. Finally, as Meuser and Marwit suggested (2005), the shorter version of MMCGI might be less responsive to the various grief-related issues covered fully in the original 50-item version. This concern is also accentuated by the relatively lower Cronbach alpha values found in the shorter version when compared to those found in the original version. Still, Meuser and Marwit (2005) claimed that MMCGI-SF is a viable alternative when there are problems with time, place and comprehension of the lengthy questionnaires.

Factors Associated with Depression

The first hierarchical regression analysis revealed that neither background/contextual variables nor primary stressors/disease-related variables explained a significant amount of variance in caregivers’ depression scores. In fact, researchers have long debated about the roles of disease and caregiving related variables on negative caregiver outcomes. While some findings suggested that objective stressors including stage of disease, length of caregiving and caregiving hours per week were associated with poorer mental health outcomes among informal caregivers (Conde-Sala et al. 2010; Kim et al., 2012; Iavarone, Rosario Ziello, Pastore, Fasanaro, & Poderico, 2007; Mohamed et al., 2010; Pinquart & Sörensen, 2003; Raggi et al., 2015); others found no association between these variables and negative caregiver outcomes (Andrén & Elmståhl, 2008; Ferrara et al., 2008). The latter explained this lack of relationship by the fact that rather than the objective stressors, appraisals of these stressors might have a more powerful impact on caregivers’ well-being (Schulz, & Martire, 2004; Sörensen et al., 2006). In that respect, our results seem to give further support for this conclusion necessitating an in-depth investigation of caregivers’ perception of disease and caregiving related circumstances, rather than only focusing on the stressors associated with disease trajectory.

Our results are also in line with the previous studies establishing a robust positive relationship between subjective caregiver burden and caregivers’ depressive symptoms (Andrén & Elmståhl, 2008; Conde-Sala et al., 2010; Savundranayagam et al., 2011). AD caregiving requires performing various daily and instrumental living tasks usually over long periods of time. Coupled with the changing nature of caregiving tasks due to ever-changing nature of the disease trajectory, caregivers usually experience moderate to high levels of subjective caregiver burden (Baldwin, 1988; Garity, 1998; Iavarone et al., 2009; Jonker, & Greef, 2009). Plausibly, emotional, social and financial fluctuations resulting from intense caregiving demands were associated with negative caregiver outcomes, including depression (Cooper, Balamurali, & Livingston, 2007; Conde Sala et al., 2010; Iavarone et al., 2009) In that regard, the present findings also confirmed the positive association between subjective caregiver burden and depression among adult children caregivers of AD.

The current findings also revealed that higher levels of optimistic/seeking social support coping and perceived social support were associated with lower caregiver depression, while there was a positive relationship between helplessness coping and depressive scores of Turkish caregivers. This finding associating optimism with lower depression among Turkish caregivers is in accord with the emerging literature favoring optimism and optimism-based coping strategies to cope with dementia caregiving distress (Gottlieb & Rooney, 2004; Schulz & Martire, 2004; Trapp et al., 2015). This pattern might be partially explained by the fact that positive expectancies on the part of caregivers might enhance caregivers' perceptions of available resources to handle the disease and caregiving related difficulties (Carver, Scheier, & Weintraub, 1989; Carver, Spencer, & Scheier, 1998). Besides, it seems plausible that an optimistic outlook and realization of the bright side of the disease process might provide some degree of relief to AD caregivers as they have nearly no control on the negative impacts of the disease on the care recipients (William, Morrison & Robinson, 2014). The finding associating seeking social support and increased perceived social support with lower depression was also in line with the previous findings highlighting both direct and indirect protective role social support plays on caregivers' distress levels (Brodaty & Donkin, 2009; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Haley et al., Han et al., 2014; 1996; Heo, 2014; Williamson, & Schulz, 1993). As the instruments of perceived support used in the current study focused on the emotional support received from others, it might be suggested that the emotional sharing with others provide a partial respite from the caregiving role and provided a chance for ventilation, thereby decreasing depressive symptoms of Turkish AD caregivers. Finally, the finding associating increased helplessness coping with depressive symptoms also provides further support for the existing findings (Pagel, Becker, & Coppel, 1985, William, Morrison & Robinson, 2014; Williamson & Schulz, 1993). AD has a disease trajectory full of uncertainties due to the continuous cognitive decline. Caregivers usually have little, if any, control over the disease-related changes resulting from neural damage, which lead them to feel helpless and paralyzed as a family caregiver (Boss, 2000; Doka, 2010). In other words, the disease itself creates an objective state of helplessness on the behalf of family members, in a sense. Consequently, the objective situation of having no control over disease-related changes might increase subjective feelings of helplessness, which might leave no room for searching for alternatives over controllable aspects of the caregiving, thereby increasing depressive symptoms of the AD caregivers.

Factors Associated with Anxiety

The second hierarchical regression analysis revealed that among background/contextual variables and primary stressors/disease-related variables, only quality of past relationship with the care recipient explained a significant amount of variance in caregivers' anxiety scores. Particularly, a poor past relationship with the affected patient prior to disease formation was associated with higher levels of anxiety among Turkish adult children caregivers of AD. This association seems as a new pattern since, to our knowledge, as there is no study examining the relation between past relationship quality and anxiety symptoms in the literature. Nevertheless, some prior findings suggested that a satisfactory past relation with the care recipient prior to the development of the disease provide greater motivation for caregiving and facilitate positive caregiving experiences (Lopez et al., 2005, Motenko, 1989). It is a well-known fact that a problematic past relationship could create some unique challenges in the face of physical death (Bowlby, 1963; Freud, 1917). Unfinished businesses become evident, and a turmoil of emotions including sadness, anger and guilt come to the surface. Regarding the dementia context, caregivers continuously have to face mini-deaths as the caregiving responsibilities may restrict time for respite to process grief-related issues (Boss, 2000; Doka, 2010). Hence, for caregivers who have a conflicting past relationships with the affected parents, both the loss situation and the caregiving role might be particularly burdensome. These caregivers might feel on edge as they are in a caregiver position for a person with whom they have had problems with. They might feel guilty as they have negative feelings towards the care recipient during care provision. The upcoming changes might lead them to feel more insecure and uncertain about their future, as well. They might continuously question their roles as a caregiver and as an adult child. As a result, all these conflicting emotions and uncertainties might evoke a constant influx of anxiety in them, which might explain the association between past relation quality and anxiety scores in the Turkish caregivers.

The current findings also indicated that higher caregiver burden, higher scores on helplessness coping; and decreased optimistic/social support and perceived social support were associated with greater levels of anxiety symptoms, as were the case in depressive symptoms. As depression and anxiety are comorbid psychological states, and examined in relation to each other in the dementia context, the explanations provided for the relations between aforementioned variables and depressive scores is also thought to be applicable to explain the observed associations for anxiety scores.

Factors Associated with Grief

The third hierarchical regression analysis revealed that among background/contextual variables and primary stressors/disease-related variables, only the stage of care recipient's disease explained a significant amount of variance in caregivers' grief scores. Particularly, more severe stages of disease were associated with increased pre-death grief symptoms among AD caregivers. The stage sensitive nature of pre-death grief seems to be consistent with other research findings which found that grief reaches to its peak levels particularly in the final stages of the disease (Adams & Sanders, 2004; Ponder & Pomeroy, 1996; Sanders, Marwit, Meuser, & Harrington, 2007). Accordingly, grief reactions of informal caregivers most resemble to the traditional grief symptoms in the advanced stages of the disease. A possible explanation for this association may be the profound cognitive and physical function loss in the severe stage of AD. As the disease approaches to its terminal phase, care recipients usually become bed-ridden and unresponsive to their surroundings (AA, 2016; AS, 2014). An intense care provision period is obliged as almost all basic needs of the patient are met by the family caregiver. Additionally, changes related to the terminal stage signal the impending death which might lead to profound sadness, anger, yearning and fear for the upcoming future (Meuser & Marwit, 2001). Taken together, both primary (e.g. loss of relationship with the care recipient, upcoming physical separation) and secondary (e.g. loss of social-recreational activities, loss of personal well-being) losses become intensified in the final stages, which might explain the increased pre-death grief reactions in AD caregivers.

The present findings also indicated that higher levels of perceived caregiver burden were associated with greater levels of pre-death grief among Turkish adult children caregivers. This association remained significant even after controlling for the effects of other variables. This result is in agreement with Holley & Mast (2009), Marwit and Mueser (2002; 2005), and Walker and Pomeroy's (1997) associating caregiver burden and distress with anticipatory grief responses of AD caregivers. The observed association between caregiver burden and pre-death grief could be explained in this way: caregivers who were highly burdened usually had a more one-to-one relationship with the care recipient and provide care for a series of duties over long periods of time (AA, 2016; AS, 2014). This intense caregiving process bring along bearing primary and secondary losses associated with the disease and caregiving more readily (Holley & Mast, 2009; Marwit & Mueser, 2001). Hence, it is plausible that caregivers with higher levels of burden experience more anticipatory grief symptoms as the losses come along with the burdensome nature of the disease. However, a note of caution is due here. As personal sacrifice burden subscale of MMCGI-SF and caregiver burden both include items related to restrictions in caregivers' life due to caregiving role, this positive association between grief and burden might be criticized to be inflated. However, examination of items of both scales indicated that while burden inventory was more related to difficulties in psychological, emotional, social and financial restrictions, personal sacrifice burden subscale aimed to measure grief-related affect developing in response to perceived secondary losses. Additionally, studies utilizing another pre-death grief inventory (e.g. AGS) which did not include items related to burden produced similar results providing additional support for the relationship between caregiver burden and pre-death symptoms of AD caregivers (Holley & Mast, 2009). As for the roles of coping strategies and perceived social support on grief scores, only increased use of helplessness coping was associated with increased pre-death symptoms among Turkish offspring. This result was expected as the literature pointed out that the use of coping styles leading to a fixation on negative emotions were associated with increased caregiver distress and pre-death grief (Chan et al., 2012; Ott, Sanders, & Kelber, 2007). The impact of helplessness coping might be more pronounced on anticipatory grief responses as the situation is objectively a helpless one regarding the symptom progression of disease, and caregivers adopting a helplessness coping approach might experience exacerbated grief symptoms in this already unchangeable situation.

Contrary to our expectations, this study did not find a positive relation either between fatalistic coping and grief; or perceived social support and grief scores. The lack of association between fatalistic coping and grief responses might be explained in this way: fatalism might be a multidimensional concept which includes functional and dysfunctional aspects depending on the cultural and religious context. To illustrate, “doing best and leaving rest to God” might lead to acceptance and a sense of relief in some contexts, while the same belief might lead to feelings of helplessness and powerlessness in other. When the items of the fatalistic coping subscale of WCI were examined, it was inferred that some items (e.g. *bunun alın yazım olduğunu ve değişmeyeceğini düşünürüm*) might imply such conflicting meanings for Turkish caregivers. Such an ambiguity in the perceptions of items might create heterogeneity in the responses, thereby leading to a non-significant relation between fatalistic coping and grief-related symptoms.

Surprisingly, the association between perceived social support and pre-death grief symptoms was also found to be non-significant in the present study. In fact, this lack of association might be related with the more intra-psychic nature of the grief-related processes (Shear & Shair, 2005). Grief is an experience dealt with at a more personal level through internal re-organization of relationship with the deceased. This internal process might be less affected by the external factors, such as perceived support from others. Besides, considering the never-ending losses associated with the disease progression, AD caregivers live in a constant state of flux, and they usually bear witness to a series of losses on a daily basis where the absolute end (physical death in this situation) is unclear (Boss, 2000). In addition to past, present and future losses, they also have to deal actively with caregiving tasks and responsibilities on a strict schedule (Boss, 2000; Dupuis, 2008; Marwit & Meuser, 2001). This complex nature of dementia grief and caregiving might also explain the resistance of grief symptoms to social support as the grief responses are usually compounded by the caregiver burden itself.

An important note should be provided here. In all the regression analyses examining different sets of variables with respect to negative caregiver outcomes (i.e. depression, anxiety and grief) separately, only subjective caregiver burden remained as a significant predictor in the final steps. This robust association of burden with negative caregiver outcomes suggested that subjective burden is an important variable in understanding the distress that Turkish caregivers experienced while providing care to their demented parent.

Factors Associated with Growth

Among all sets of variables, only optimistic/seeking social support coping style explained a unique variance in growth scores of Turkish AD caregivers. Particularly, greater use of optimistic/seeking social support was associated with increased levels of growth among Turkish AD caregivers. This finding supported the evidence associating both optimism and seeking social support coping strategies with positive caregiving outcomes in AD context (Cho, Ory, & Stevens, 2015; Cohen & Gold, 1994; Schulz, Newsom, Fleissner, de Camp, & Nieboer, 1997). While some caregivers felt helpless and stuck while providing care to a loved one with AD, others displayed a more resilient attitude in response to various stressors associated with the disease trajectory (Fernández-Calvo, Bernardino, Castillo, Israel Contador et al, 2016). Particularly, individuals who had a positive mindset, perceived the positive sides of the adverse situation (Fernandez-Calvo et al., 2016), and benefited from instrumental and emotional support (Cho et al., 2015) offered by social and community networks were more likely to thrive under the stressful conditions of dementia caregiving.

The Moderator Role of Problem-Solving Coping on the Relationship Between Caregiver Burden and Depression

The results of the moderation analyses revealed that when caregivers used problem-solving coping strategies less, caregiver depression tended to increase at higher levels of caregiver burden. Nevertheless, hihger levels of problem-focused coping did not have an effect on the relationship between caregiver burden and depression. In other words, lower levels of problem-solving approach had intensified the negative effect burden had o depression scores. Current literature suggested that problem-focused or task-oriented strategies are among the most commonly used coping styles of dementia caregivers. Caregivers make plans, search for alternative solutions and develop practical solutions to problems encountered during the disease and caregiving process. It seems that such active and effortful coping alleviated their subjective burden and distress, subsequently (Di Mattei, Prunas, Novella, Marcone, Cappa, & Sarno, 2008; Kneebone & Martin, 2003; Kramer, 1993). In this respect, our finding regarding the negative effect problem-solving coping had on the burden-depression relationship seem to make sense. Nevertheless, it is important to keep in mind that only greater levels of problem-solving coping buffered the negative effect of higher levels of burden on caregiver depression. AD is a disease and caregiving trajectory that is full of uncertainties (Boss, 2000). Caregiving tasks rapidly change as cognitive and physical decline happen on an unpredictable time course (Conde-Sala et al., 2010). Accordingly, it seems plausible that highly burdened caregivers feel more trapped and more helpless when their use of problem-solving coping strategies are at lower levels in such an uncontrollable and unpredictable disease context.

The Moderator Role of Social Support on the Relationship Between Caregiver Burden and Depression

The results of the moderation analyses revealed that when caregivers perceived greater social support from others, caregiver depression tended to decrease at higher values of caregiver burden. By contrast, when the perceived social support level was lower, caregiver depression tended to increase at higher values of caregiver burden. This finding suggested that higher levels of perceived social support had a protective role on caregiver depression when the levels of caregiver burden were also high. This finding supports the previous research into dementia caregiving linking social support with better mental health outcomes (Brodaty & Donkin, 2009; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Haley et al., Han et al., 2014; 1996; Heo, 2014; Williamson, & Schulz, 1993). This robust buffering effect of social support in the current study might be relevant to the general Turkish cultural texture, as well. In most Eastern oriented context, extended family and friendship networks are usually expected to become mobilized when a family encounters with a life crisis. In-group members spend effort to ameliorate the detrimental effects of the crisis through providing emotional, instrumental and financial support (Connell et al., 2001; Kağıtçıbaşı, 1994; Lai, 2009; Sun et al., 2012). Such a social union is usually appreciated under times of stress as the benefit of groups are assumed to be more important than the individual benefits (Sun et al., 2012). Thus, it is plausible that even under higher levels of burden, Turkish adult children felt less depressed when they perceived that they received adequate levels of social support. By contrast, as social and family relations are important determinants of daily life practices, lack of perceived social support might have created a unique challenge for Turkish caregivers resulting in greater distress and isolation (Harper & Lund, 1990). This cultural pattern might provide an alternative explanation for the higher scores of depression among Turkish offspring in response to increased burden, when the perceived social level was insufficient.

The Moderator Role of Social Support on the Relationship Between Caregiver Burden and Anxiety

The results of the moderation analyses revealed that when caregivers perceived greater social support from others, anxiety tended to decrease at higher values of caregiver burden. By contrast, when the perceived social support levels were lower, caregiver anxiety tended to increase at higher values of caregiver burden. Hence, social support has a protective role on caregiver anxiety symptoms at higher levels of subjective burden. In fact, in contrast to the well-established relationship between social support and caregiver depression/distress, previous studies reported more inconsistent findings regarding the relationship between caregiver anxiety and social support (Cooper, Balamurali, & Livingston, 2007). Nevertheless, our study revealed that higher perceived social support buffered the negative effect of burden on caregiver anxiety, while lower levels of it intensified the negative effect of burden on anxiety scores. The same explanation provided for the moderator role of social support on burden-depression relationship could also be the basis for the present finding (Connell et al., 2001; Kağıtçıbaşı, 1994; Lai, 2009; Sun et al., 2012). It might be the fact that highly burdened Turkish caregivers felt more secure and calm as they received adequate support from others, which protected them from the adverse effects of subjective burden. By contrast, their feelings of nervousness and being on edges might be accentuated in the face of higher perceived burden, specifically when perceived social levels were lower.

The Moderator Role of Perceived Social Support on the Relationship Between Caregiver Burden and Growth

The results of the moderation analyses revealed that when the levels of perceived social support decreased, growth levels of caregivers tended to decrease at the higher values of caregiver burden. By contrast, when the levels of perceived social support increased, caregivers experience greater growth even at the higher levels of caregiver burden. The first finding that lower levels of social support intensified the negative effect of burden on caregiver growth was anticipated, as previous studies pointed out that greater social support ease the mobilization of internal and external resources to cope with caregiver burden, thereby was associated with more positive experiences of AD caregiving (Cho et al., 2015; Fernandez-Calvo et al., 2016). Considering this, it is plausible that caregivers might have difficulties in thriving while performing burdensome caregiving duties, especially when they thought they did not receive enough emotional support from others.

The most interesting finding that emerged from the moderation analysis was that caregivers experienced higher levels of growth even when they felt highly burdened, as long as they received satisfactory levels of social support. This result may be explained by the complicated nature of relationship between caregiver burden and growth. Interestingly, some findings indicated that caregivers providing more intense care for a greater variety of tasks experience higher levels of positive caregiving outcomes (Andren, & Elmstahl, 2005; Ory et al., 2000). It was claimed that more burdensome caregivers experience greater mastery over a higher number of tasks, and they developed a more empathetic outlook towards the patient, which in turn, increase the satisfaction they derived from caregiving. In the present study, however, the positive relationship between caregiver burden and growth was significant only when caregivers received higher levels of perceived social support. This result implies that perceived social support might provide a psychosocial resource for the caregivers to remain in the caregiver role, and help them to positively reframe such a burdensome situation. Besides, the positive effect of social support on the positive relation between burden and growth might be particularly relevant in Turkish culture, as sacrificing one’s own needs for the sake of the elderly is appreciated and reinforced by the society (Lai, 2009; Narayan et al., 2001). Such an encouraging attitude displayed during social encounters might help caregivers to perceive the silver linings of the caregiving situation more readily, even under highly burdensome conditions (Narayan et al., 2001).

Conclusions

This study has identified different variables in predicting negative (i.e. depression, anxiety and grief), and positive (i.e. growth) caregiver outcomes. Hierarchical regression analyses showed that increased subjective burden, increased use of helplessness coping, decreased use of optimistic/seeking social support approach and lower levels of perceived social support were associated with higher levels of both depression and anxiety symptoms among Turkish AD caregivers. Besides, increased subjective burden and decreased use of helplessness coping were associated with greater pre-death grief symptoms for this population. Regarding positive caregiver outcomes, only increased use of optimistic/seeking social support were found to be related with greater growth scores.

One of the more significant findings to emerge from this study is that subjective burden was the only variable remained significant after all other contextual and disease-related variables were controlled in the regression analyses; indicating that it is a robust predictor of negative caregiver outcomes among Turkish AD caregivers.

As for the roles of moderator variables, higher levels of perceived social support had protective role both on caregiver depression and anxiety, especially at the higher levels of subjective burden. Perceived social support also moderated the relationship between caregiver burden and growth, as well. Findings suggested that highly burdened caregivers experience greater growth when they received higher levels of social support. By contrast, growth levels of more burdened caregivers tended to decrease when they received lower levels of social support. Finally, optimistic/seeking social support coping strategy had only played a protective role on depressive scores of AD caregivers, especially when the subjective burden levels were also higher.

Limitations

Although the present study has important contributions, it is not free from limitations. Firstly, lack of a grief related measure in the validation of MMCGI-SF is a problem encountered both in the previous studies, and in the present study, as well. Such a measure was not used in this study since there wasn’t any reliable and valid tool in the Turkish literature measuring grief reactions experienced prior to the actual death of an individual. Still, this difficulty was tried to be compensated through the use of other empirically valid measures to establish the validity of the MMCGI-SF. Secondly, the same sample was used to test both psychometric properties of MMCGI-SF and correlates of caregiver outcomes. Hence, the current findings should be interpreted with caution, and future studies should employ independent samples to test the preliminary associations found in the current study. Thirdly, PTGI was used to examine positive caregiving outcomes of Turkish caregivers in AD context. In fact, PTGI is a tool to assess positive transformations occurring in the aftermath of the traumatic life events. Although the items of this scale might not completely capture the positive experiences of AD caregivers under persistent stress, the current study employed it to provide a general base for the associates of positive caregiving experiences. In that respect, scales more responsive and specific to positive caregiver transformations (e.g. Positive Aspects of Caregiving Scale (PAC), Tarlow et al., 2004), while care provision still continues, should be adapted to the Turkish culture in the future studies as positive caregiving outcomes might also be relevant for Turkish AD caregivers. Fourthly, disease and care recipient variables were collected based on caregivers' own accounts rather than obtaining objective measures. Subjective caregiver evaluations were preferred due to the difficulties in reaching out the patients' information from archives of the hospitals. Hence, it would be better if future research benefit from both caregivers' accounts and objective disease related information. Finally, although the findings indicated valuable associations between variables, there was still a significant amount of unexplained variance in the outcome variables. Therefore, future studies are suggested to identify and test other possible variables (e.g. instrumental support, community support, gratitude) predicting negative and positive caregiver outcomes in informal AD caregivers.

Clinical Implications

The current study has several implications for the clinical health psychology practices. Firstly, anticipatory grief is usually a neglected aspect of AD caregiving due to the intense focus on caregiving distress-coping paradigm (Meuser & Marwit, 2001; Marwit & Meuser, 2002; Marwit & Meuser, 2005). The multiple losses associated with the disease trajectory and the unique nature of the disease necessitated a closer look on the grief-related issues in AD context. In this regard, Turkish adaptation of the MMCGI-SF is seen as an important contribution for the current literature to assess levels and associates of pre-death grief responses of Turkish AD caregivers. Secondly, it was revealed that modifiable factors (i.e.

optimistic/seeking social support coping, helplessness coping and perceived social support) played differential impacts on various negative and positive caregiver outcomes. While optimistic/seeking social support, problem-focused coping, helplessness coping and perceived social support were more relevant to caregiver depression; helplessness coping was the only predictor associated with pre-death grief symptoms of informal caregivers. Besides, only optimistic/seeking social support coping and increased social support were found to have significant influences on caregivers' growth scores. In that respect, these preliminary results provided a baseline for the differential correlates of various caregiver outcomes, which necessitates development of different intervention strategies while targeting different caregiver outcomes. To illustrate, it seems that caregiver grief might be more amenable to change with more individually and affect-based strategies rather than incorporating components of social support to intervention programs. By contrast, a multi-component approach enhancing both adaptive coping strategies (e.g. optimistic/seeking social support, problem-focused coping) and social support networks might be more effective in alleviating depressive and/or anxiety symptoms, and in boosting caregiver growth. Last but not least, the current study revealed that subjective caregiver burden plays an important role in determining negative caregiver outcomes. In that respect, intervention programs should employ strategies to facilitate adaptive coping strategies (e.g. optimistic/seeking social support) and social support networks of informal caregivers in order to mitigate negative effects of burden on negative caregiver outcomes.

Directions for Future Studies

This research has thrown up many questions in need of further investigation. Firstly, further work is required to establish psychometric properties of MMCGI-SF in Turkish population with independent and greater sample sizes. Secondly, it is suggested that the associations of moderator variables with caregiver outcomes should be investigated with instruments more sensitive to the needs of Turkish caregivers. Furthermore, since subjective burden is an important predictor of negative caregiver outcomes, further research needs to investigate various factors shaping subjective caregiver burden among Turkish AD caregivers.

CHAPTER 5

GENERAL DISCUSSION

In this chapter, the findings obtained from the qualitative and the quantitative strands will be discussed together within the scope of current literature. Later on, general conclusions and limitations; the implications for the clinical health psychology practices and future directions for research, will be presented, respectively.

5.1. General Discussion

The main research question of the current thesis was what are the possible caring outcomes and associated factors in adult children caregivers of AD patients". To seek answers for this question, a multi-method design was employed, and two studies were conducted separately at different time points, each having its own methodology. A multi-method approach was purposefully utilized as Turkish AD caregivers' experiences have not been explored against multiple caregiver outcomes so far.

The main purpose of the qualitative strand was to understand the experiences of Turkish AD caregivers regarding caregiver outcomes, coping strategies, and attitudes towards NHP. The study aimed to produce a culturally relevant framework while understanding particular experiences of caregivers in Turkey; and to provide knowledge for determining which caregiver outcomes need to be studied, in the second study. The second study, on the other hand, aimed to identify factors associated with caregiver outcomes based on two prominent models in the dementia caring literature and the data obtained from the qualitative study.

In general, findings obtained from each study provided further support for the "Caregiver Stress Model" (Pearlin et al., 1990) and "Model of Carer Stress and Burden" (Sörensen et al., 2006). The most notable finding that emerged from the current thesis was the emergence of anticipatory grief and positive caregiving experiences as important dimensions in assessing caregiving process in AD context. Particularly, it was impressive to find that caregivers not only talked about losses, burden, distress, and anxiety; but also gains from coping with the disease and the caregiving process while describing their experiences. Their accounts were in accord with the prior findings suggesting that caregiver burden is a complex and multi-dimensional construct (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Savundranayagam, Montgomery, & Kosloski, 2011). Therefore, although anticipatory grief and positive caregiving experiences were not presented in the aforementioned models, they were included as outcome variables in the quantitative strand in an attempt to provide a more comprehensive understanding of the caregiving experiences of Turkish caregivers.

Furthermore, religious/fatalistic coping was also found as an important strategy to handle disease and caregiving related difficulties in the qualitative part. Qualitative findings indicated that some of the Turkish caregivers found comfort and relief in the belief that every unfortunate event is given by God for a higher purpose. It seems that their belief in fate eased the acceptance of the uncontrollable aspects of the disease. Besides, the gratitude they felt for not being in a worse condition helped them to reframe the illness into a more positive perspective and to perceive the silver linings of their current condition. Nevertheless, this protective effect of the religious/fatalistic coping that emerged in the qualitative strand was not confirmed in the quantitative part, in which fatalistic coping had no significant effect on the studied outcomes. As mentioned in the previous chapter, this incongruence between the qualitative and quantitative strands might be related to the item content and structure of the WCI used to measure coping strategies of caregivers. It is plausible that the items that are supposed to measure fatalistic coping in the WCI used in the quantitative part might not have captured the fate understanding as represented in the Islamic beliefs of our sample. To exemplify, while expressing gratitude to God was a frequently mentioned aspect of religious/fatalistic coping in qualitative strand, WCI does not include any items tapping the meaning of this dimension. Hence, a culturally relevant coping scale measuring different aspects of religious and fatalistic coping in Turkish culture might be more sensitive to the issues presented by our sample. However, a note of caution is due here. Although not presented by the current sample, it is also likely that religious and fatalistic coping might also lead to negative caregiving outcomes due to its great emphasis on conformity, respect and interdependence with elderly family members (Merritt, & McCallum, 2014). Besides, the notions such as “providing care for a parent is a good deed” might result in extreme self-sacrificing tendencies and suppressed anger, which could bring about “compassion fatigue” in our culture (Day, Anderson, & Davis, 2014). Therefore, a deeper level of analysis is warranted to understand the differential impacts of Islamic beliefs on Turkish adult children’s caregiving practices.

Additionally, social support seems as a key mitigating factor while understanding negative and positive caregiving experiences of Turkish AD caregivers. Qualitative findings indicated that both tangible and emotional support seem to provide resilience to Turkish adult offspring in the face of unrelenting caregiving demands. By contrast, insufficient mobilization of social networks resulted in resentment, anger and conflictual family relationships. Findings of the quantitative strand provided complimentary data to the qualitative findings regarding the protective effect of social support on Turkish AD caregivers, as well. It was reported that higher levels of perceived social support not only directly were associated with increased well-being; but also buffered the negative impact of burden on negative caregiving outcomes. On the other hand, lower levels of social support seem to accentuate the negative effect that subjective burden had on caregiving outcomes. Taken together, Turkish caregivers became more resilient in facing AD related stress as long as they received sufficient support from others, while they became more vulnerable to disease related stressors when they perceived the level of support they received was not satisfactory. The consistently observed association between social support and caregiver outcomes might be explained in this way: Turkish culture values a socially related approach over a detached stance in the interpersonal encounters. In-group members are expected to be mobilized and to spend their resources for the affected person who is undergoing a stressful time period (Kağıtçıbaşı, 1994; Lai,2009). In that respect, it seems that social support eases the caregiving process for Turkish caregivers as it is a culturally-valued resource in this context. Nevertheless, the reverse situation, where adequate support is not received, seems to bring about a particular challenge for them as their normative expectations regarding external help is not satisfied. It might be inferred that their disappointment related to their network not being there for them put extra stress and burden on them, in addition to their current stressful situation.

Last but not least, subjective caregiver burden was also an important dimension of caregiving experiences of Turkish offsprings. In the qualitative strand, Turkish caregivers reported various negative changes in their psychosocial well-being in response to disease and caregiving related processes. This finding was also supported in the quantitative study, as well. Findings indicated that caregiver burden was the most robust variable in explaining various negative caregiver outcomes after controlling for the effects of contextual and disease-related variables. Its effect on negative caregiver outcomes were also greater when compared to coping strategies and perceived social support. This finding is consistent with the current literature emphasizing that disease trajectory in AD requires a very debilitating and burdensome form of caregiving on the behalf of the caregivers. The neurocognitive decline, the non-mutual grieving process, long periods of caregiving, and behavioral disruptions create a unique form of burden on these caregivers (AA, 2016; Brodaty & Donkin, 2009; Harris et al., 2011; Schulz & Martire, 2004, Smith, et al., 2001). It could be argued that this particular burden is so overwhelming for the caregivers that the effects of other factors on caregiver outcomes might be relatively smaller.

5.2. Clinical Implications

Overall, the findings of the current thesis provide valuable information for developing appropriate intervention programs for combatting negative caregiving outcomes and for facilitating positive ones for the Turkish AD caregivers. Firstly, as suggested by the current literature (Cheung, Lau, Wong, Leung, Lou, Chan et al., 2014; Gitlin, Burgio, Mahoney, Burns, Zhang, Schulz et al., 2003), a multicomponent intervention strategy targeting different caregiving outcomes at the same time might be more effective for Turkish AD caregivers. Rather than focusing only to ameliorate negative effects of AD caregiving, a strength-based approach might be more effective to foster the resilience of this population. Secondly, since burden is a strong predictor of negative caregiver outcomes, strategies specifically aiming to alleviate objective and subjective caregiver burden (i.e. respite care, psycho-education about the management of disease-related symptoms, group-based therapies to enhance effective coping strategies) should be included in the future intervention strategies. Thirdly, intervention programs sensitive to religious and fatalistic resources of Turkish caregivers might be particularly employed to facilitate acceptance-based coping strategies, which were consistently reported as functional ways to handle dementia related distress (Jeongim, 2014; Kneebone & Martin, 2003; Li et al., 2012; Weisman de Mamani et al., 2014). However, caution must be applied at this point as Turkey is a heterogeneous country and there are substantial within groups differences regarding cultural and religious practices being applied. Therefore, such a culturally sensitive approach should only be applied when the sample being studied is appropriate for such an intervention. Besides, further work is required to assess the possible negative impacts of religious and fatalistic coping on AD caregiving outcomes in Turkey; and culturally sensitive intervention programs should also aim to reduce dysfunctional coping strategies based on Islamic beliefs and doctrines. Last but not least, possible interventions should include social support, both at a group and community level, to alleviate negative caregiving outcomes while fostering positive aspects of AD caregiving.

5.3. Policy Implications

The findings of the present thesis might also offer insightful data for policy implications. Firstly, it seems that Turkish caregivers refrain from using nursing home services for cultural (e.g. perceptions of caregiving as an obligation), moral (e.g. the belief that placing a loved one to a nursing home is immoral) and practical reasons (i.e. negative representations of care facilities in Turkey). Hence, continued governmental effort is needed to improve both the conditions and media representations of such institutions in Turkey. Formal interventions should also be applied at a national level to challenge dysfunctional attributions of nursing home care in our country. In that respect, rather than only adopting Westernized applications, more culture-sensitive strategies are suggested to be developed. To illustrate, the conditions of nursing home facilities could be arranged in a way that still allow Turkish family members to be actively involved in care process, thereby preventing feelings of abandoning the caregiver role and the affected parent.

In Turkey, there is not any nationally implemented dementia strategy to empower both dementia patients and their families, although such strategies are widely available in US and Europe (AA, 2016; Alzheimer Europe, 2016). To illustrate, in USA, unpaid respite care and group-based treatment programs are regularly delivered by the government to enhance informal caregivers' well-being, thereby increasing the quality of informal home care provided to the patients. Considering the fact that subjective burden is an important aspect of caregiving for Turkish caregivers, appropriate services for caregivers should be developed and integrated to current health care system as Turkish caregivers might be an invisible second patient group due to detrimental effects of dementia caregiving.

5.4. Limitations and Directions for Future Research

Overall, it is unfortunate that the current study still had some limitations. Firstly, scales used in the quantitative strand might have been more sensitive to the issues raised during semi-structured interviews conducted in the qualitative part. In that regard, a particular instrument measuring positive aspects of caregiving and a more relevant coping inventory could have been utilized. Although researchers were quite aware of these shortcomings, they still preferred to use WCI and PTGI as there aren't any available alternative scales in Turkish literature covering aforementioned issues, and adaptation of more sensitive scales would be beyond the scope of this thesis. Secondly, although the qualitative strand sampled caregivers providing care for moderate or severe stage AD patients, quantitative strand included caregivers caring for milder forms of dementia, as well. Since caregiving trajectories might differ depending on the stage of patient's disease, a more homogenous and complimentary sample could have been employed to provide a more focused framework. Thirdly, patient and disease related information was gathered based on caregivers’ own accounts in both studies, rather than utilizing objective measures of such indices. The main reason for this shortcoming was the bureaucratic and practical obstacles in obtaining such records through contacting with hospitals. Still, future studies are suggested to include objective records of AD patients (e.g. Mini Mental State Exam scoring) to establish more reliable relations between disease-related variables and various caregiver outcomes. Finally, the findings of the present study should be evaluated cautiously, as the qualitative nature of the first study and the cross-sectional nature of the quantitative strand do not allow to detect cause-effect relations between variables.

5.5. Conclusions

The main goal of this thesis was to understand experiences of Turkish adult children caregivers of AD, and to provide a context-relevant framework for the predictors of various caregiver outcomes. Overall, findings revealed that Turkish caregivers might have some unique concerns during caregiving trajectory of AD, and a comprehensive framework explaining relationships among various variables at multiple levels could be more beneficial to understand their particular experiences. Within this framework, rather than objective disease-related stressors, subjective appraisals of burden, specific coping strategies (e.g. optimistic/seeking social support coping, helplessness coping and problem-focused coping) and perceived social support were found to be more important determinants of caregiver outcomes.

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APPENDICES

APPENDIX A: ANNOUNCEMENT FOR THE QUALITATIVE STUDY

Sayın Grup Üyeleri,
Orta Doğu Teknik Üniversitesi Klinik Psikoloji alanında doktora eğitimime devam etmekteyim. Doktora tezim kapsamında Alzheimer Hasta yakınlarının hastalık ve bakım verme sürecine ilişkin deneyimlerini anlamayı amaçlayan bir araştırma yürütüyorum.

Araştırmam kapsamında (1) ANNE ya da BABASI Alzheimer hastalığı tanısı almış ve (2) halen Alzheimer hastası anne/babasına bakım vermekte olan hasta yakınlarıyla hastalık ve bakım verme sürecini daha kapsamlı anlayabilmek adına yarı-yapılandırılmış görüşmeler yapmak istiyorum. Eğer bu 2 kriteri karşılıyorsanız bu görüşmelere katılımınız benim için çok değerli olacaktır. Görüşmeye katılmak isteyen hasta yakınları aşağıda belirteceğim e-mail adresinden benimle iletişime geçebilirler. Desteğiniz için şimdiden teşekkür ederim.

Uzm. Klinik Psk. Yağmur Ar

e-mail: yagmurrar@gmail.com

APPENDIX B: ANNOUNCEMENT FOR THE QUANTITATIVE STUDY

Sayın Grup Üyeleri,
Orta Doğu Teknik Üniversitesi Klinik Psikoloji alanında doktora eğitimime devam etmekteyim. Doktora tezim kapsamında Alzheimer Hasta yakınlarının hastalık ve bakım verme sürecine ilişkin deneyimlerini anlamayı amaçlayan bir araştırma yürütüyorum.

Araştırmam kapsamında (1) ANNE ya da BABASI Alzheimer hastalığı tanısı almış ve (2) halen Alzheimer hastası anne/babasına bakım vermekte olan hasta yakınlarına bir takım anketler uyguluyorum. Eğer bu 2 kriteri karşılıyorsanız araştırmama katılımınız benim için çok değerli olacaktır. Ayrıca, araştırmaya katılan ve anketleri yanıtlayan hasta yakınlarına hastalık ve bakım sürecinde baş etme önerilerini kapsayan bir bilgilendirme broşürü gönderilecektir. Araştırmanın linki aşağıda yer almaktadır. Katılımınız için şimdiden teşekkür ederim.

Uzm. Klinik Psk. Yağmur Ar

APPENDIX C: BROCHURE*

***It will be provided in a separate sheet in its original version upon request.**

APPENDIX D: QUESTIONS OF SEMI-STRUCTURED INTERVIEWS

1. Cinsiyet: ☐ Kadın ☐ Erkek

2. Yaş: ________

3. Medeni durum:

   Bekar ☐ Evli ☐ Dul ☐ Boşanmış ☐ Birlikte yaşıyor ☐ Diğer ☐

4. Eğitim durumu *(Son alınan diplomaya göre belirtiniz)*

   Okur-yazar değil ☐ Okur-yazar ☐ İlkokul ☐ Ortaokul ☐
   Lise ☐ Yüksekokul ☐ Üniversite ☐ Yüksek Lisans ☐
   Doktora

5. Halen ücret veya mal karşılığı bir işte çalışıyor mu?
   Çalışıyor ☐ Çalışmıyor ☐ Diğer (*belirtiniz*): ☐ _______

6. Hasta neyiniz oluyor? Anne ☐ Baba ☐

7. Bakım verdiğiniz hastanın Alzheimer düzeyi nedir?

   Hafif ☐ Orta ☐ İleri ☐

8. Hastanızın problemleri ne kadar zaman önce başladı. Ay olarak belirtiniz.______
9. Hastanıza tanı koyulalı ne kadar zaman oldu? Ay olarak belirtiniz. _______
10. Hastanızla haftada kaç saat ilgileniyorsunuz/ihtiyaçlarını karşılıyorsunuz? Lütfen belirtiniz. _______
11. Hastanızla ne kadar zamandır ilgileniyorsunuz/ihtiyaçlarını karşılıyorsunuz? Ay olarak belirtiniz. _______
12. Hastanız ile birlikte mi yaşıyorsunuz? Evet ☐ Hayır ☐
13. Hastanız sürekli sizin yanınızda mı kalıyor?
    Evet ☐ *(Evet ise kiminle kaldığını ve ne kadar süre boyunca kaldığını belirtiniz)*____

    Hayır ☐
14. Hastanızın bakımında size yardımcı olan kimse var mı? Evet ☐ Hayır ☐

Evet ise belirtiniz: Kardeş ☐ Anne/Baba ☐ Eş ☐ Çocuk ☐ Diğer ☐

15. Ebeveyninizin hastalığı süresince/hastalığına bağlı tedavi gerektiren ruhsal bir rahatsızlık geçirdiniz mi? Evet ☐ Hayır ☐

    Evet ise bu rahatsızlık nedeni ile nasıl bir tedavi gördünüz?
    Psikolojik tedavi ☐ İlaç tedavisi ☐ Diğer (*belirtiniz*):
    ____

    Halen bu ruhsal sorun nedeniyle tedavi görüyor musunuz ? Evet ☐ Hayır ☐

16. Sizce bu hastalık neden oldu? Nedenlerini önem sırasına göre belirtiniz.

GÖRÜŞME SORULARI

1.Hastanızda fark ettiğiniz ilk belirtiler nelerdi?/Hastalık nasıl ortaya çıktı?

2.Anne/babanızın hastalığı sizi nasıl etkiledi, neler hissettiniz?

3.Bakım vermenin sizi nasıl etkiledi?/Anne-babanıza bakım vermek hayatınızı nasıl etkiledi?/Neler hissettiniz?

4.Bu sıkıntılarla baş etmede size neler yardımcı oldu?/Bu sıkıntılarla baş edebilmek için neler yaptınız?

5. Olumlu bir etkisi de oldu mu bu hastalığın?/Olumlu yönde neler değişti hayatınızda?/Hastalık hayatınızı iyi yönde nasıl etkiledi? Neler değişti?

6.a. Hasta olmadan önce anneniz/babanız nasıl birisiydi? (kişilik, ilgi alanları, hayatınızdaki rolü bakımından)
    b. Hastalık ile birlikte anneniz/babanızda ne gibi değişimler gözlemlediniz? (kişilik, ilgi alanları, hayatınızdaki rolü bakımından)

7.a. Hastalıktan önce annenizle/babanızla nasıl bir ilişkiniz vardı?
    b. Hasta olduğundan beri annenizle/babanızla nasıl bir ilişkiniz var?/Hastalık ve bakım verme süreci anneniz/babanızla olan ilişkinizi nasıl etkiledi?
    c. Bu değişim size ne hissettiriyor?

8.Bu hastalıkla baş ederken hangi özellikleriniz size yardımcı oldu?

9.Bu hastalıkla baş ederken hangi yönleriniz başa çıkmanızı zorlaştırdı?

10. Farklı bakım verme yollarını hiç düşündünüz mü? (Bakıcı tutmak, bakım evine yatırmak vs.)/Neden tercih ettiniz?/Neden tercih etmediniz?

APPENDIX E: INFORMED CONSENT FORM

GÖNÜLLÜ KATILIM FORMU

Bu araştırma, ODTÜ Psikoloji Bölümü'nde klinik psikoloji doktorasına devam eden Araş. Gör. Yağmur Ar tarafından, Prof. Dr. A. Nuray Karancı danışmanlığında yürütülen doktora tezi kapsamında hazırlanmıştır. Araştırmanın amacı **ANNESİ ya da BABASI AlZHEİMER HASTALIĞI** tanısı almış ve tanı alan ebeveynine **HALEN BAKIM VERMEKTE OLAN** yetişkinlerin hastalık ve bakım verme deneyimlerini kayıplar, bakım verme yükü ve olumlu kazanımlar çerçevesinde değerlendirmektir. Araştırmada size yöneltilen soruların **DOĞRU ya da YANLIŞ cevapları yoktur.** Lütfen her sayfanın başında yazan yönergeleri dikkatlice okuyarak, size en doğru gelen yanıtı vermeye çalışınız ve mümkün olduğunca **BOŞ SORU BIRAKMAYINIZ.** Vereceğiniz yanıtlar tamamen gizli tutulacak ve sadece bu araştırma kapsamında değerlendirilicektir. Yanıtlarınız kişi bazında değil, tüm katılımcılar çerçevesinde değerlendirilecektir. Bu çalışmadan elde edilecek bilgiler bilimsel yayınlarda kullanılacaktır. Çalışmaya katılım tamamiyle gönüllülük temelinde olmalıdır.

Araştırma, genel olarak kişisel rahatsızlık verecek soruları içermemektedir. Ancak, katılım sırasında sorulardan ya da herhangi başka bir nedenden ötürü kendinizi rahatsız hissederseniz cevaplama işini yarıda bırakmakta serbestsiniz. Çalışma hakkında daha fazla bilgi almak için Psikoloji Bölümü araştırma görevlisi Yağmur Ar (Oda: A232B; Tel: 0 312 210 5110 ; E-posta: yagmurrar@gmail.com) ile iletişim kurabilirsiniz. Çalışmaya katıldığınız için şimdiden teşekkür ederiz.

Araştırmaya katılan katılımcılara Alzheimer hasta bakımı sırasında yaşayabilecekleri **ZORLUKLAR VE BAŞ ETME BİÇİMLERİNE ilişkin bir bilgilendirme kitapçığı gönderilecektir.** Kitapçığın sorunsuz bir şekilde tarafınıza ulaşabilmesi için lütfen e-mail adresinizi belirtiniz.

e-mail: ____________________

Bu çalışmaya tamamen gönüllü olarak katılıyorum ve istediğim zaman yarıda kesip cevaplamayı bırakacağımı biliyorum. Verdiğim bilgilerin bilimsel amaçlı yayımlarda kullanılmasını kabul ediyorum.

☐ Evet

☐ Hayır

APPENDIX F: DEMOGRAPHIC INFORMATION FORM

DEMOGRAFİK BİLGİ FORMU

- Yaşınız: __________
- Cinsiyetiniz: __________
- Mesleğiniz: __________ Yaptığınız iş: __________
- Eğitim durumunuz nedir? (Son aldığınız diploma göre)
  - ☐ Okuma yazmam yok
  - ☐ Okuma yazmam var
  - ☐ İlkokul
  - ☐ Ortaokul
  - ☐ Lise
  - ☐ Üniversite
  - ☐ Yüksek Lisans
  - ☐ Doktora
- Medeni durumunuz nedir?
  - ☐ Bekar
  - ☐ Evli
  - ☐ Boşanmış
  - ☐ Dul
  - ☐ Birlikte yaşıyor
  - ☐ Diğer
- Gelir durumunuz
  - ☐ 1000 TL ve altı
  - ☐ 1001-1499 TL
  - ☐ 1500-1999 TL
  - ☐ 2000-2499 TL
  - ☐ 2500 TL ve üstü
- Hasta neyiniz oluyor?
  - ☐ Anne
  - ☐ Baba
- Bakım verdiğiniz hastanın Alzheimer düzeyi nedir?
  - ☐ Başlangıç Seviyesi
  - ☐ Orta Şiddetli

☐ İleri Seviye

- Hastanızın problemleri **YAKLAŞIK** ne kadar zaman önce başladı. (Kaç yıl önce başladığını belirtiniz) __________

- Hastanıza tanı koyulalı **YAKLAŞIK** ne kadar zaman oldu? (Yaklaşık **KAÇ YIL ÖNCE TANI KOYULDUĞUNU** belirtiniz)__________

- Hastanızla **HAFTADA YAKLAŞIK KAÇ SAAT** ilgileniyorsunuz/ihtiyaçlarını karşılıyorsunuz? Lütfen belirtiniz. _______

- Hastanızla **NE KADAR ZAMANDIR** ilgileniyorsunuz/ihtiyaçlarını karşılıyorsunuz? (Hastanızla **YAKLAŞIK KAÇ YILDIR** ilgilendiğinizi/ihtiyaçlarını karşıladığınızı belirtiniz.) _______

- Hastanız ile birlikte mi yaşıyorsunuz?
  ☐ Evet
  ☐ Hayır

- Hastanızın bakımında size yardımcı olan kimse var mı?
  ☐ Evet
    - Anne/Baba
    - Kardeş
    - Eş
    - Çocuk
    - Diğer (Belirtiniz) __________

  ☐ Hayır
- Ebeveyninizin hastalığı süresince/hastalığına bağlı tedavi gerektiren ruhsal bir rahatsızlık geçirdiniz mi**?**
  ☐ Evet
  ☐ Hayır

Evet ise bu rahatsızlık nedeni ile nasıl bir tedavi gördünüz?
☐ Psikolojik
☐ İlaç kullanımı
☐ Diğer (Belirtiniz) __________
Halen bu ruhsal sorun nedeniyle tedavi görüyor musunuz?
☐ Evet
☐ Hayır

APPENDIX G: MARWIT-MEUSER CAREGIVER GRIEF INVENTORY-SHORT FORM (SAMPLE ITEMS)

MEUSER-MARWİT BAKICI YAS ÖLÇEĞİ KISA FORM (ÖRNEK MADDELER)

YÖNERGE: Bu ölçek Alzheimer tanısı almış hastalara **HALEN BAKIM VERMEKTE OLAN** hasta yakınlarının yaşadıkları kayıp deneyimini ölçmeyi amaçlamaktadır. Lütfen her bir maddeyi dikkatlice okuyun ve her bir maddeye ne kadar katıldığınıza karar verin.

Kesinlikle katılmadığınız maddeler için 1'i, katılmadığınız maddeler için 2'yi, biraz katıldığınız maddeler için 3'ü, katıldığınız maddeler için 4'ü, kesinlikle katıldığınız maddeler için ise 5'i işaretletiniz.

1. Kesinlikle katılmıyorum
2. Katılmıyorum
3. Biraz katılıyorum
4. Katılıyorum
5. Kesinlikle katılıyorum

MADDELER	1	2	3	4	5
1. Ona bakabilmek için pek çok şeyden vazgeçmek zorunda kaldım.					
2. Ona bakmaktan dolayı özgürlüğümü kaybettiğimi hissediyorum.					
3. Beni anlayan ve dinleyen hiçkimse yok.					
4. Annemin/Babamın o eski kişi olmadığını bilmek boşluk duygusuna kapılmama ve kötü hissetmeme neden oluyor.					
5. Hastalığın ilerlemesinden dolayı endişelenerek çok fazla zaman harcıyorum.					

APPENDIX H: BECK DEPRESSION INVENTORY

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

1. (a) Kendimi üzgün hissetmiyorum.

(b) Kendimi üzgün hissediyorum.

(c) Her zaman için üzgünüm ve kendimi bu duygudan kurtaramıyorum.

(d) Öylesine üzgün ve mutsuzum ki dayanamıyorum.

2. (a) Gelecekten umutsuz değilim.

(b) Geleceğe biraz umutsuz bakıyorum.

(c) Gelecekten beklediğim hiçbir sey yok.

(d) Benim için bir gelecek yok ve bu durum düzelmeyecek.

3. (a) Kendimi başarısız görmüyorum.

(b) Çevremdeki birçok kişiden daha fazla başarısızlıklarım oldu sayılır.

(c) Geriye dönüp baktığımda, çok fazla başarısızlığımın olduğunu görüyorum.

(d) Kendimi tümüyle başarısız bir insan olarak görüyorum.

4. (a) Her şeyden eskisi kadar zevk alabiliyorum.

(b) Her şeyden eskisi kadar zevk alamıyorum.

(c) Artık hiçbir şeyden gerçek bir zevk alamıyorum.

(d) Bana zevk veren hiçbir şey yok. Her şey çok sıkıcı.

5. (a) Kendimi suçlu hissetmiyorum.

(b) Arada bir kendimi suçlu hissettiğim oluyor.

(c) Kendimi çoğunlukla suçlu hissediyorum.

(d) Kendimi her an için suçlu hissediyorum.

6. (a) Cezalandırıldığımı düşünmüyorum.

(b) Bazı şeyler için cezalandırılabileceğimi hissediyorum.

(c) Cezalandırılmayı bekliyorum.

(d) Cezalandırıldığımı hissediyorum.

7. (a) Kendimden hoşnutum.

(b) Kendimden pek hoşnut değilim.

(c) Kendimden hiç hoşlanmıyorum.

(d) Kendimden nefret ediyorum.

8. (a) Kendimi diğer insanlardan daha kötü görmüyorum.

(b) Kendimi zayıflıklarım ve hatalarım için eleştiriyorum.

(c) Kendimi hatalarım için çoğu zaman suçluyorum.

(d) Her kötü olayda kendimi suçluyorum.

9. (a) Kendimi öldürmek gibi düşüncelerim yok.

(b) Bazen kendimi öldürmeyi düşünüyorum, fakat bunu yapmam.

(c) Kendimi öldürebilmeyi isterdim.

(d) Bir fırsatını bulsam kendimi öldürürdüm.

10. (a) Her zamankinden daha fazla ağladığımı sanmıyorum.

(b) Eskisine göre şu sıralarda daha fazla ağlıyorum.

(c) Şu sıralarda her an ağlıyorum.

(d) Eskiden ağlayabilirdim, ama şu sıralarda istesem de ağlayamıyorum.

11. (a) Her zamankinden daha sinirli değilim.

(b) Her zamankinden daha kolayca sinirleniyor ve kızıyorum.

(c) Çogu zaman sinirliyim.

(d) Eskiden sinirlendiğim şeylere bile artık sinirlenemiyorum.

12. (a) Diğer insanlara karşı ilgimi kaybetmedim.

(b) Eskisine göre insanlarla daha az ilgiliyim.

(c) Diğer insanlara karşı ilgimin çoğunu kaybettim.

(d) Diğer insanlara karşı hiç ilgim kalmadı.

13. (a) Kararlarımı eskisi kadar kolay ve rahat verebiliyorum.

(b) Şu sıralarda kararlarımı vermeyi erteliyorum.

(c) Kararlarımı vermekte oldukça güçlük çekiyorum.

(d) Artık hiç karar veremiyorum.

14. (a) Dış görünüşümün eskisinden daha kötü olduğunu sanmıyorum.

(b) Yaşlandığımı ve çekiciliğimi kaybettiğimi düşünüyor ve üzülüyorum.

(c) Dış görünüşümde artık değiştirilmesi mümkün olmayan olumsuz değişiklikler olduğunu hissediyorum.

(d) Çok çirkin olduğumu düşünüyorum.

15. (a) Eskisi kadar iyi çalışabiliyorum.

(b) Bir işe başlayabilmek için eskisine göre kendimi daha fazla zorlamam gerekiyor.

(c) Hangi iş olursa olsun, yapabilmek için kendimi çok zorluyorum.

(d) Hiçbir iş yapamıyorum.

16. (a) Eskisi kadar rahat uyuyabiliyorum.

(b) Şu sıralarda eskisi kadar rahat uyuyamıyorum.

(c) Eskisine göre 1 veya 2 saat erken uyanıyor ve tekrar uyumakta zorluk çekiyorum.

(d) Eskisine göre çok erken uyanıyor ve tekrar uyuyamıyorum.

17. (a) Eskisine kıyasla daha çabuk yorulduğumu sanmıyorum.

(b) Eskisinden daha çabuk yoruluyorum.

(c) Şu sıralarda neredeyse her şey beni yoruyor.

(d) Öyle yorgunum ki hiçbir şey yapamıyorum.

18. (a) İştahım eskisinden pek farklı degil.

(b) İştahım eskisi kadar iyi degil.

(c) Şu sıralarda iştahım epey kötü.

(d) Artık hiç iştahım yok.

19. (a) Son zamanlarda pek fazla kilo kaybettiğimi sanmıyorum.

(b) Son zamanlarda istemediğim halde üç kilodan fazla kaybettim.

(c) Son zamanlarda istemediğim halde beş kilodan fazla kaybettim.

(d) Son zamanlarda istemediğim halde yedi kilodan fazla kaybettim.

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

20. (a) Sağlığım beni pek endişelendirmiyor.

(b) Son zamanlarda agrı, sızı, mide bozukluğu, kabızlık gibi sorunlarım var.

(c) Ağrı, sızı gibi bu sıkıntılarım beni epey endişelendirdiği için başka şeyleri düşünmek zor geliyor.

(d) Bu tür sıkıntılarım beni öylesine endişelendiriyor ki, artık başka hiçbir şey düşünemiyorum.

21. (a) Son zamanlarda cinsel yaşantımda dikkatimi çeken bir şey yok.

(b) Eskisine oranla cinsel konularla daha az ilgileniyorum.

(c) Şu sıralarda cinsellikle pek ilgili değilim.

(d) Artık cinsellikle hiçbir ilgim kalmadı.

APPENDIX I: ZARIT BURDEN INVENTORY

ZARİT BAKICI YÜK ÖLÇEĞİ

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 belirtin: Asla, nadiren, ara sıra, oldukça sık, neredeyse her zaman şeklinde. Yanlış ya da doğru cevap bulunmamaktadır.

	Asla	**Nadiren**	**Ara sıra**	**Oldukça Sık**	**Neredeyse Her zaman**
1. Yakınınızla geçirdiğiniz zaman yüzünden kendiniz için yeterli zamanınız olmadığını düşünür müsünüz?	**1**	**2**	**3**	**4**	**5**
2. Yakınınıza bakma ve aileniz yada işinizle ilgili diğer sorumlulukları yerine getirmeye çalışma arasında kalmaktan dolayı kendinizi sıkıntılı hisseder misiniz?	**1**	**2**	**3**	**4**	**5**
3. Yakınınızla birlikteyken kızgınlık hisseder misiniz?	**1**	**2**	**3**	**4**	**5**
4. Yakınınızın şu anda ailenin diğer üyeleri ya da arkadaşlarınızla olan ilişkinizi olumsuz şekilde etkilediğini düşünür müsünüz?	**1**	**2**	**3**	**4**	**5**
5. Yakınınızın geleceği ile ilgili korkularınız olur mu?	**1**	**2**	**3**	**4**	**5**
6. Yakınınızın size bağımlı olduğunu düşünür müsünüz?	**1**	**2**	**3**	**4**	**5**
7. Yakınınızla birlikteyken kısıtlanmış hisseder misiniz?	**1**	**2**	**3**	**4**	**5**

8. Yakınınızla uğraşmaktan dolayı sağlığınızın bozulduğunu hisseder misiniz?	**1**	**2**	**3**	**4**	**5**
9. Yakınınız yüzünden istediğiniz düzeyde bir özel hayatınız olmadığını düşünür müsünüz?	**1**	**2**	**3**	**4**	**5**
10. Yakınınıza bakmanız nedeniyle sosyal hayatınızın bozulduğunu hisseder misiniz?	**1**	**2**	**3**	**4**	**5**
11. Yakınınız nedeniyle arkadaşlarınızı davet etmekten rahatsızlık duyar mısınız?	**1**	**2**	**3**	**4**	**5**
12. Yakınınızın sanki sırtını dayayabileceği tek kişi sizmişsiniz gibi, sizden ona bakmasını beklediğini hisseder misiniz?	**1**	**2**	**3**	**4**	**5**
13. Kendi harcamalarınıza ek olarak yakınınıza bakacak kadar paranız olmadığını düşünür müsünüz?	**1**	**2**	**3**	**4**	**5**
14. Yakınınız hastalandığından beri yaşamınızı kontrol edemediğinizi hisseder misiniz?	**1**	**2**	**3**	**4**	**5**
15. Yakınınızın bakımını biraz da başkasına bırakabilmiş olmayı diler misiniz?	**1**	**2**	**3**	**4**	**5**
16. Yakınınızla ilgili ne yapacağınız konusunda kararsızlık hisseder misiniz?	**1**	**2**	**3**	**4**	**5**
	Asla	**Nadiren**	**Ara sıra**	**Oldukça Sık**	**Neredeyse Her zaman**
17. Yakınınız için daha fazlasını yapmanız gerektiğini düşünür müsünüz?	**1**	**2**	**3**	**4**	**5**
18. Yakınınızın bakımı ile ilgili olarak daha iyisini yapabilirdim diye düşünür	**1**	**2**	**3**	**4**	**5**

	müsünüz?					
19.	Tümüyle değerlendirdiğinizde yakınınızın bakımı ile ilgili kendinizi ne kadar yük altında hissedersiniz?	**1**	**2**	**3**	**4**	**5**

APPENDIX J: CAREGIVER WELL-BEING SCALE

Basic Needs Subscale

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

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

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

Activities of Living Subscale

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

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

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

(4. madde “Bahçe işleri ile ilgilenmek” geçerlik-güvenirlik çalışması sonrasında çıkarılmıştır)

APPENDIX K: MULTIDIMENSONAL SCALE OF PERCEIVED SOCIAL SUPPORT

ÇOK BOYUTLU ALGILANAN SOSYAL DESTEK ÖLÇEĞİ

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

1. İhtiyacım olduğunda yanımda olan özel bir insan var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

2. Sevinç ve kederimi paylaşabileceğim özel bir insan var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

3. Ailem bana gerçekten yardımcı olmaya çalışır.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

4. İhtiyacım olan duygusal yardımı ve desteği ailemden alırım.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

5. Beni gerçekten rahatlatan bir insan var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

6. Arkadaşlarım bana gerçekten yardımcı olmaya çalışırlar.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

7. İşler kötü gittiğinde arkadaşlarıma güvenebilirim.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

8. Sorunlarımı ailemle konuşabilirim.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

9. Sevinç ve kederlerimi paylaşabileceğim arkadaşlarım var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

10. Yaşamımda duygularıma önem veren özel bir insanım.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

11. Kararlarımı vermede ailem bana yardımcı olmaya isteklidir.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

12. Sorunlarımı arkadaşlarımla konuşabilirim.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

APPENDIX L: STATE-TRAIT ANXIETY INVENTORY-STATE FORM

YÖNERGE:Aşağıda kişilerin kendilerine ait duygularını anlatmada kullandıkları bir takım ifadeler verilmiştir. Her ifadeyi okuyun, sonra da o anda nasıl hissettiğinizi ifadelerin şağ tarafındaki parantezlerden uygun olanını işaretlemek suretiyle belirtin. Doğru ya da yanlış cevap yoktur. Herhangi bir ifadenin üzerinde fazla zaman sarfetmeksizin **anında** nasıl hissettiğinizi gösteren cevabı işaretleyin.

		HİÇ	BİRAZ	ÇOK	TAMAMİYLE
1.	Şu anda sakinim	(1)	(2)	(3)	(4)
2.	Kendimi emniyette hissediyorum	(1)	(2)	(3)	(4)
3	Su anda sinirlerim gergin	(1)	(2)	(3)	(4)
4	Pişmanlık duygusu içindeyim	(1)	(2)	(3)	(4)
5.	Şu anda huzur içindeyim	(1)	(2)	(3)	(4)
6	Şu anda hiç keyfim yok	(1)	(2)	(3)	(4)
7	Başıma geleceklerden endişe ediyorum	(1)	(2)	(3)	(4)
8.	Kendimi dinlenmiş hissediyorum	(1)	(2)	(3)	(4)
9	Şu anda kaygılıyım	(1)	(2)	(3)	(4)
10.	Kendimi rahat hissediyorum	(1)	(2)	(3)	(4)
11.	Kendime güvenim var	(1)	(2)	(3)	(4)
12	Şu anda asabım bozuk	(1)	(2)	(3)	(4)
13	Çok sinirliyim	(1)	(2)	(3)	(4)
14	Sinirlerimin çok gergin olduğunu hissediyorum	(1)	(2)	(3)	(4)
15.	Kendimi rahatlamış hissediyorum	(1)	(2)	(3)	(4)
16.	Şu anda halimden memnunum	(1)	(2)	(3)	(4)
17	Şu anda endişeliyim	(1)	(2)	(3)	(4)
18	Heyecandan kendimi şaşkına dönmüş hissediyorum	(1)	(2)	(3)	(4)
19.	Şu anda sevinçliyim	(1)	(2)	(3)	(4)
20.	Şu anda keyfim yerinde.	(1)	(2)	(3)	(4)

APPENDIX M: POST-TRAUMATIC GROWTH INVENTORY

TRAVMA SONRASI GELİŞİM ÖLÇEĞİ-TSGÖ

Aşağıda **HASTALIK SÜRECİ VE HASTA OLAN ANNE/BABANIZA BAKIM VERMEKTEN** dolayı yaşamınızda olabilecek bazı değişiklikler verilmektedir. Her cümleyi dikkatle okuyunuz ve belirtilen değişikliğin sizin için ne derece gerçekleştiğini aşağıdaki ölçeği kullanarak belirtiniz.

0= Hastalık süreci ve bakım vermekten dolayı böyle bir değişiklik yaşamadım
1= Hastalık süreci ve bakım vermekten dolayı bu değişikliği çok az derecede yaşadım
2= Hastalık süreci ve bakım vermekten dolayı bu değişikliği az derecede yaşadım
3= Hastalık süreci ve bakım vermekten dolayı bu değişikliği orta derecede yaşadım
4= Hastalık süreci ve bakım vermekten dolayı bu değişikliği oldukça fazla derecede yaşadım
5= Hastalık süreci ve bakım vermekten dolayı bu değişikliği aşırı derecede yaşadım

	Hiç yaşamadım					**Aşırı derecede yaşadım**
1. Hayatıma verdiğim değer artı.	0	1	2	3	4	5
2. Hayatımın kıymetini anladım.	0	1	2	3	4	5
3. Yeni ilgi alanları geliştirdim.	0	1	2	3	4	5
4. Kendime güvenim arttı.	0	1	2	3	4	5
5. Manevi konuları daha iyi anladım.	0	1	2	3	4	5
6. Zor zamanlarda başkalarına güvenebileceğimi anladım.	0	1	2	3	4	5

7. Hayatıma yeni bir yön verdim.	0	1	2	3	4	5
8. Kendimi diğer insanlara daha yakın hissetmeye başladım.	0	1	2	3	4	5
9. Duygularımı ifade etme isteğim arttı.	0	1	2	3	4	5
10. Zorluklarla başa çıkabileceğimi anladım.	0	1	2	3	4	5
11. Hayatımı daha iyi şeyler yaparak geçirebileceğimi anladım.	0	1	2	3	4	5
12. Olayları olduğu gibi kabullenmeyi öğrendim.	0	1	2	3	4	5
13. Yaşadığım her günün değerini anladım.	0	1	2	3	4	5
14. Hastalığımdan sonra benim için yeni fırsatlar doğdu.	0	1	2	3	4	5
15. Başkaların karşı şefkat hislerim arttı.	0	1	2	3	4	5
16. İnsanlarla ilişkilerimde daha fazla gayret göstermeye başladım.	0	1	2	3	4	5
17. Değişmesi gereken şeyleri değiştirmek için daha fazla gayret göstermeye başladım.	0	1	2	3	4	5
18. Dini inancım daha güçlendi.	0	1	2	3	4	5
19. Düşündüğümden daha güçlü olduğumu anladım.	0	1	2	3	4	5
20. İnsanların ne kadar iyi olduğu konusunda çok şey öğrendim.	0	1	2	3	4	5
21. Başkalarına ihtiyacım olabileceğini kabul etmeyi öğrendim.	0	1	2	3	4	5

APPENDIX N: WAYS OF COPING INVENTORY

Baş Etme Yolları Ölçeği

Aşağıda insanların sıkıntılarını gidermek için kullanabilecekleri bazı yollar belirtilmektedir. Cümlelerin her birini dikkatlice okuduktan sonra, **İÇİNDE BULUNDUĞUNUZ HASTALIK VE BAKIM VERME SÜRECİNİ DÜŞÜNEREK**, bu yolları hiç kullanmıyorsanız hiçbir zaman, kimi zaman kullanıyorsanız bazen, çok sık kullanıyorsanız her zaman seçeneğini belirtiniz.

	Hiçbi zama	**Baze**	**Her zama**
1. Aklımı kurcalayan şeylerden kurtulmak için değişik işlerle uğraşırım.	1	2	3
2. Bir mucize olmasını beklerim.	1	2	3
3. İyimser olmaya çalışırım.	1	2	3
4. Çevremdeki insanlardan sorunları çözmemde bana yardımcı olmalarını beklerim.	1	2	3
5. Bazı şeyleri büyütmeyip üzerinde durmamaya çalışırım.	1	2	3
6. Sakin kafayla düşünmeye ve öfkelenmemeye çalışırım.	1	2	3
7. Durumun değerlendirmesini yaparak en iyi kararı vermeye çalışırım.	1	2	3
8. Ne olursa olsun direnme ve mücadele etme gücünü kendimde hissederim.	1	2	3
9. Olanları unutmaya çalışırım.	1	2	3
10. Başa gelen çekilir diye düşünürüm.	1	2	3
11. Durumun ciddiyetini anlamaya çalışırım.	1	2	3
12. Kendimi kapana sıkışmış gibi hissederim.	1	2	3
13. Duygularımı paylaştığım kişilerin bana hak vermesini isterim.	1	2	3
14. 'Her işte bir hayır var' diye düşünürüm.	1	2	3
15. Dua ederek Allah'tan yardım dilerim.	1	2	3
16. Elimde olanlarla yetinmeye çalışırım.	1	2	3
17. Olanları kafama takıp sürekli düşünmekten kendimi alamam.	1	2	3
18. Sıkıntılarımı içimde tutmaktansa paylaşmayı	1	2	3

	tercih ederim.			
19.	Mutlaka bir çözüm yolu bulabileceğime inanıp bu yolda uğraşırım.	1	2	3
20.	'İş olacağına varır' diye düşünürüm.	1	2	3
21.	Ne yapacağıma karar vermeden önce arkadaşlarımın fikrini alırım.	1	2	3
22.	Kendimde her şeye yeniden başlayacak gücü bulurum.	1	2	3
23.	Olanlardan olumlu bir şeyler çıkarmaya çalışırım.	1	2	3
24.	Bunun alın yazım olduğunu ve değişmeyeceğini düşünürüm.	1	2	3
25.	Sorunlarıma farklı çözüm yolları ararım.	1	2	3
26.	'Olanları keşke değiştirebilseydim' diye düşünürüm.	1	2	3
27.	Hayatla ilgili yeni bir bakış açısı geliştirmeye çalışırım.	1	2	3
28.	Sorunlarımı adım adım çözmeye çalışırım	1	2	3
29.	Her şeyin istediğim gibi olamayacağını düşünürüm	1	2	3
30.	Dertlerimden kurtulayım diye fakir fukaraya sadaka veririm.	1	2	3
31.	Ne yapacağımı planlayıp ona göre davranırım.	1	2	3
32.	Mücadele etmekten vazgeçerim.	1	2	3
33.	Sıkıntılarımın kendimden kaynaklandığını düşünürüm.	1	2	3
34.	Olanlar karşısında 'kaderim buymuş' derim.	1	2	3
35.	'Keşke daha güçlü bir insan olsaydım' diye düşünürüm.	1	2	3
36.	'Benim suçum ne' diye düşünürüm.	1	2	3
37.	'Allah'ın takdiri buymuş deyip' kendimi teselli etmeye çalışırım.	1	2	3
38.	Temkinli olmaya ve yanlış yapmamaya çalışırım.	1	2	3
39.	Çözüm için kendim bir şeyler yapmak isterim.	1	2	3
40.	Hep benim yüzümden oldu diye düşünürüm.	1	2	3
41.	Hakkımı savunmaya çalışırım.	1	2	3
42.	Bir kişi olarak olgunlaştığımı ve iyi yönde geliştiğimi hissederim.	1	2	3

APPENDIX O: PERCEIVED PARTNER RESPONSIVENESS SCALE

PERCEIVED PARTNER RESPONSİVENESS-PPR

Lütfen aşağıdaki soruları anne/babanız HASTA OLMADAN ÖNCEKİ İLİŞKİNİZİ düşünerek cevaplayınız

1	2	3	4	5	6	7	8	9
hiç doğru değil		biraz doğru		orta derecede doğru		oldukça doğru		tamamen doğru

Hasta olmadan önce annem/babam:

_____ 1. ... nasıl biri olduğumu çok iyi bilirdi
_____ 2. ... “gerçek ben”i görürdü
_____ 3. ... iyi yönlerimi ve kusurlarımı, benim kendimde gördüğüm gibi görürdü
_____ 4. … söz konusu bensem yanılmazdı
_____ 5. ... zayıf yönlerim de dahil her şeyimi takdir ederdi
_____ 6. ... beni iyi tanırdı
_____ 7. ... iyisiyle kötüsüyle “gerçek ben”i oluşturan her şeye değer verir ve saygı gösterirdi
_____ 8. ... çoğu zaman en iyi yönlerimi görürdü
_____ 9. ...ne düşündüğümün ve hissettiğimin farkındaydı
_____ 10. ... beni anlardı
_____ 11. ... beni gerçekten dinlerdi
_____ 12. ... bana olan sevgisini gösterir ve beni yüreklendirirdi
_____ 13. ... ne düşündüğümü ve hissettiğimi duymak isterdi
_____ 14. ... benimle birlikte bir şeyler yapmaya hevesliydi
_____ 15. ... yetenek ve fikirlerime değer verirdi
_____ 16. ... benimle aynı kafadaydı
_____ 17. ... bana saygı duyardı
_____ 18. ...ihtiyaçlarıma duyarlıydı

APPENDIX R: TURKISH SUMMARY/TÜRKÇE ÖZET

BÖLÜM 1

GİRİŞ

Bu araştırma, Alzheimer hastalığı tanısı almış ebeveynlerine bakım vermekte olan Türk yetişkinlerin olumlu ve olumsuz yaşantılarını anlamak ve bu yaşantıları etkileyen etmenleri araştırmak için yürütülmüştür.

1.1. Alzheimer Hastalığı'nın Tanımı ve Yaygınlığı

Alzheimer hastalığı bireyin bilişsel, duygusal, davranışsal ve fizyolojik işleyişine zarar veren, ilerleyici bir nörolojik hastalıktır. En yaygın olarak bilinen belirtisi hafıza kaybı olmasına karşın, muhakemede sınırlılıklar, yargılamada güçlük, karar verme zorlukları, konuşma güçlükleri ve fiziksel işlev kaybı hastalığın diğer önemli belirtileri arasında yer almaktadır (Alzheimer's Society [AS], 2014).

Dünyada yaklaşık olarak 30 milyon Alzheimer hastası yaşamaktadır. Amerika'da ise bu sayının 5.5 milyon olduğu bilinmektedir (Brodaty & Donkin, 2009). Bu sayısının 2020 yılında iki katına çıkması beklenmektedir çünkü ilerleyen tıp artık kişilerin uzun yıllar kronik sağlık sorunlarıyla yaşamasına olanak vermektedir.

Ulusal düzeyde arşivlenmiş veriler olmamasına karşın Türkiye'de de yaklaşık 600.000 Alzheimer hastasının yaşadığı düşünülmektedir (Türk Alzheimer Derneği, 2016).

1.2. Alzheimer Hastalığı'nın Bakım Veren Üzerindeki Etkileri

İlerleyici nörolojik yıkımdan dolayı Alzheimer hastaları zaman içerisinde neredeyse tüm yaşam fonksiyonları için bakım ve denetlenmeye ihtiyaç duymaktadır.

Hastalığın çok uzun yıllar bakım gerektiyor olması, bakım verenlerin oldukça fazla çeşitlilikte bakım verme görevini yerine getirmeleri, ve bilişsel yıkımın geçmiş ilişki kalitesine zarar vermesi nedeniyle Alzheimer hastalığına bakım vermekte olan aile bireylerinin fiziksel ve psikolojik olarak diğer bakım verme gruplarına göre daha fazla risk altında oldukları bilinmektedir (AA, 2016; Brodaty & Donkin, 2009; Smith, Lauret, Peery, & Mueller, 2001).

1.2.1. Olumsuz Bakım Veren Sonuçlarını Açıklayan Modeller

Literatürde olumsuz bakım verme sonuçlarını açıklayan en yaygın model Pearlin ve arkadaşları (1990) tarafından geliştirilmiş olan stress süreç modelidir. Bu modele göre bağlam değişkenleri, birincil stresörler, ikincil stresörler, ara değişkenler ve sonuç değişkenleri etkileşimli bir şekilde birbirleriyle ilişki içinde bulunarak bir stres süreci oluşturmaktadır. Bağlam değişkenleri bakımın verildiği ortamın özellikleri ve koşullarına vurgu yapmaktadır. Bu bağlamda, bakım veren kişinin cinsiyeti, yaşı, ekonomik düzeyi ve ait olduğu kültürün özellikleri bu öğe altında incelenmektedir. Birincil değişkenler ise direk olarak hastalık ve hastaya ilişkin özellikleri kapsamaktadır ve hastalığın şiddeti, davranışsal sorunların sıklığı ve hastanın bakım verene olan işlevsel bağımlılığı gibi değişkenleri içine almaktadır. İkincil stresörler, aslında, birincil stresörlerin bakım veren kişilerin hayatında yarattığı olumsuz sonuçlar ile ilgilidir. Bu bağlamda, sosyal yaşamda meydana gelen kısıtlılıklar, iş-bakım verme çatışlamaları, kişinin kendine olan güveninin örselenmesi ve durum üzerindeki kontrol algısı bu öğeyi oluşturmaktadır. Ara değişkenler ise benzer stresörlere sahip olan bakım verenlerin neden farklı bakım verme sonuçları yaşadıklarını incelemek amacıyla bu modele eklenmiştir. Bu öğe, bakım verenin sosyal destek düzeyini ve baş etme stretejilerini kapsamaktadır.

Literatürde Alzheimer hastalığının bakım veren üzerindeki etkilerini araştırmayı amaçlayan bir diğer model ise Sörensen ve arkadaşlarının geliştirdiği Bakım Veren Stresi ve Yükü Modeli'dir (2006). Bu model her ne kadar bir önceki model ile yapısal olarak benzerlikler taşısa da, ara değişkenler öğesi moderator değişkenler olarak değiştirilmiştir. Ayrıca, yeni bir öğe olan “değerlendirme” öğesi modele eklenmiştir.

1.2.2. Bakım Vermenin Bakım Veren Üzerindeki Olumsuz Etkileri

1.2.2.1. Bakıcı Yükü

Çok yönlü bir kavram olan bakım verme yükü, bakım verenlerin hastalık ve bakım verme sürecine ve bilişsel yıkım nedeniyle bozulan ilişki kalitesine ilişkin genel stresini kapsamaktadır. Ayrıca, bakım verme yükünün paylaşılmasına ilişkin oluşan aile problemleri ve bakım verme görevleri nedeniyle yaşanan sosyal yaşam kısıtlamaları da bakım verme yükü kavramı altında incelenmektedir (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Savundranayagam, Montgomery, & Kosloski, 2011). Araştırmalar, Alzheimer hastalarına bakmakta olan kişilerin oldukça yüksek derecede bakım verme yükü deneyimlediklerini ortaya koymaktadır (Mittelman et al., 2006; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Savundranayagam et al., 2011).

1.2.2.2. Psikolojik Etkiler

Depresyon ve kaygının Alzheimer hastalarına bakım vermekte olan kişilerde en yaygın olarak görülen psikolojik belirtiler olduğu bilinmektedir. Bunun yanı sıra, hayat kalitesinde düşme, yaşamdan zevk alamama ve umutsuzluk diğer psikolojik belirtiler arasında yer almaktadır (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Kim, Chang, Rose, & Kim, 2012; Martire & Hall, 2002; Schulz & Martire, 2004; Teri, Logsdon, Uomoto, & McCurry, 1997).

1.2.2.3. Fiziksel Etkiler

Alzheimer hastalarına bakım vermekte olan kişilerin kortisol seviyelerinde artış olduğu, uyku düzenlerinin bozuluğu, yaralarının yavaş iyileştiği ve bağışıklık sistemlerinin zayıfladığı bilinmektedir (Allen et al., 2016; Bauer et al., 2000). .

1.2.2.4. Ölüm Öncesi Yas

Literatürdeki araştırmalar Alzheimer hastalarına bakım vermenin bakım veren üzerindeki olumsuz etkilerini genel olarak stres-baş etme paradigması çerçevesinde incelemişlerdir. Ancak son dönem araştırmacı ve teorisyenler Alzheimer bakım verenlerinin sevdikleri kişinin gün be gün ölümüne tanık olduklarını, bu nedenle de yasın oldukça nadir rastlanan bir türünü yaşıyor olabileceklerini vurgulamışlardır (Mesuer & Marwit, 2001; Romero, Ott & Kelber, 2007). Bu bağlamda, bugüne kadar bakım veren depresyonu olarak varsayılmış belirtileri açıklayan yüzde elli oranındaki varyansın aslında ölüm öncesi yas belirtileriyle açıklanabileceği ortaya koyulmuştur (Collins, Liken, King, & Kokinakis, 1993; Sanders & Corley, 2003).

1.2.3. Bakım Vermenin Bakım Veren Üzerindeki Olumlu Etkileri

Alzheimer hastalığının bakım veren üzerindeki etkilerini inceleyen çalışmalar çoğunlukla olumsuz yaşantılara odaklanmışlardır. Ancak, olumsuz ve olumlu etkilerin bu tarz stresli yaşam olaylarında eş zamanlı olarak görülebileceği ve hatta olumlu etkilerin olumsuz etkiler üzerinde koruyucu bir etki sağlayabilecekleri bilinmektedir. (Andrén & Elmståhl, 2008; de Labra ve ark.ları, 2015) Bu doğrultuda yapılan araştırmalar, Alzheimer hastası yakınlarına bakım vermekte olan kişilerin hastaları ile olan ilişkilerinden keyif aldıklarını, kendilerini faydalı hissetiklerini ve bakım vermekten zevk aldıklarını ortaya koymuştur. Tüm bu olumlu etkilerin de daha az bakım veren yükü ve depresif belirti ile ilişkili olduğu ifade edilmiştir (Cohen ve ark.ları, 1994).

1.3. Bakım Veren Sonuçları ile İlişkili Faktörler

1.3.1. Hasta ve Hastalık ile İlişkili Faktörler

1.3.1.1. Hastalığın Seviyesi

Kimi araştırmalar ileri seviyede Alzheimer hastası kişilere bakan bakım verenlerin daha fazla yük ve depresif belirtiler yaşadıklarını ortaya koyarken (Conde-Sala ve ark.ları. 2010; Kim ve ark.ları, 2012; Mohamed et al., 2010; Pinquart & Sörensen, 2003; Raggi ve ark.ları, 2015) , diğer araştırmalar ise hastalığın seviyesi ve olumsuz bakım veren etkileri arasında bir ilişki ortaya koyamamaktadır (Andrén & Elmståhl, 2008; Ferrara ve ark.ları, 2008). Bu tutarlı olmayan ilişki, hastalık ile ilgili nesnel özelliklerdense bu özelliklerin bakım veren tarafından algılanış biçiminin olumsuz sonuçlar üzerinde daha etkili olabileceği hipotezi ile açıklanmaktadır.

1.3.1.2. Davranışsal Belirtiler

Hastalık ve hastaya ilişkin özellikler arasında tutarlı ve sistematik olarak olumsuz bakım veren sonuçlarnı yordayan en önemli özellik davranışsal belirtiler olarak ifade edilmektedir (Mohamed ve ark.ları, 2010; Pinquart & Sörensen, 2003).. Davranışsal belirtilerin bakım verenleri hem fiziksel olarak yorduğu hem de psikolojik olarak kaybettikleri kişiyi gün be gün hatırlattığı için olumsuz bakım veren sonuçları ile ilişkili olabileceği düşünülmektedir (Boss, 2000; Meuser & Marwit, 2001).

1.3.2. Bakım Veren ile İlişkili Faktörler

1.3.2.1. Bakım Verenin Cinsiyeti

Alzheimer hastalarına bakım vermekte olan kişilerin çoğunun kadın olduğu bilinmektedir. Buna ek olarak, kadınların erkeklere göre daha fazla bakım veren yükü, depresyon ve kaygı yaşadıkları gözlemlenmiştir. Ayrıca ölüm öncesi yasın yaşanma biçimleri açısından da kadınlar ve erkekler arasında farklar olabileceği belirtilmektedir (Ashley & Kleinpeter, 2008; Barber & Pasley, 1995; Bédard, Chambers, & Pedlar, 2000; Kim ve ark.ları, 2012; Roche, Croot, MacCann, Cramer, & Diehl-Schmid, 2015; Papastavrou ve ark.ları, 2011) .

1.3.2.2. Baş Etme Stratejileri

Baş etme stratejileri kişilerin stresli durumlar karşısında olumsuz duygularını azaltmak amacıyla kullandıkları bilişsel, duygusal ve davranışsal yolları kapsamaktadır (Lazarus & Folkman, 1984; Raggi, Tasca, Panerai, Neri, & Ferri, 2015) . Literatürde genel olarak problem odaklı baş etme stratejilerinin (örneğin, davranışsal belirtilere alternatif çözümler bulmak) ve kabullenmeyi arttıran baş etme stratejilerinin daha az bakım veren yükü ve depresyon ile ilişkili olduğu ortaya koyulmuştur. Öte yandan, çaresiz baş etme stratejisi genel olarak olumsuz bakım veren sonuçları ile ilişkilendirilmiştir (Ashley & Kleinpeter, 2008; Geiger ve ark.ları, 2014; Papastavrou et al., 2011; Raggi ve ark.ları, 2015).

1.3.3. Diğer Faktörler

1.3.3.1. Bakım Veren ve Hasta Arasındaki İlişkinin Tipi

Bakım veren ve hasta arasındaki ilişkinin tipinin stresin yaşanış biçimi üzerinde oldukça etkili olduğu bilinmektedir. Ebeveynlerine bakım vermekte olan kişilerde tanının hemen ardından stres düşük düzeyde yaşanırken, hastalık ortaya seviyeye geldiğinde stresin normal seviyelerde seyrettiği ve ileri derecede tekrar yükseldiği bilinmektedir. Öte yandan, eşlerine bakım vermekte olan kişilerde stres hastalık tanısının ardından kademeli olarak artmakta ve özellikle bakım evine yatırılma yaşantısından sonra en yüksek seviyeye ulaşmaktadır (Marwit & Meuser, 2002).

1.3.3.2. Kültür

Bakım verme yaşantısının gerçekleştiği kültürel bağlamın bakım verme deneyimi ve etkileri üzerinde önemli etkileri olabileceği düşünülmektedir. Bilindiği üzere Doğu kültürleri yaşlanma, bakım verme ve aile ilişkileri hakkında Batı kültürlerinden oldukça farklılaşabilen algılara sahiptir. Bu bağlamda, ataya saygı ve aile uyumunun korunmasına yönelik tutumların bakım verenler üzerinde olumlu ve/ya olumsuz etkilerinin olabileceği ortaya koyulmuştur (Fung, 1998; Gallagher-Thompson et al., 2000; Mahoney, Cloutterbuck, Neary, & Zhan, 2005; Min, 1995).

1.3.3.3. Sosyal Destek

Genel olarak sosyal desteğin olumsuz bakım verme yaşantıları üzerinde hem direk hem de dolaylı bir koruyucu etkisinin olduğu bilinmektedir (Brodaty & Donkin, 2009; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Haley et al., Han et al., 2014; 1996; Heo, 2014) . Öte yandan, aile ilişkilerine önem veren toplumlarda, beklenen sosyal destek düzeyine sahip olamamanın çok daha fazla stres oluşturabileceği de elde edilen bulgular arasındadır (Edwards & Cooper, 1988).

1.4. Tezin Kapsamı ve Amaçları

Literatürdeki bulgular incelendiğinde, nesnel stresörler ve olumsuz bakım veren yaşantıları arasındaki ilişkinin oldukça sık olarak incelenmesine karşın, bakım veren ile ilişkili faktörlerin (örneğin, baş etme stratejileri, sosyal destek) görece daha az çalışıldığı görülmektedir. Ayrıca, bakımın sağlandığı kültürel bağlam, olumlu bakım verme yaşantıları ve ölüm öncesi yas süreçlerinin de daha az çalışıldığı gözlemlenmiştir. Bu bağlamda, bu tezin amacı Alzheimer hastası anne ya da babasına bakım vermekte olan yetişkinlerin ortak ve biricik deneyimlerini incelemek olarak belirlenmiştir.

BÖLÜM 2

GENEL YÖNTEM

2.1 Genel Araştırma Yöntemi

Anne ya da babasına bakım vermekte olan Türk yetişkinlerin ortak ve biricik deneyimlerini araştırmak amacıyla bu tez kapsamında çoklu yöntem metodolojisi uygulanmıştır. Bu kapsamda, sırasıyla niteliksel ve niceliksel, iki araştırma yürütülmüştür. Her ne kadar bu iki araştırma temel araştırma sorusuna cevap bulmak amacıyla gerçekleştirilmiş olsa da, araştırmalar metodolojileri açısından birbirinden bağımsızdır (Tassakkori & Teddle, 2003). Bir diğer deyişle, her iki araştırmada da veri toplama ve analizi ile ilişkili tüm temel istatistiksel ve teorik varsayımlara uyulmuştur. Her iki araştırmadan elde edilen bulgular, sonrasında birleştirilerek benzerlikler ve farklılıklar ilgili literatür bulguları ışığında tartışılmıştır (Cresswell, 2014; Tassakkori & Teddle, 2003).

2.2. Genel İşlem

Her iki araştırmanın veri toplama aşamasından önce ODTÜ Uygulamalı Etik Araştırma Merkezi'nden etik kurul onayı alınmıştır.

Gerek niteliksel gerek ise niceliksel araştırma kapsamında katılımcı havuzunu oluşturmak amacıyla Facebook'da Alzheimer hasta yakınları için kurulmuş destek gruplarına duyurular yazılmıştır, ve ilgili katılımcılarla iletişime geçilmiştir.

BÖLÜM 3

ÇALIŞMA 1: EBEVEYNLERİNE BAKIM VERMEKTE OLAN TÜRK YETİŞKİNLERİN DENEYİMLERİ

3.1. Giriş

Batı ve Doğu kültürleri bakım verme, yaşlılık ve aile ilişkilerine ilişkin farklı değer ve normlara sahiptir. Bu farklı normlar baş etme stratejileri ve algılar üzerinden bakım verme süreci üzerinde farklılaşan etkilere neden olmaktadır. Literatürdeki araştırmaların çoğunlukla Batı kültürlerinde yaşamakta olan bakım verenlerin bakım verme deneyimini araştırdıkları, öte yandan Doğu kültürlerinde Alzheimer hastalarına bakım verme deneyimi ile ilişkili çalışmaların oldukça az sayıda olduğu görülmektedir. Bu nedenle bu araştırmanın amacı Alzheimer hastası anne ya da babasına bakım vermekte olan Türk yetişkinlerin kültür ile ilişkili algılarını, baş etme stratejilerini ve bakım verme deneyimlerini incelemek olarak belirlenmiştir (Lee & Sung, 1997; Sun et al., 2012; Youn et al., 1999).

3.1.1. Araştırma Sorusu

Alzheimer hastası anne ya da babasına bakım vermekte olan Türk yetişkinler bakım verme yaşantısını algılar, baş etme stratejileri ve bakım vermenin olumlu/olumsuz etkileri açısından nasıl deneyimlemektedirler?

3.2. Yöntem

3.2.1. Yöntemsel Arka Plan

Doğu kültürlerinde Alzheimer hastalarına bakım sağlayanların deneyimleri oldukça kısıtlı sayıda araştırma tarafından incelendiği için, Yorumlayıcı Fenomonolojik Analiz (YFA) söz konusu araştırma için uygun yöntem olarak belirlenmiştir. YFA özellikle görece olarak az çalışılmış konuları araştırmak amacıyla uygulanan bir yöntemdir ve hedefi bireylerin anlatımlarından yola çıkarak bireysel yaşantıları derinlemesine bir şekilde anlamaktır (Smith, Osborn, & Jarman, 1999; Willig, 2008).

3.2.2. Katılımcılar

İlk olarak 23 katılımcıya ulaşılmasına ragmen, 3 katılımcı sağlık sorunları nedeniyle görüşmelere katılamayacaklarını bildirmişledir. Bu nedenle en son örneklem anne ya da babasına bakım vermekte olan 20 bakım verenden oluşmuştur.

3.2.3. Etik Kurul Onayı

Veri toplama aşamasından önce ODTÜ Uygulamalı Etik Araştırma Merkezi'nden etik kurul onayı alınmıştır. Ayrıca, hasta yakınlarına destek sağlamak için oluşturulan Facebook gruplarının yöneticilerinden de sözel ve yazılı izin alınmıştır.

3.2.4. İşlem

Araştırmanın katılımcılarına amaçlı örnekleme yöntemi ile ulaşılmıştır ki bu örneklem seçme yönteminin YFA için uygun olduğu bilinmektedir (Willig, 2008).

Araştırmacılar tarafından 10 tane açık uçlu sorudan oluşan yarı-yapılandırılmış bir görüşme formatı oluşturulmuştur. Soruların yönlendirici olmamasına önem gösterilmiştir (Ek D). Görüşmeler ortalama olarak 54 dakika sürmüştür.

3.2.5. Veri Analizi

Tüm görüşmelerin ses kaydı alınmıştır. Birinci araştırmacı (Ar) ham veriye aşina olmak amacıyla yazı dökümü yapılan görüşmeleri tekrar tekrar okumuş ve incelemiştir. Ayrıca bu inceleme sırasında, içerik ve kendi gözlemlerine dayalı notlar almış ve bu notları sonrasında veriyi kavramsallaştırma amacı ile kullanmıştır.

YFA yaklaşımı ile uyumlu olarak, analiz ilk katılımcının yazı dökümünün detaylı bir şekilde kodlanması ile başlamıştır. İlk katılımcı için üst ve alt temalar oluşturulduktan sonra, ikinci katılımcının görüşmesinin analizine geçilmiş ve aynı işlemin uygulanmasının ardından her iki katılcımının kodlamaları detaylı bir şekilde karşılaştırılmıştır. İşlem her bir katımcının yazı dökümü için tekrarlanmıştır.

3.2.6. Kendini Yansıtma

Niceliksel araştırma yöntemleri, öznelliği verinin analizi ve yorumlamasında bir engel olarak görmemekte, aksine bu öznelliğin net bir şekilde açıklanması durumunda veriyi zenginleştiren bir kavram olduğunu ileri sürmektedir. Bu bağlamda araştırma ekibinin söz konusu konu ile ilişkisi şu şekildedir:

"Yağmur Ar ODTÜ'de araştırma görevlisidir ve aynı zamanda uzman klinik psikologdur. Araştırma konuları arasında muğlak kayıp ve kronik hasta gruplarına bakım verenlerin psiko-sosyal iyilik halleri yer almaktadır. Ayrıca, dedesi ileri derece Alzheimer hastasıdır ve annesi dedesinin birincil bakım verenidir."

"Prof. Dr. Nuray Karancı ise şizofreni hastalarının aileleri ve travma yaşamış kişilerle uzun yıllardır çalışmakta olan tecrübeli bir klinik psikologdur. Özellikle stresli ve olumsuz yaşam olaylarının dönüştürücü olumlu etkisine özel bir ilgisi bulunmaktadır."

3.3. Sonuçlar

Yirmi kişiden elde edilen verinin analizi sonucunda (1) hastalığın nedenleri, (2) değişimler ve kayıplar, (3) baş etme stratejileri, (4) sürece yardımcı olan ya da süreci zorlaştıran faktörler, (5) hastalığın biricik özellikleri ve (6) hastayı bakım evine yatırma konusundaki isteksizlik olmak üzere toplam 6 üst tema oluşturulmuştur.

3.3.1. Hastalığın Nedenleri

Bakım verenlerin oldukça nadir olarak biyolojik faktörleri hastalığın oluşumu ile ilişkilendirdikleri, öte yandan olumsuz aile yaşantıları (örneğin, aile içi çatışma, aile içi şiddet, çatışmalı ebeveyn-çocuk ilişkileri) ve hastalık öncesi bazı kişilik özelliklerini (örneğin, evhamlı olmak, duygularını bastırmak) hastalığın oluşumundan sorumlu tuttukları görülmektedir.

3.3.2. Değişimler ve Kayıplar

Bakım verenlerin ebeveyn-çocuk ilişkisinin kaybı, iletişimin azalması ve rol değişimleri gibi pek çok olumsuz değişimi dile getirdikten sonra hasta ve hastalık süreci ile ilişkili bir takım olumlu deneyimleri de aktardıkları gözlemlenmiştir. Hasta ile yeni ve daha yakın bir ilişki kurulması, yeni bir bakış açısı kazanma ve daha sabırlı olmak bu olumlu değişimlere verilen örnekler arasındadır.

3.3.3. Baş Etme Stratejileri

Katımcıların özellikle dini ve kaderci baş etme stratejilerinden oldukça faydalandıkları görülmüştür. Şükür, tevekkül ve "her işte bir hayır vardır" gibi dini kavramların bakım verenleri rahatlattıkları gözlemlenmiştir. Bunun yanı sıra, sosyal destek, problem-odaklı baş etme, dikkat dağıtma ve kaçınma bakım verenler tarafından belirtilen diğer baş etme stratejileri arasında yer almaktadır.

3.3.4. Sürece Yardımcı olan ya da Süreci Zorlaştıran Faktörler

Bakım verenler sahip oldukları bazı kişilik özelliklerinin hastanın bilişsel-davranışsal belirtileri ve bakım verme süreci ile baş etmede süreci kolaylaştırdığını belirtmişlerdir. Örneğin, sabırlı olmak, merhametli olmak, sosyal olmamak ve yüksek toleranslı olmak bu özellikler arasında yer almaktadır. Öte yandan, sabırsız olmak, sosyal hayata düşkün olmak ve geçmişte hasta ile çatışmalı bir ilişkiye sahip olmak süreci zorlaştıran faktörler olarak belirtilmiştir.

3.3.5. Hastalığın Biricik Özellikleri

Kimi bakımverenlere göre bilişsel yıkım sebebiyle hastanın kendi durumunun farkında olmaması hastalığın en acı özelliğidir, öte yandan diğer bakım verenler bu özelliği bir avantaj olarak değerlendirmektedir. Buna ek olarak, bağırma, sürekli aynı soruyu sorma ve eşyaların yerini karıştırma gibi davranışsal belirtilerin bakım verenlerde yoğun üzüntü ve acıya neden olduğu gözlemlenmiştir.

3.3.6. Hastayı Bakım Evine Yatırma Konusunda İsteksizlik

İlginç bir şekilde, neredeyse bütün bakım verenler sevdikleri kişiyi bakım evine yatırmak istemediklerini ifade etmişlerdir. Kimi bakım verenler bakım evine yatırmayı etik olmayan ve ahlaksız bir davranış olarak değerlendirirken, kimi bakım verenler ise Türkiye’deki bakım evlerinin kötü koşulları nedeniyle böyle bir seçeneği değerlendirmeyeceklerini ifade etmişlerdir.

3.4. Tartışma

Bu araştırmanın sonuçları Alzheimer hastası anne ya da babasına bakım vermekte olan Türk yetişkinlerin ortak ve biricik deneyimler yaşadıklarını ortaya koymaktadır.

3.4.1. Hastalığın Nedenleri

Türk bakım verenlerin hastalığın nedenlerini açıklarken biyolojik faktörlerdense psiko-sosyal faktörlere ağırlık vermelerinin literatür bulguları ile tutarlı olduğu düşünülmektedir. Önceki araştırmalara göre de azınlık gruplarının hastalık tanımlarında ailesel ve toplumsal faktörlere ağırlık verdikleri ortaya koyulmuştur (Chi-Chan, 2011; Gilbert, Bhundia, Mitra, McEwan, Irons, & Sanghera, 2007). Bakım verenlerin özellikle çatışmalı aile yaşantılarına yaptıkları vurgunun da Türk toplumunda aile uyumu ve bütünlüğüne verilen önem ile ilişkili olabileceği düşünülmektedir (Triandis & Suh, 2002).

3.4.2. Değişimler ve Kayıplar

Türk bakım verenlerin hastalık ve bakım verme sürecine ilişkin yaptıkları vurgunun literatürdeki diğer bakım veren çalışmaları ile tutarlı olduğu düşünülmektedir (Ablitt, Jones & Muers, 200; Connell et al., 2001; Frank, 2007; Harris et al., 2011; Mesuer & Marwit, 2001; Romero, Ott & Kelber, 2007).

Öte yandan, örneklemi oluşturan yetişkinlerin olumsuzluklardan sonra pek çok olumlu değişime de açıklamalarında yer vermelerinin çarpıcı olduğu düşünülmektedir. Literatürde de farklı kültürel grupların ilişkiden alınan haz ve bakım verme tatmini gibi olumlu değişimleri daha sıklıkla rapor ettiği bilinmektedir Connell et al., 2001; Hebbert & Schulz, 2006; Heo, 2014; Ivey et al., 2012).

3.4.3. Baş Etme Stratejileri

İslam dini ile ilişkili dinsel ve kaderci baş etme stratejisinin örneklemi oluşturan yetişkinlerde kabullenmeyi kolaylaştırdığı düşünülmektedir. İslam'ın "her şerde bir hayır vardır" inancının aynı zamanda bakım verme motivasyonunu arttırdığı ve bakım verenleri durumun olumlu yönlerini görmeye teşvik ettiği düşünülmektedir (Heo, 2014; Lim, Griva, Goh, Chionh, &Yap, 2010). Her ne kadar söz konusu örneklem tarafından rapor edilmemiş olsa da, dini ve kaderci baş etmenin aşırı kendini feda davranışı ile ilişkilendirilebileceği de düşünülmektedir, bu noktada gelecek araştırmaların dini ve kaderci baş etmenin bu yönlerini araştırmalarının önemli olduğu izlenimi edinilmiştir.

Bunun yanı sıra, sosyal destek alma, problem-çözme, dikkat dağırma ve kaçınma literatür ile tutarlı olarak rapor edilen diğer baş etme stratejileri arasında yer almaktadır (Brodaty & Donkin, 2009; Clyburn et al., 2000; Haley et al., Han et al., 2014; 1996; Heo, 2014).

3.4.4. Sürece Yardımcı Olan ya da Süreci Zorlaştıran Faktörler

Her ne kadar literatürdeki araştırmalar sınırlı olsa da, kimi kişilik özelliklerinin ve geçmiş ilişki kalitesinin hastalık süreci üzerindeki olumlu ve olumsuz etkilerinin bulunmasının literatürdeki önceki bulgularla tutarlı olduğu izlenimi edinilmiştir (Fauth et al., 2012; Quinn, Clare, & Woods, 2008; Williamson & Shaffer, 2001; Williamson & Schulz, 1990).

3.4.5. Hastalığın Biricik Özellikleri

Önceki bulgularla tutarlı olarak, hastanın durumunun farkında olmaması ve davranışsal problemler bakım verenleri en fazla zorlayan ve acı veren hastalık özellikleri olarak belirtilmiştir (Austrom et al., 1990; Frank, 2008; Harris et al., 2011; Meuser & Marwit, 2001). Öte yandan, kimi bakım verenler hastanın kendi durumunun farkında olmamasının bir avantaj olduğunu düşündüklerini rapor etmişlerdir.

3.4.6. Hastayı Bakım Evine Yatırma Konusunda İsteksizlik

Neredeyse tüm katılımcıların evde resmi olmayan bakım verme seçeneğine devam etme motivasyonlarının, bakım vermenin Doğu kültürlerinde daha normatif bir yaşantı olması ile ilişkilendirilebileceği düşünülmektedir. Bu kültürlerde yetişkinler ebeveynlerine bakım vererek saygı ve sevgi gösterdiklerini düşünmekte, bu nedenle kendi fiziksel ve psikolojik kaynaklarını ebeveynlerinin iyiliği için harcayabilmektedirler. Bir diğer deyişle, bu kültürlerde bakım verme toplum tarafından takdir edilen ve ödüllendirilen bir davranıştır (Ho ve ark.ları, 2003; Mahoney ve ark.ları, 2005; Min, 1995).

3.4.7. Sonuçlar ve İmplikasyonlar

Bu araştırmanın bulguları Türk bakım verenlerinin ortak ve biricik bir takım yaşantıları olabileceğini ortaya koymuştur. Bu sebeple, bu grup ile çalışırken kültüre duyarlı müdahale programlarının geliştirilmesinin önemli olduğu düşünülmektedir. Bu programlarda işlevsel kültürel baş etme stratejilerinin kullanımının desteklenirken, işlevsel olmayan baş etme stratejilerinin azaltılmasına yönelik uygulamaların faydalı olacağı izlenimi edinilmiştir. Özellikle bakım evi ile ilişkili kültürel ve bireysel inançların ele alınması da bu müdahale programlarının önemli bir parçası olmalıdır.

3.4.8. Sınırlılıklar

Her ne kadar toplumsal değerlerden yoğun olarak etkilenmiş olsa da, Türkiye'de bireyselciliğe ilişkin değerlerin de günlük hayat üzerinde etkisi olduğu bilinmektedir. Bu nedenle, ileriki çalışmalarının Türkiye'nin farklı bölgelerinde yaşamakta olan bakım verenlerle gerçekleştirilmesinin söz konusu deneyimin anlaşılması açısından önemli olacağı düşünülmektedir.

BÖLÜM 4

ÇALIŞMA 2: ALZHEİMER HASTASI EBEVEYNİNE BAKIM VERMEKTE OLAN TÜRK YETİŞKİNLERDE DEPRESYON, KAYGI, YAS VE BÜYÜME İLE İLİŞKİLİ FAKTÖRLER

3.1. Giriş

Niteliksel araştırmanın sonuçları olumlu bakım verme deneyimlerinin, ölüm öncesi yasın ve kültür ile ilişkili baş etme stratejilerinin Türk bakım verenlerin deneyimlerinde önemli bir rol oynayabileceğini ortaya koymuştur. Bu sebeple, bu üç değişken daha önce de bahsedilen Pearlin ve ark.ları (1990) ve Sörensen ve ark.larının (2004) modellerine entegre edilmiştir.

3.1.1. Araştırma Sorusu

1. Bağlamsal değişkenler (örneğin, yaş, cinsiyet, eğitim durumu, SES ve geçmiş ilişkinin kalitesi), birincil stresörler (örneğin, hastalığın düzeyi, ilk belirtilerin fark edilmesinin ardından geçen süre, tanı alındığından beri geçen süre, ne kadar süredir bakım verildiği, haftada kaç saat bakım sağlandığı, ve hasta ile birlikte yaşama durumu), ikincil stresörler (öznel bakımveren yükü) ve biçimleyici değişkenlerin (örneğin, baş etme stratejileri ve algılanan sosyal destek düzeyi) olumsuz (depresyon, kaygı vey as) ve olumlu (büyüme) bakım verme sonuçları ile nasıl ilişkileri vardır?

2. Baş etme stratejileri ve algılanan sosyal desteğin bakıcı yükü ve olumsuz bakım verme sonuçları arasındaki ilişkide biçimleyici bir rolü var mıdır?

3. Baş etme stratejileri ve algılanan sosyal desteğin bakım verme yükü ve olumlu bakım verme sonuçları (büyüme) arasındaki ilişkide biçimleyici bir rolü var mıdır?

4.3. Niceliksel Araştırmanın Hipotezleri

Bağlamsal değişkenler (örneğin, yaş, cinsiyet, eğitim durumu, SES ve geçmiş ilişkinin kalitesi), birincil stresörler (örneğin, hastalığın düzeyi, ilk belirtilerin fark edilmesinin ardından geçen süre, tanı alındığından beri geçen süre, ne kadar süredir bakım verildiği, haftada kaç saat bakım sağlandığı, ve hasta ile birlikte yaşama durumu), ikincil stresörler (öznel bakımveren yükü) ve biçimleyici değişkenlerin (örneğin, baş etme stratejileri ve algılanan sosyal destek düzeyi) olumsuz (depresyon, kaygı vey as) ve olumlu (büyüme) bakım verme sonuçları ile ilişkili olacağı düşünülmektedir. Ayrıca, baş etme stratejileri ve algılanan sosyal desteğin bakıcı yükü-olumsuz bakım verme sonuçları ve bakıcı yükü-büyüme arasındaki ilişkilerde biçimleyici bir role sahip olacağı beklenmektedir.

4.4. Yöntem

4.4.1. Katılımcılar

Araştırmanın örneklemini Alzheimer hastası anne ya da babasına haftada en az 4 saat bakım vermekte olan 190 Türk yetişkin oluşturmaktadır.

4.4.2. Araçlar

4.4.2.1. Demografik Bilgi Formu

Demografik bilgi formu hastanın hastalık ile ilişkili özellikleri, bakım verme sürecinin doğasına ilişkin bilgiler ve bakım veren kişinin sosyo-demografik özelliklerini araştırmak amacıyla oluşturulmuş bir formdur (Ek F).

4.4.2.2. Marwit-Meuser Bakıcı Yası Ölçeği-Kısa Form (MMBYÖ-KF)

Marwit-Meuser Bakıcı Yası Ölçeği-Kısa Form (MMBYÖ-KF)'u orinal versiyonunda 50 maddeden oluşmaktadır (Meuser & Marwit, 2001). Ölçeğin geniş kapsamlı projelerde uygulamasını kolaylaştırmak amacıyla kısa formu 2002 yılında Marwit ve Meuser tarafından oluşturulmuştur. Kısa form 18 maddeden oluşmaktadır ve cevaplar 5'li Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin gerek orjinal gerek ise kısa formunun psikometrik özellikleri istatistiksel ve teorik açıdan tatmin edici bulunmuştur. Ölçeğin Türkçeye uyarlanması söz konusu araştırma kapsamında gerçekleştirilecektir (Ek G).

4.4.2.3. Beck Depresyon Envanteri (BDI)

Beck ve arkadaşları tarafından geliştirilen ölçek (1961), depresyonun duygusal, fiziksel ve davranışsal belirtilerini ölçmeyi hedeflemektedir. Ölçek 21 maddeden oluşmaktadır ve cevaplar 4'lü Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin Türkçe uyarlaması Hisli tarafından gerçekleştirilmiştir (1989). Ölçeğin bu araştırmadaki iç tutarlılığı .88 olarak bulunmuştur (Ek H).

4.4.2.4. Zarit Bakıcı Yükü Ölçeği

Zarit ve arkadaşları tarafından geliştirilen ölçek (1980), bakım veren yükünün sosyal ve psikolojik boyutlarını ölçmeyi hedeflemektedir. Ölçek 22 maddeden oluşmaktadır ve cevaplar 5'li Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin Türkçe uyarlaması Özlü ve arkadaşları tarafından gerçekleştirilmiştir (2009). Ölçeğin bu araştırmadaki iç tutarlılığı .91 olarak bulunmuştur (Ek I).

4.4.2.5. Bakıcı İyilik Ölçeği

Berg-Weger ve arkadaşları tarafından geliştirilen ölçek (200), bakım verenlerin psikolojik ve fizyolojik ihtiyaçlarını ne dereceye kadar karşıladıklarını ölçmektedir. Ölçek 46 maddeden oluşmaktadır ve cevaplar 5'li Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin Türkçe uyarlaması Demirtepe-Saygılı ve Bozo tarafından gerçekleştirilmiştir (2009). Ölçeğin bu araştırmadaki iç tutarlılığı .93 olarak bulunmuştur (Ek J).

4.4.2.6. Çok Boyutlu Algılanan Sosyal Destek Ölçeği

Zimet ve arkadaşları tarafından geliştirilen ölçek (1970), kişilerin algılanan sosyal destek düzeylerini ölçmeyi amaçlamaktadır. Ölçek 12 maddeden oluşmaktadır ve cevaplar 7'li Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin Türkçe uyarlaması Eker ve arkadaşları tarafından gerçekleştirilmiştir (2001). Ölçeğin bu araştırmadaki iç tutarlılığı .90 olarak bulunmuştur (Ek K).

4.4.2.7 Durumluluk-Süreklilik Kaygı Ölçeği-Süreklilik Formu (STAI-S)

Spielberger ve arkadaşları tarafından geliştirilen ölçeğin durumluluk formu (1970), kişilerin stresli bir olay karşısındaki kaygı belirtilerini ölçmeyi amaçlamaktadır. Ölçek 20 maddeden oluşmaktadır ve cevaplar 4'lü Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin Türkçe uyarlaması Öner ve Le Compte tarafından gerçekleştirilmiştir (1994). Ölçeğin bu araştırmadaki iç tutarlılığı .94 olarak bulunmuştur (Ek L).

4.4.2.8. Travma Sonrası Büyüme Ölçeği

Tedeschi ve Calhoun tarafından geliştirilen ölçek (1996), travmatik bir olay sonrasında yaşanan olumlu değişimleri ölçmeyi amaçlamaktadır. Ölçek 21 maddeden oluşmaktadır ve cevaplar 6'lı Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin Türkçe uyarlaması Kılıç tarafından gerçekleştirilmiştir (2004). Ölçeğin bu araştırmadaki iç tutarlılığı .92 olarak bulunmuştur (Ek M).

4.4.2.9. Baş Etme Stratejileri Ölçeği

Lazarus ve Folkman tarafından geliştirilen ölçek (1980), travmatik bir olay sonrasında yaşanan olumlu değişimleri ölçmeyi amaçlamaktadır. Ölçek 42 maddeden oluşmaktadır ve cevaplar 3'lü Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin Türkçe uyarlaması Karancı ve Erkam tarafından gerçekleştirilmiştir (2007). Ölçeğin bu araştırmadaki iç tutarlılığı .72 olarak bulunmuştur (Ek N).

4.4.2.10. Algılanan Partner Duyarlılığı Ölçeği

Reis tarafından geliştirilmiştir (2013). Ölçek 18 maddeden oluşmaktadır ve cevaplar 9'lu Likert tipi ölçek üzerinden değerlendirilmektedir. Ölçeğin Türkçe uyarlaması Taşfiliz ve arkadaşları tarafından gerçekleştirilmiştir (2016). Ölçeğin bu araştırmadaki iç tutarlılığı .97 olarak bulunmuştur (Ek O).

4.4.3. İşlem

Veri toplama aşamasından önce ODTÜ Uygulamalı Etik Araştırma Merkezi'nden etik kurul onayı alınmıştır. Ayrıca, hasta yakınlarına destek sağlamak için oluşturulan Facebook gruplarının yöneticilerinden de sözel ve yazılı izin alınmıştır.

4.5. Sonuçlar

4.5.1. Marwit-Meuser Bakıcı Yas Ölçeği Kısa Formu'nun Psikometrik Özellikleri

4.5.1.1. Marwit-Meuser Bakıcı Yas Ölçeği Kısa Formu'nun Faktör Yapısı

Ölçeğin 3 faktörlü yapısını doğrulamak amacıyla Doğrulayıcı Faktör Analizi gerçekleştirilmiş ve ilk model original yapıya tam olarak uyum sağlamamıştır (χ 2(132) = 411.416, p < .000, RMSEA = .10, CFI = .84, GFI = .79). Modifikasyon indekslerinin önerdiği 3 değişim gerçekleştirildiğinde ise modelin geliştiği ve iyi bir uyum sağladığı gözlemlenmiştir (χ 2(129) = 303.681, p < .000, RMSEA = .08, CFI = .90, GFI = .85).

4.5.1.2. Ölçeğin İç Tutarlılığı

Gerek toplam ölçeğin gerek ise 3 alt faktörün iç tutarlılık katsayıları tatmin edici olarak belirlenmiştir.

4.5.1.3. Ölçüşmeli Geçerlilik

Ölçüşmeli geçerliliği incelemek için ölçeğin depresyon, bakıcı yükü, ve kaygı ölçekleri ile korelasyonlarına bakılmıştır. Ölçeğin depresyon ve kaygı ölçümleri ile orta derecede bir korelasyona sahip olduğu, öte yandan bakıcı yükü ölçeği ile ise güçlü pozitif bir ilişkisinin olduğu bulunmuştur.

4.5.1.4. Ayırtedici Geçerlilik

Ayırdedici geçerliliği incelemek için ölçeğin sosyal destek ve bakıcı iyilik ölçekleri, ile korelasyonlarına bakılmıştır. Ölçeğin her iki ölçüm aracı ile de zayıf negatif bir ilişkisinin olduğu bulunmuştur.

4.5.2.3. Temel Analizler: Olumsuz ve Olumlu Bakım Veren Sonuçları ile İlişkili Değişkenler

Olumsuz ve olumlu bakım veren sonuçları ile ilişkili değişkenleri incelemek amacıyla dört ayrı aşamalı hierarşik regresyon analizi gerçekleştirilmiştir. Her analiz için dört blok bağımsız değişken analize eklenmiştir. İlk blokta bağlamsal değişkenler, ikinci blokta birincil stresörler, üçüncü blokta ikincil stresörler ve son blokta ise biçimleyici değişkenler analize sokulmultur.

4.5.2.4. Depresyon ile İlişkili Değişkenler

Analize sokulan değişkenler depresyon skorlarındaki varyansın % 54’ünü açıklamıştır. Birinci ve ikinci bloktaki değişkenlerin depresyon skorlarında anlamlı bir varyans açıklamadığı gözlemlenirken, bakıcı yükü % 19’luk ek bir varyans açıklamıştır. Özellikle, çaresiz baş etme stratejisinin fazla kullanılmasının ($\beta = .14$, $t[172] = 5.81$, $p < .01$) ; öte yandan iyimser baş etme skorlarının ($\beta = -.26$, $t\ [172] = -3.33$, $p < .001$) ve algılanan sosyal destek düzeyinin düşük olmasının ($\beta = -.13$, $t[172] = -2.35$, $p < .05$) artan depresif belirtilerle ilişkili olduğu bulunmuştur.

4.5.2.5. Kaygı ile İlişkili Değişkenler

Analize sokulan değişkenler kaygı skorlarındaki varyansın % 50’sini açıklamıştır. Bakıcı yükü ise % 19’luk ek bir varyans açıklamıştır. Özellikle, çaresiz baş etme stratejisinin fazla kullanılmasının ($\beta = .35$, $t[172] = 4.85$, $p < .01$).; öte yandan iyimser baş etme skorlarının ($\beta = -.28$, $t[172] = -3.47$, $p < .01$) ve algılanan sosyal destek düzeyinin düşük olmasının ($\beta = .-11$, $t[172] = -1.99$, $p < .05$).) artan kaygı belirtileri ile ilişkili olduğu bulunmuştur.

4.5.2.6. Yas ile İlişkili Değişkenler

Analize sokulan değişkenler ölüm öncesi yas skorlarındaki varyansın % 67’sini açıklamıştır. Bakıcı yükü ise % 55’luk ek bir varyans açıklamıştır. Özellikle, çaresiz baş etme stratejisinin fazla kullanılmasının ($\beta = .19$, $t[172] = 3.28$, $p < .01$) artan yas belirtileri ile ilişkili olduğu bulunmuştur.

4.5.2.7. Büyüme ile İlişkili Faktörler

Analize sokulan değişkenler büyüme skorlarındaki varyansın % 13'ünü açıklamıştır. Sadece, iyimser baş etme stratejisinin fazla kullanılmasının ($\beta = .23$, $t[172] = 2.19$, $p < .05$) büyüme ile ilişkili olduğu bulunmuştur.

4.5.3. Moderatör Analizi

4.5.3.1. Problem-Çözme Baş Etme Stratejisinin Bakıcı Yükü ve Depresyon İlişkisinde Biçimleyici Rolü

Analiz sonuçlarına göre problem-çözme baş etme strategisi skorları düşük olduğunda, bakıcı yükünün depresyon üzerindeki olumsuz etkisi şiddetlenmektedir.

4.5.3.2. Algılanan Sosyal Desteğin Bakıcı Yükü ve Depresyon İlişkisinde Biçimleyici Rolü

Analiz sonuçlarına göre, algılanan sosyal destek düzeyi düşük olduğunda, bakım verme yükünün depresyon üzerindeki olumsuz etkisi artarken; algılanan sosyal destek düzeyi yüksek olduğunda depresyon skorları yüksek bakıcı yüküne rağmen azalma göstermektedir.

4.5.3.3. Algılanan Sosyal Desteğin Bakıcı Yükü ve Kaygı İlişkisinde Biçimleyici Rolü

Analiz sonuçlarına göre, algılanan sosyal destek düzeyi düşük olduğunda, bakım verme yükünün kaygı üzerindeki olumsuz etkisi artarken; algılanan sosyal destek düzeyi yüksek olduğunda kaygı skorları yüksek bakıcı yüküne rağmen azalma göstermektedir.

4.5.4. Algılanan Sosyal Desteğin Bakıcı Yükü ve Büyüme İlişkisinde Biçimleyici Rolü

Analiz sonuçlarına göre, algılanan sosyal destek düzeyi düşük olduğunda bakım verme yükünün büyüme üzerindeki olumsuz etkisi artmaktadır. Öte yandan, sosyal destek düzeyi tatmin edici olduğunda bakım verenler yüksek bakıcı yüküne ragmen daha fazla büyüme deneyimlemektedir.

4.6. Tartışma

Bu araştırmadan elde edilen veriler ilk olarak Marwit-Meuser Bakıcı Yas Ölçeği-Kısa Formu'nun anne ya da babasına bakım vermekte olan Türk yetişkinlerin ölüm öncesi yas belirtilerini ölçmek amacıyla kullanılabilecek geçerli ve güvenilir bir ölçüm aracı olduğuna işaret etmektedir.

Ayrıca bulgular, bakıcı yükünün olumsuz bakım veren sonuçlarında önemli bir rol oynadığına işaret etmektedir.

Çaresiz baş etme stratejisi ve iyimser baş etme stratejilerinin bakım veren sonuçlarıyla olan ilişkilerinin de literatür ile tutarlı olduğu düşünülmektedir.

Sosyal desteğin bakım veren sonuçları üzerindeki olumlu etkisi ise bu araştırmanın ortaya koyduğu önemli bulgulardan biridir. Bu bağlamda, Türk bakımverenlerin sosyal destel kaynaklarını yeterli bulduklarında daha az olumsuz psikolojik problem yaşadıkları gözlemlenmiştir. Ayrıca, Türk bakım verenlerinin bakıcı yükleri fazla olsa bile tatmin edici bir sosyal destek ağına sahip olduklarında daha fazla büyüme yaşadıkları görülmektedir. Bu bağlamda, grup içi ilişkilere ve beraberliğe önem veren Türk bakım verenleri için sosyal destek önemli bir psiko-sosyal kaynaktır (Brodaty & Donkin, 2009; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Haley et al., Han et al., 2014; 1996; Heo, 2014; Williamson, & Schulz, 1993).

BÖLÜM 5

GENEL TARTIŞMA

5.1. Genel Tartışma

Her iki araştırmadan elde edilen bulgular, Türk bakımverenlerin Alzheimer bakım verme deneyimi sırasında biricik ve ortak bazı yaşantılarının olabileceğine işaret etmektedir. Özellikle sosyal desteğin olumsuz yaşantıları azaltmada ve olumlu etkileri arttırmada önemli bir rol oynadığı gözlemlenmiştir. Bu bulgu, Türk bakım verenleri için aile, arkadaş ve önemli diğer kişilerden gelen sosyal desteğin önemli bir kaynak olduğuna işaret etmektedir. Sosyal desteğin bu koruyucu rolünün Türk kültürünün ilişkiselliğe önem veren yapısıyla açıklanabileceği düşünülmektedir. Niteliksel araştırmadan elde edilen bulguların aksine, niceliksel araştırmada dini ve kaderci baş etme stretejisinin olumlu ya da olumsuz bakım veren sonuçları ile anlamlı bir ilişki içerisinde olmadığı gözlemlenmiştir. Bu istatistiksel olarak anlamlı olmayan sonucun kullanılan ölçeğin Türk kültürüne uygun olmaması ile ilişkili olabileceği izlenimi edinilmiştir. Son olarak, her iki araştırmada bakımveren yükünün Türk bakım verenlerin bakım verme deneyimlerinin önemli bir parçası olduğunu ortaya koymuştur.

5.2. Klinik İmplikasyonlar

Türk bakım verenlerim olumlu ve olumsuz yaşantıları eş zamanlı olarak deneyimledikleri düşünüldüğünde, olumsuz etkileri azaltmayı amaçlarken olumlu tarafları destekleyen müdahale programlarının bu popülasyon için daha faydalı olabileceği düşünülmektedir. Ayrıca, bakım veren yükü azaltmayı hedefleyen stratejilerin müdahale programlarına eklenmesi oldukça önemli olacaktır.

APPENDIX P: CURRICULUM VITAE

Ad-Soyad : Yağmur Ar

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Yazışma Adresi : Çamlıtepe Mah., Şehit Coşkun Sok. 14/1 Çankaya, Ankara

Öğrenim Durumu :

Derece	Bölüm/Program	Üniversite	Yıl
Lisans	Psikoloji (Yüksek Şeref Derecesi)	ODTÜ	2010
Lisans Sonrası Doktora	Uygulamalı (Klinik) Psikoloji	ODTÜ	2017

Doktora Tezi Başlığı ve Danışmanı:

Predictors of Anticipatory Grief, Depression and Growth among Adult Children Caregivers of Alzheimer's Disease: A Multimethod Study (Beklenilen Bitirme Tarihi Temmuz, 2017)

Tez Danışmanı: Prof. Dr. A. Nuray Karancı

Görevler:

Görev Ünvanı	**Görev Yeri**	**Yıl**
Araştırma Görevlisi	ODTÜ, Psikoloji Bölümü	Kasım 2011 – ...
Uzm. Klinik Psk. (Terapist)	AYNA Klinik Psikoloji Destek Ünitesi, ODTÜ	Eylül 2011 – ...
Uzm. Klinik Psk (Süpervizör)	ODTÜ, Psikoloji Bölümü	Şubat 2016 – Haziran 2016
Uzm. Klinik Psk (Süpervizör)	ODTÜ, Psikoloji Bölümü	Eylül 2013 – Eylül 2014

Stajlar:

Eylül 2013 – Eylül 2014	Orta Doğu Teknik Üniversitesi AYNA Klinik Psikoloji Destek Ünitesi, Süpervizör
Eylül 2011 – Eylül 2014	Orta Doğu Teknik Üniversitesi AYNA Klinik Psikoloji Destek Ünitesi, Psikoterapist
Şubat 2012 – Haziran 2012	Hacettepe Üniversitesi Tıp Fakültesi Çocuk ve Ergen Ruh Sağlığı ve Hastalıkları Ana Bilim Dalı
Ocak 2010 – Şubat 2010	Hacettepe Üniversitesi Tıp Fakültesi Ruh Sağlığı ve Hastalıkları Ana Bilim Dalı
Temmuz 2009 – Ağustos 2009	Hacettepe Üniversitesi Tıp Fakültesi Ruh Sağlığı ve Hastalıkları Ana Bilim Dalı
Ağustos 2009 – Eylül 2009	Nazilli Devlet Hastanesi, Psikiyatri Polikliniği
Temmuz 2008 – Ağustos 2008	Nazilli İlk Yorum Özel Eğitim ve Rehabilitasyon Merkezi

Projeler:

Eylül 2014 - ...	Turkish Muslim Religious Healers: A Qualitative Investigation of Hocas and Their Methods, Doç. Dr. Deniz Canel Çınarbaş, ODTÜ Psikoloji Bölümü, BAP Projesi (Araştırmacı)
Şubat 2012 – Mayıs 2012	Building Resilience Amongst Communities in Europe (emBRACE), Prof. Dr. Nuray Karancı (Araştırmacı)
Mart 2010 – Haziran 2010	ODTÜ Psikoloji Bölümü ve TÜBİTAK Yetişkinlerde Olumsuz Yaşam Olayları Araştırması—Boylamsal Bir Çalışma, Prof. Dr. Nuray Karancı, Ankara (Veri Toplama)

Yayınlar:

Uluslararası hakemli dergilerde yayınlanan makaleler (SCI, SSCI, Arts and Humanities):

Ar, Y. & Karanci, N. (2017). Turkish adult children as caregivers of parents with Alzheimer's disease. *Dementia: The International Journal of Social Research and Practice*, Online First, 15 Feb, 2017. doi: 10.1177/1471301217693400 **[SSCI]**

Ulusal hakemli dergilerde yayınlanan makaleler (ULAKBİM, Türk Psikiyatri Dizini):

Ar, Y. (2014). Büyüklenmecilik ya da incinebilirlik: Narsisistik kişilik örgütlenmesinin Şema Terapi yaklaşımı çerçevesinde ele alınması, *AYNA Klinik Psikoloji Dergisi, 1*(3), p. 29–43.

Ar, Y. (2013). Fallus ve kastrasyon kavramları çerçevesinde bir anne-oğul ilişkisi: "Kevin Hakkında Konuşmalıyız", *AYNA Klinik Psikoloji Dergisi, 1*(1), p. 62–69.

Değerlendirilme ya da Hazırlık Aşamasındaki Çalışmalar:

Ar, Y. & Karanci, N. (hazırlık aşamasında). The reliability and validity study of the Turkish version of Meuser-Marwit Caregiver Grief Inventory Short Form.

Canel-Çınarbaş, D., Tuna, E. & **Ar, Y.** (hazırlık aşamasında). Turkish Muslim Religious Healers: A Qualitative Investigation of Hocas and Their Methods.

Bozo, Ö., **Ar, Y.,** & Eldoğan, D. (değerlendirilme aşamasında). Does Marital Adjustment Mediate Type C Personality-Depressive Symptoms Relation? A Comparison between Breast Cancer Patients and Cancer-Free Women.

Konferans Sunumları:

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Paneller:

Yılmaz, T., **Ar, Y**., Ünal, B., Avcı, H., & Koçak, Ö. (2014). Farklı Kuramsal Bakış Açılarından Terapötik İlişkinin Kavramsallaştırılması: Ortaklıklar ve Farklılıklar. 18. Ulusal Psikoloji Kongresi, Bursa.

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Ar, Y. (2014). *Şizofreni*. Şahin, M. (Çev. Ed.) *Anormal psikolojisi/psikopatoloji* (12. Baskı) Nobel Akademik Yayıncılık: Ankara.

Ödüller ve Burslar:

Türkiye Bilimsel ve Teknolojik Araştırma Kurulu, Bilim İnsanı Destekleme Programı, Lisans Sonrası Doktora Bursu, 2010−...

Orta Doğu Teknik Üniversitesi, Psikoloji Lisans Programı, Yüksek Şeref Öğrencisi, 2006-2010.

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Araştırma Alanları:

- Kayıp ve Yas
- Kronik Hasta Grupları ve Ailelerinde Muğlak Kayıp (Ölüm Öncesi Yas)
- Terapötik İlişki
- Süpervizör-Terapist İlişkisi
- Kişilik Bozuklukları
- Bakım Verme Sürecinde Psikolojik Dayanıklılık ve Gelişme
- Psikoterapi ve Psikopatolojide Kültür ile İlişkili Faktörler
- Kronik Hasta Gruplarında Psikososyal Değişkenler
- Baş Etme Becerileri
- Psikolojide Nitel Analiz Yöntemleri

Yayın Kurulu Üyelikleri ve Hakemlikler:

Ekim 2014 - ... AYNA Klinik Psikoloji Dergisi (Yayın Kurulu Üyeliği ve Hakemlik)

Düzenleme Kurulu Üyelikleri

Kasım 2014 Psikoloji ve Sanat Sempozyumu – 3, ODTÜ

Bilimsel Kuruluşlara Üyelikler

Türk Psikologlar Derneği

APPENDIX S: TEZ FOTOKOPİSİ İZİN FORMU

ENSTİTÜ

Fen Bilimleri Enstitüsü ☐

Sosyal Bilimler Enstitüsü ☒

Uygulamalı Matematik Enstitüsü ☐

Enformatik Enstitüsü ☐

Deniz Bilimleri Enstitüsü ☐

YAZARIN

Soyadı : Ar
Adı : Yağmur
Bölümü : Psikoloji

TEZİN ADI (İngilizce) : Predictors of Depression, Anxiety, Grief and Growth in Turkish Offspring as Caregivers of Parents with Alzheimer's Disease: A Multi-Method Study

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 (1) yıl süreyle fotokopi alınamaz. ☐

TEZİN KÜTÜPHANEYE TESLİM TARİHİ: