

**THE EXPERIENCES OF TURKISH FAMILY CAREGIVERS OF
INDIVIDUALS WITH ALZHEIMER’S DISEASE DURING COVID-19
PANDEMIC:
AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS**



ESRA YÜZEN ARDALI

AUGUST 2022

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ABSTRACT

THE EXPERIENCES OF FAMILY CAREGIVERS OF INDIVIDUALS WITH ALZHEIMER’S DISEASE DURING COVID-19 PANDEMIC: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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The aim of this study is to in-depth examination of how family relatives who care for people with Alzheimer's disease make sense of their caregiving experiences during the COVID-19 pandemic. Interpretive Phenomenological Analysis was used in order to understand the caregiving experiences of family caregivers during the pandemic, taking into account both the individual's unique aspects and cultural dynamics. As a result of the purposive sampling, the participants are consisted of eight adult women who care for their parents. Semi-structured interviews were conducted with each participant and these interviews were analyzed with the method of Interpretive Phenomenological Analysis (IPA).

According to the results of this analysis, three main themes were emerged: “Forced proximity”, “Riding through the waves of emotions”, and “Turning crisis into an opportunity”. The sub-themes that came to the fore in the “Forced proximity” main theme are: “Providing intensive care”, “Psychological closeness”, “Need for respite” and “Overprotection”. Also, the sub-themes of the upper theme of “Riding through the waves of emotions” were: “Living in fears”, “Under the burden of caregiving” and “Away from the outside world”. Finally, the sub-themes being

included in the main theme of ‘‘Turning the crisis into an opportunity’’ were: ‘‘Adapting to constant changes’’, ‘‘It is a learning process’’ and ‘‘Vitality of social support’’. The findings of this study were discussed in the light of the relevant literature and the implications for clinical intervention were stated in line with the current findings.

Keywords: Alzheimer’s disease, caregiving experience, COVID-19. Interpretative Phenomenological Analysis, qualitative methodology



ÖZ

ALZHEIMER HASTALIĞINA SAHİP KİŞİLERE BAKIM VEREN AİLE YAKINLARININ COVID-19 PANDEMİSİ SIRASINDAKİ DENEYİMLERİ: YORUMLAYICI FENOMENOLOJİK ANALİZ ÇALIŞMASI

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Bu çalışmanın amacı, Alzheimer hastalığı olan kişilere bakım veren aile yakınlarının COVID-19 pandemisi sürecindeki bakım verme deneyimlerini nasıl anlamlandırdıklarını derinlemesine bir şekilde incelemektir. Bakım veren aile yakınlarının pandemi sırasındaki bakım verme deneyimlerinin, hem kişinin kendisine özgü taraflarını hem de kültürel dinamiklerini göz önünde bulundurarak anlaşılabilmesi amacıyla Yorumlayıcı Fenomenolojik Analiz (YFA) kullanılmıştır. Amaca yönelik yapılan örneklem sonucunda, katılımcıları ebeveynlerine bakım veren sekiz yetişkin kadın oluşturmaktadır. Her bir katılımcı ile yarı yapılandırılmış görüşmeler gerçekleştirilmiş ve bu görüşmeler Yorumlayıcı Fenomenolojik Analiz yöntemi ile analiz edilmiştir.

Analiz sonuçlarına göre, “Zorunlu yakınlık”, “Duygu dalgaları arasında yolculuk”, ve “Krizi fırsata çevirmek” olmak üzere üç ana tema oluşturulmuştur. “Zorunlu yakınlık” üst temasında ön plana çıkan alt temalar: “Yoğun bakım” sağlamak, “Psikolojik yakınlık”, “Nefes alma ihtiyacı” ve “Aşırı koruma”dır. Ayrıca, “Duygu dalgaları arasında yolculuk” üst temasının alt temaları ise şu şekildedir: “Korkular içinde yaşamak”, “Bakım verme yükünün altında” ve “Dış dünyadan uzakta”. Son olarak, “Krizi fırsata çevirmek” üst temasında ön plana çıkan

alt temalar: ‘‘S rekli deęişikliklere adapte olmak’’, ‘‘Bu bir  ęrenme s reci’’ ve ‘‘Sosyal desteęin yařam g c ’’ d r. Bu  alıřmanın sonu ları, ilgili alanyazın ıřıęında tartıřılmıř ve mevcut bulgular doęrultusunda klinik m dahaleye dair yapılan  ıkarımlar belirtilmiřtir.

Anahtar Kelimeler: Alzheimer, bakım verme deneyimi, COVID-19, Yorumlayıcı Fenomenolojik Analiz, nitel metodoloji



*To my family
and
all families living with Alzheimer's disease...*



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Chapter 1

Introduction

The number of patients living with Alzheimer's disease (AD) is dramatically increasing worldwide and their primary caregivers are usually family members (Küçükgülü et al., 2017). While extant literature has investigated the experiences of AD patients' family caregivers, there is still limited research focusing on the experiences of family caregivers of AD's, particularly in the time of COVID-19. Research has shown that mass health, economic, social and psychological problems significantly arise after this outbreak (Chakraborty & Maity, 2020). Especially, most recent studies have revealed that some individuals involved in "vulnerable groups" such as elderly, socioeconomically disadvantaged people, etc, are estimated as at higher risk for being exposed to the significant impacts of COVID-19. Even in "normal times" before this pandemic, persons of older age with AD and other dementias are among vulnerable population because of their dependency to others for their daily living. In addition to the AD patients, earlier literature provide a substantial evidence about further challenges which individuals caring for their loved ones with AD can face with due to their caregiving role during natural disasters and other crisis (Gibson et al., 2018). However, very little is known related to the experiences of family caregivers of AD, specifically in this unprecedented time.

Thus, this study is aimed to better understand the experiences of family caregivers of AD patients in Turkey during the COVID-19 pandemic. To explain and ensure to grasp the phenomenon of giving care for individuals living with AD in the COVID-19 pandemic adequately the term of Alzheimer's disease and its prevalence in Turkey are first described. After that, the concept of caregiving and its related notions together with their psychological aspects for caregivers are mentioned and the process of COVID-19 pandemic and its psychological impacts on individuals and of course, caregiver's of Alzheimer's disease are briefly introduced. Eventually, problem statement was included to provide an overview regarding the caregiving experiences of family carers of Alzheimer's disease during COVID-19 outbreak. In addition to this; the goal of the study, research questions and the significance of study are briefly explained.

1.1 Statement of the Problem

Since the beginning of the coronavirus outbreak, it has deeply affected the lives of many people, especially vulnerable people. Alzheimer's patients are in a vulnerable position because they are both older and need the support of someone else, and the experiences and needs of those who care for these people during the covid process could be overlooked from time to time. Until now, the number of detailed and comprehensive studies on the caregiving experiences of family members caring for Alzheimer's patients in Turkey during the COVID-19 process is very limited. For this reason, the purpose of this study was to understand the experiences of family caregivers of individuals living with Alzheimer's disease, particularly during the COVID-19 crisis.

1.2 Purpose of the Study

The goal of this study is to describe caregiving experiences of the eight Turkish family caregivers of patients with Alzheimer's disease in the times of coronavirus outbreak. In accordance with this purpose, Interpretative Phenomenological Analysis IPA was used and it is aimed at gaining an in-depth and idiosyncratic understandings of being a family caregiver of AD individuals during COVID-19 pandemic.

1.3 Research Questions

Research questions consist of these inquiries: ‘‘How do family caregivers of individuals with AD experience caregiving during COVID-19 pandemic?’’, ‘‘How have the caregiving experiences of individuals who give care for their loved ones with AD changed after the COVID-19 pandemic?’’ and ‘‘How do family caregivers of individuals with AD describe their experiences of caregiving during the time period of COVID-19?’’ and ‘‘What are needs of family caregivers of AD individuals during COVID-19 pandemic?’’

1.4 Significance of the Study

Although studies about the experience of AD individuals' family carers during the COVID-19 pandemic have been increasing until recently, there is still a paucity in literature that contain in-depth understanding of the lived experience of Turkish family caregivers' of individuals with AD by taking into consideration their subjectivity along with shared notions. Within this scope, this research will provide comprehensive understanding about the caregiving experiences of Turkish carers who give care for their loved ones with AD. Also, this study will shed light on the needs of family caregivers while giving care to their AD relatives during COVID-19 and some potential implications for them.

Chapter 2

Literature Review

2.1 Alzheimer's disease

2.1.1 Definition and Prevalence of AD

Alzheimer's disease (AD) is a serious brain disorder comprising of deficits in cognitive, physical or behavioral functioning (Vas et al., 2001). AD is progressive and irreversible since it is one of the neurodegenerative dementias leading to the damage of nerve cells (Manteau-Rao, M., 2017; Vas et al., 2001). The term "dementia" reflects on the bunch of symptoms with pertinent to deterioration of brain functions, regardless of the natural consequence of aging. Furthermore, it is related to the loss of intellectual abilities such as memory, language, orientation, problem-solving, calculation, etc. (American Psychiatric Association, 2013; Vas et al., 2001). Older adults are more prone to suffer from dementia and related symptoms, but these can be also seen in younger individuals (Alzheimer's Association, 2021). Various diseases, (i.e. Lewy body dementia, Parkinson's disease, Alzheimer's disease) can contribute to the development of dementia (Alzheimer's Society, 2021). However, AD is known as the most common cause of dementia which accounts for approximately 60-80 % of cases (Alzheimer's Association, 2021).

There is still a paucity of knowledge regarding the etiology of the illness, but research has shown that aggregation of amyloid plaques and neurofibrillary (tau) tangles are two main features of Alzheimer's disease (Ballard et al., 2011; Joe & Ringman, 2019). Thereby, in addition to other alterations in brain, the deterioration of links between nerve cells (neurons), which plays a vital role for cognitive functions (e.g. learning, memory) is occurred (National Institute on Aging, 2021; Mucke, 2009). The progression of Alzheimer's disease is insidious and symptoms are unfortunately getting worse over time. In fact, changes in the brain may begin nearly 10-20 years prior to the manifestation of the symptoms (Beason-Held et al., 2013). Everyone has been influenced by Alzheimer's disease differently, yet it's process is generally divided

into three main stages as early, middle and late, in other words; mild, moderate and severe stages (Zvěřová, 2019; Alzheimer's Association, 2021).

During the early stage, individuals may be able to easily remember past memories whereas disturbances of recent episodic memories, such as recalling names or latest events, are usually experienced. Nevertheless, individuals may live an independent life and involve in the community. On the one hand, their relatives can notice some difficulties in language, making a decision or organizing. Despite these challenges, people with AD can still make a plan for their health and re-evaluate priorities of their life (Alzheimer's Association, 2021; Apostolova et al., 2016). As AD progresses, symptoms become more severe and debilitating. In the moderate stage, symptoms may span for years and they can feature as impairments in cognitive abilities. Forgetting experiences or personal history can be more recognizable by others, as well as mood and behavior alterations such as suspiciousness, delusions, compulsive behaviors, etc. (Alzheimer's Association, 2021). In addition to possessing reduced self-care skills, AD patients may have slurred speech or become lost outside their homes (Barlas & Onan, 2007). During the final stage, the necessity for help with daily tasks and personal care becomes crucial. Patients with AD have a decreased ability to move, walk and/or sit. They can be bedridden and unable to do fundamental tasks for daily life, such as dressing oneself, having a bath or eating, without assistance. Also, becoming mute and difficulty in swallowing are typically observed (Allen et al., 2003). In this stage, vulnerability of infections such as pneumonia, malnutrition and dehydration are frequent causes of death related to AD. The lifespan of this patients with AD can be usually estimated as four to eight years, yet this process can prolong up to 20 years (Alzheimer's Association, 2017).

According to the World Health Organization (WHO), approximately 50 million people are predicted as suffering from dementia all over the world and most of these are living in low and middle-income countries. Between 2030 to 2050, the number of patients having dementia is supposed to rise from 82 million to 152 million worldwide (World Health Organization, 2020). There are some indications that aging could be one of the most prominent risk factors for AD; so, as a result of the population's shift to elderliness, the number of Alzheimer's disease cases also dramatically increase, especially beyond age 70 (Alzheimer's Association, 2017).

2.1.2 AD in Turkey

Studies show that as the average age of the people in the society increases, the probability of the disease's prevalence and lethality increases (GBD 2016 Dementia Collaborators, 2019). Similarly, Turkey's population is likely to getting older in recent years. Turkish Statistical Institute (TUIK) reported that the overall incidence among those older than 65 will reach above 10% in 2023, whilst other age groups do not display such an increase in this rate (TUIK, 2020). Thus, this increasing trend in the number of people living with AD is also observed in Turkey. In 2000, 250.000 people had Alzheimer's disease (Tufan, 2015), yet Turkish Alzheimer Association estimated that there are now about 600.000 families who struggle with AD (Turkish Alzheimer Association, 2020).

Great majority of those patients are looked after by their family members; for instance, their spouses and children, at home (Taşçı et al., 2012; Yılmaz et al., 2009). In fact, many studies demonstrated that most of community-dwelling frail elderly, who have any vulnerabilities about their health and are incapable of perform the Activities of Daily Life (ADL) tasks without aid from others, have received care by informal carers, such as their friends or relatives (Lopez-Hartmann et al., 2012). Because of the inadequacy of medical and social support, relatives of elderly with AD are predominantly responsible for care in underdevepoled and developing countries, including Turkey (World Health Organization, 2015; Küçükgülü et al., 2017). Although the number of AD patients are rapidly increasing, facilities and hospitals suitable for the care of these people do not have sufficient capacity or health personnel in our country (Tufan, 2015). Additionally, the presence of chronic diseases and the ever-changing aging of the young population cause economic damage and serious health problems in developing countries (Zencir et al., 2005), like Turkey.

2.2 Caregiving

2.2.1 Explanation of Caregiving

One should bear in mind that caring starts in prenatal period and continues till death. In other words, there is always care during the life span of a human being. Rather than being only care recipient, people can also learn to give care throughout the life time. This, in a word, is a shared experience for all humanity (Talley, 2013). However, the term ‘‘caregiving’’ usually refers to a more specific experience. Caregiving is conceptualized as an attempt to take care of someone else’s needs about health and welfare. It is generally characterized by helping other people with a wide range of tasks such as clothing, bathing, feeding, etc. and not only physical care, but also psychological support is included (Alzheimer’s Association, 2021). In this respect, caregiving might be requiring much physical, social, emotional or financial effort (Kent et al., 2016).

Many studies in the literature have pursued to understand how caregiving affects health and wellness of individuals who take on the role of caregiver (Ory et al., 1999; Schulz & Quittner, 1998). Pearlin et al. suggested that caregiving is like having a career starting from giving care for AD relatives until the end of the care recipient’s life (Pearlin et al., 1990). Also, this caregiving process includes some transitional circumstances; for instance, progression of the disease or admission of residential care facilities (Quinn et al., 2008; Ganguli & Hendrie, 2005). Regarding progressive characteristics of Alzheimer’s disease and related dementias, individuals living with AD are tend to experience various alterations throughout the course of the illness and both patient’s and caregivers’ lives are radically changed (Ganguli & Hendrie, 2005). Researchers studied on caregiving for patients with dementia have thoroughly investigated the personal, social, and health effects regarding caregiving (Schulz, O’Brien et al., 1995; Ory et al., 1999). Many findings have mentioned the complexity and variation of impacts depending on numerous factors which may regulate feelings and behaviors of caregivers (Brodaty & Donkin, 2009).

Two types of caregiver groups are often mentioned in the caregiving field: informal and formal caregivers. While informal carers are likely to devoting their time continuously for their demented relatives (Gaugler et al., 2003; Schulz & Tomkins,

2010), formal caregivers or health-care professionals (i.e. nurses, rehabilitation specialists) play a leading role in supplying any needs of patients (Ku et al., 2013).

2.2.2 Informal caregivers

Informal caregiver mainly refers to those providing routine care without charge for their relatives with any disabilities, chronic illnesses or being in other circumstances, in which particular care and attention is necessary (Schulz and Tompkins, 2010; Triantafillou et al., 2010). It was defined that informal carers generally try to fulfill assistance and take responsibility for doing various tasks of care recipients. In addition to individuals who have a kinship bond with individuals having chronic illness or disability (i.e. Alzheimer's disease), cohabitants and neighbors can also be included in informal caregivers (Talley, 2013; Family Caregiver Alliance, 2017).

Individuals with Alzheimer's disease (AD) are mostly cared for by their family members all around the world (Brodaty & Donkin 2009; Şahiner, 2012; Taşçı et al., 2012; Vellone et al., 2008; Yılmaz et al., 2009;). Although nearly 80-90% of individuals having dementia in early and middle stage are provided home care by their spouses and adult children, those in the late stage are provided support by nursing homes (Özdemir & Taşçı, 2013). Thus, the role of family or informal caregivers in the disease process is paramountly important for AD elders (Clyburn et al., 2000).

2.2.2.1 Gender differences in caregiving

Previous studies have revealed that women (i.e. daughters, spouses or other female relatives) are mostly take responsibility for care in many countries due to the expectation about the fact that caregiving role was necessarily adopted by female adults (Özyeşil et al., 2014; Ganguli & Hendrie, 2005), and they are mostly perceived as nurturing and having care duties for both their children and also their partner suffering from chronic diseases (Huang, 2004). That's why the majority of studies have focused on the female caregiver groups (Hysiao, 2010). Similar with these findings, it was estimated that approximately 80% of people providing care to AD patients are women in Turkey (Karlıkaya et al., 2005; Lök et al., 2017). Yet, there is a

growing population of male caregivers globally (Campbell & Martin-Mathews, 2000; Russel, 2008; Baker et al., 2010) because of increasing in rates of nuclear families and number of working women, concurrent with changes in the social structure (Akpınar et al., 2011). Due to the culturally shaped gender roles, women can be associated with nurturance and giving care for their relatives, especially having a chronic health conditions (Hsiao, 2010). Caregiving literature has well documented that the prominent role in the provision of support for individuals with mental illness falls on family members, especially on women (Saunders 2003, Zauszniewski et al. 2008, Huang et al. 2009).

2.2.3 Negative Aspects of Caregiving

Being dementia caregiver can be highly demanding and stressful because they might face numerous challenges. As an example, about 40% of caregivers look after relatives with AD between one and four years while approximately 30% of those can provide care up to twenty years. Apart from a long-time of caregiving, functioning and behaviors of AD patients, specifically in early and middle stages, might be inconsistent and unpredictable (Manteau-Rao, 2017). As the disease progresses, individuals having Alzheimer's disease gradually turn from competence to disability. They need to around-a-clock care to survive and become totally dependent on others. This process can be considered as a return from adulthood to infancy (Akyar & Akdemir, 2009). Therefore, physical strength, emotional stamina and patience become necessities for caregivers of people having AD (Alzheimer's Association, 2021).

When family relatives have to care for someone with AD, their lives may be negatively affected by physical, social, emotional and financial problems (Barlas & Onan, 2007). A number of studies have linked providing care for relatives with AD to financial difficulties (DaDalt et al., 2016). Family caregivers usually try to deal with socio-economic problems (Akyar & Akdemir, 2009), financial strain (Barlas & Onan, 2007; Ho et al., 2003; Arélavo-Flechas, 2019), and work-related issues (Liu et al, 2020; Farcnik & Persyko, 2002). The responsibilities of caring for a person living with AD or related dementia can interfere with carers' ability to carry out their work, and can worsen economic hardship (Liu et al, 2020). It was also implied that individuals responsible for care of AD patients might be at high risk of feeling disturbed at work or quit their job (Farcnik & Persyko, 2002). In addition, family caregivers of AD

patients can effort to cope with some financial constraints due to the cost of extra paid care or medical expenses (Sun et al., 2009). Notably, many studies related to caregiving for elderly highlighted the association between financial strain due to caregiving and its negative consequences for physical health, quality of life, and psychological well-being of caregivers (Drentea & Goldner, 2006; Pinquart & Sörensen, 2007; Vellone et al., 2008).

To deliver effective care for individuals with AD, family caregivers are likely to delay important needs, for example; having a rest, interacting with others, going for check-ups or spending time with other relatives and thus, these conditions may lead to family conflicts or social isolation (Ory et al., 1999; Kovaleva et al., 2018). They might also have difficulties in balancing between care-related responsibilities and their other duties, such as child rearing, relationships, and career (Brodaty & Donkin, 2009). Moreover, the interruption of schedule and lifestyle of family members who give assistance to AD patients can have an increased risk for social isolation and feelings of loneliness (Liu et al., 2020).

2.2.3.1 Physical and Mental Health Outcomes

A large number of existing studies have also examined the impacts of providing care for patients with AD on physical and mental health of AD caregivers. The substantial association between being a family caregiver of individuals having AD and psychiatric conditions such as increased level of stress, depression, and anxiety is well documented (Quadir et al., 2019; Farcnik & Persyko, 2002; Campbell et al., 2008; Cooper et al., 2006; Gaugler et al., 2008). Recognition of the changes in patients with AD day by day and the absence of sufficient resources might exacerbate these symptoms of AD caregivers (Quadir et al., 2019). However; being women and especially, being a wife of a person with AD, having stressful life events, having family history of psychological disorders, and other variables might be strongly related to the mental health of family members responsible for giving care to AD patients (Brodaty & Donkin, 2009).

It has been found that negative health consequences are fairly common among family caregivers of people diagnosed with AD (Sörensen & Conwell, 2011). Commonly, they have a greater propensity for sleep deprivation and use of prescription

drugs, alcohol or smoking whereas they are less likely to take action for their health like doing exercise (Brodaty & Donkin, 2009). Moreover, caregivers are tend to have weakened immuned system and chronic illnesses (Farcnik & Persyko, 2002). Several risk factors, including long-term care, caregiver burden, depression, elderliness, low socio-economic status, etc. can also be associated with poor health of caregivers (Richardson et al., 2013).

2.2.3.2 Stress and Burden

Extensive research has focused on the robust relationship between having a caregiver role and burden of family caregivers who give assistance to AD patients (Clyburn et al., 2000). The term ‘‘caregiver burden’’ is spesifically used for providing a measurement in studies related to caregiving (Campbell et al., 2008). Even though there are diverse descriptions of ‘‘caregiver burden’’ in the literature, it can be defined as caregivers’ perceived stress or strain due to the having difficulty in coping with the demands of caregiving (Arévalo-Flechas, 2019; Richardson et al., 2013). Financial, psychological, physical or social predicaments are, in essence, subsumed by the experiences of caregiving burden (Richardson et al., 2013). Besides, it can be evaluated by self-reports of distress and outcomes of caregiving, such as decreased leisure time, financial difficulties, and so forth. Numerous factors such as revenue, age, longevity of caregiving, etc. can be exacerbate the risk of experiencing caregiver burden (Richardson et al., 2013; Mohamed et al., 2010).

2.2.3.3 Caregiver Guilt

Several studies have pointed out that nearly two thirds (65%) of those who cared for a loved one with dementia are prone to feel guilt (Roach, Laidlaw, Gillanders, & Quinn, 2013; Prunty & Foli, 2018). Consistent with the previous literature, the study of Gonyea et al. (2008) was demonstrated that 65% of adult daughthers who assumed the caregiving role for their mothers with dementia experienced guilty feelings (Gonyea et al., 2008). Unlike family carers of other long-term illnesses, a sense of guilt expressed by people caring for their relatives with AD may emerge from the distinct nature of Alzheimer’s disease. Juozapavicius and Weber (2001) identified some

reasons of guilty feelings of family carers: being sorry about incomprehension or impatience towards care recipient, economic hardship, or making a decision of leaving the individual with AD in an assisted living facilities (Juozapavicius & Weber, 2001). Furthermore, Prunty and Foli (2019) argued that AD caregivers may feel guilty if they believe that they don't do a good job as a carer of AD patients, ignore their own or other's needs, or have negative emotions towards their loved ones with AD or someone else (Prunty & Foli, 2019; Losada et al., 2010). Consistent with previous studies, it was stated that guilt feelings of AD caregivers would be linked to feel bad about doing enjoyable activities rather than caring for their relatives with AD, going away from AD patient for doing personal affairs (e.g. doctor's appointment), or spending limited time with their relatives because of the responsibilities of the caregiving role (Losada et al., 2010).

Research has shown that AD caregivers' guilt is significantly related to caregiver burden and even depression, yet there may be some moderating factors; for instance, receiving social support or devoting time to qualified activities (Losada et al., 2010). Furthermore, many family carers of AD could represent sense of guilt intertwined with other negative emotions such as frustration or anger, and also have low energy and increased caregiver burden (Gonyea et al., 2008). In addition, as caregiver guilt increases, it was indicated that family members who provide care for their AD relatives might suffer from chronic stress and negative consequences for mental health, even leading to depression or anxiety (Prunty & Foli, 2019; Romero-Moreno et al., 2013).

2.2.3.4 Loss and Grief

Having Alzheimer's or other dementias is commonly associated with multiple losses for both patients and their family caregivers. For those living with Alzheimer's disease, major losses related to their memory, social role, autonomy, and selfhood are the case in point. In addition to the losses of the person with Alzheimer's, family caregivers may also confront with the "loss of a loved one" when they notice the impairment in their relative's recollections and identity day by day. It even comes to such a point that there is a completely different person, like a 'stranger'. These losses don't only include the person they knew and loved, but also includes their expectations,

relationships, support system or identity (Doka, 2010; Noyes et al., 2010). Loos and Bowd (1997) conducted a study on 68 Alzheimer's caregivers to examine personal loss experience due to their caregiving role and they reported four specific concepts about "loss", such as loss of social interaction, loss of control on their life, loss of well-being and loss of occupation. Additional empirical studies also indicated the being a caregiver of a person with AD brings overwhelming burden related to the experience of loss (Loos & Bowd, 1997).

2.2.3.4.1 Ambiguous loss

Compared to another chronic health conditions, many published studies illustrated higher level of sense of loss among family caregivers of a person with AD on account of the effects of Alzheimer's disease on the patient. Despite being physically alive, the profound change on the identity or psychological presence of the AD patients might be experienced as "psychosocial death" by their relatives (Frank, 2008). Boss and Yeats (2014) aimed at exploring this type of loss and defined it as "ambiguous loss" experienced by family relatives of individuals with AD (Boss & Yeats, 2014). It was stated that ambiguous loss is divided into two types as physical and psychological. While the former is related to the situations in which the person is physically intact but psychologically absent, the latter refers to psychological existence but physical absence of the loved one (e.g. missing children) (Frank, 2008; Boss & Yeats, 2014). For instance, caregivers' sense of loss due to the deteriorations of their AD relatives' personality and cognitive abilities can be included in the first type of ambiguous loss. According to Boss and Yeats (2014), family members of AD patients might feel this phenomenon as "saying good-bye without leaving" (Boss & Yeats, 2014). Ambiguous loss can leave alone relatives of AD patients with the ambiguity and confusion because of the ambivalence about the psychological presence or non-existence of the individuals suffering from AD. Thus, it might make much more difficult for family caregivers of AD to notice their reactions about loss, even freeze their grief (Noyes et al., 2010). In fact, AD caregivers react naturally to grief due to the losses during this illness. Every single person goes through the grief process in a unique way, but feeling grief long before the death of the relatives with AD is prevalent among carers (Doka, 2010).

2.2.3.4.2 Anticipatory Grief

One of the first famous ideas about grief was provided by Freud in his paper *Mourning and Melancholia* (1917) and he tried to explain “grief” by differentiating between mourning and melancholia as a result of loss. He defined mourning as a kind of response to the loss of loved person or other facts like hometown, freedom, etc. Additionally, this process includes being consciously aware of what he or she’s lost, separating libidinal/emotional energy to the deceased and directing this energy to other areas of his or her life. Apart from mourning, he stated that melancholia is comprised of the core features as losing self-esteem, lack of life purpose and uncertainty regarding what is lost, and thus, it can be pathological, whereas both have common characteristics such as the sense of pain, reduced interest to outer world and having difficulty in making a relationship with others. According to Freud, mourning is a normal yet time-consuming process to cope with the loss (Freud, 1917). Later on, Kübler-Ross developed her well-known model on grief, named as the five stages of grief model, in her book *On Death and Dying* (1969) based on the experiences of terminally ill patients and she conceptualized the process of grief by dividing into five consecutive stages: denial, anger, bargaining, depression and acceptance. Furthermore, she mentioned the term “anticipatory grief”, which refers to the anticipation of losing someone, and thus, experiencing a sense of grief when he or she isn’t dying yet. Nevertheless, it was highlighted that not every person necessarily has to go through the five stages of grief or the process of anticipatory grief, and additionally, everyone might have unique experiences regarding them (Kübler-Ross, 1969). Kübler-Ross and Kessler (2005) also extensively investigated the aspects of grief in their book “*On Grief and Grieving*” and gave examples of specific circumstances, such as Alzheimer’s disease, with regard to grieving. They mentioned that caregivers may begin to grieve soon after their relatives are diagnosed with AD, or they may not have time to grieve during the illness because of their caregiving work. Besides, fading of the memories and personality of AD patients can be deeply heartbreaking for their family members. To illustrate, there was one case of Alzheimer’s relatives who thought that being the witness of her relative’s mental death is so devastating rather than her relative’s physical obliteration (Kübler-Ross & Kessler, 2005).

2.2.3.4.3. *Disenfranchised Grief*

Recent studies and literature have also given increased attention to the relationship between ambiguous loss and anticipatory grief as well as “disenfranchised grief”, described as a “subtle” way of grieving in the lack of understanding and support from others or society concerning non-death losses. If individuals have a relatives with AD, they are likely to feel disenfranchised grief due to the ambiguous losses confronted throughout this illness (Boss & Yeats, 2014).

2.2.4 Positive Aspects of Caregiving

While most of the literature on caring for people with Alzheimer's disease associated caregiving with negative consequences and potential harms to the caregiver's well-being and thus, the positive aspects of caregiving can be generally overlooked. Fortunately, there are also growing attention in the positive aspects of caregiving experience (Boerner et al., 2004; Semiatin & O'Connor, 2012; Yu et al., 2018), since giving care to other people, especially those having chronic conditions or serious illnesses, has multiple facets and its complexity has been waiting to be understood. According to the survey of National Opinion Research Center in USA (2014), it was showed that American caregivers have a positive attitude towards their caregiving experiences to their relatives. In general, caregivers mentioned that their actions of providing care can deteriorate their other relations due to limited time remained from caring, but they also expressed their positive attitude about providing care continuously to their loved ones. Parallel to this, the results of many literature studies demonstrated that family members caring for people with Alzheimer's disease might experience four common positive situations: 1. Feelings of gratification, 2. Reciprocity of the caregiver/care-recipient relationship, 3. Family cohesion, and 4. Self-improvement and a sense of purpose in life. In the following part, these four conditions were tried to examined for understanding the contributions of these positive notions on caregiving process and to make sense of how caregivers have had positive experiences while giving care. Studies revealed that positive aspects of giving care may protect or reduce the negative implications like burden or anxiety Preliminary

research findings also illustrated that positive aspects of caregiving can mitigate, or even protect against some negative effects, such as stress, caregiver burden (Heo, 2014; Semiatin and O'Connor, 2012), depression (Semiatin and O'Connor, 2012), while ameliorating better emotional and caregiver outcomes (Hilgeman et al., 2007; Heo, 2014). In particular, family caregivers in collectivistic cultures where family bonds, filial piety, and devotedness are commonly important, might tend to perceive caregiving as a positive experience. As an example, studies have shown that Chinese, Chinese American, and Korean people believe that they potentially give assistance to their parents throughout their life time based on their family values, and so, being a caregiver might not cause any difference in their life (Ho et al., 2003; Ar & Karanci, 2019). Therefore, cultural values have a diverse impact on individuals who give care to their loved ones with AD (Ar & Karanci, 2019).

2.2.4.1 Feelings of gratification

Research findings showed that caring for a loved one with AD is commonly result in a sense of rewarding and gratification due to the relationship between carers and care recipients (Hilgeman et al., 2007). In the light of extensive literature examination, caregivers of people with Alzheimer's disease most frequently used the term satisfaction when describing their caregiving experience and discussed why they expressed their caregiving experience as being gratified with various dimensions. They mentioned that they have a sense of gratification related to their various experiences as including satisfaction as: "rewards of caregiving," "joy of caregiving," "improved feelings of joy," and "feeling grateful." They also expressed particular situations which exacerbates caregivers' sense of satisfaction such as; being satisfied with a former relation between caregiver and care recipient, being a gratified with their social relations, implementing problem-focused coping skills, being older and healthier than care recipient (Cohen et al., 1994; Tarlow et al., 2004). Another study about feeling satisfaction for caregiving revealed other potential conditions that contribute to gratification from caregiving experiences. To illustrate, if caregivers have a feeling of managing their life or if they achieve intended result about the condition of care recipient, such as care recipient's receiving care at home rather than any institution, they can feel a strong sense of satisfaction about their caregiving roles (de

Labra et al., 2015). Moreover, caregivers having a positive perception about caregiving are found being less prone to feel burdensome or depressed, in addition to making a decision about institutionalization of care recipient. Therefore, it can be supposed that there can be a protective impact of having a sense of satisfaction against negative and undesired outcomes of caregiving for individuals who provide care to their relatives (Cohen et al., 1994; Mausbach et al., 2004).

2.2.4.2 Reciprocity of the caregiver/care-recipient relationship

Overall quality and dynamics of the relationship between caregivers and care recipients show variations across individuals, yet research has shown that the relationship between caregiver and care recipient is highly crucial aspects regarding the physical and psychological health for both sides. As an example, findings indicated that having a close and intimate relationship with care recipients are more likely to be associated with attenuated caregiver burden, decreased level of feeling lonely and reduced stress (Macdonald et al., 2020; Conway et al., 2018).

2.2.4.3 Family cohesion

If caregivers need to get help from others, in particular their relatives, other family members can involve in caregiving tasks and then they can share the responsibility of caring with other people. It was supposed that family members can sometimes debate with each other because of task distribution but taking all responsibilities to only one person might cause negative outcomes such as anxiety, burden and fear. Hence, the importance of family support and cohesion is highly crucial for the protection of caregiver's well-being and cope with frustrations due to caregiving responsibilities.

2.2.4.4 Self-improvement/sense of purpose in life

In this regard, many caregivers also reported that they are more likely to feel empathy and intimacy towards their relatives suffering from AD, as well as establishing a stronger relationship with them (Heo, 2014). Furthermore, feelings including fellowship, joy and finding a meaning in the caregiver role are common

positive experiences among caregivers of AD patients. They can also feel themselves as being beneficial, important and adequate as a result of the meeting care duties (Boerner et al., 2004; Heo, 2014). Additionally, these feelings might be accompanied by having a sense of gratitude, better relationships with others, (Semiatin and O'Connor, 2012), higher level of self-efficacy (Ar & Karancı, 2019), and feelings of satisfaction due to dedicating their life to care for a relative with AD, which is mostly rewarded by the society (Ar & Karancı, 2019; Boerner et al., 2004).

2.3 COVID-19

2.3.1 Definition of COVID-19

The coronavirus (COVID-19) pandemics firstly appeared in Wuhan, Hubei province of China in the late 2019 and rapidly spread all around the world (Hu et al., 2021). The new coronavirus, named as SARS-CoV-2, plays a major role in the emergence of COVID-19 disease and it is actually participated in the coronavirus family, which causes severe illnesses such as MERS (Middle East Respiratory Syndrome), SARS (Severe Acute Respiratory Syndrome) (Pathak, 2021; Chakraborty & Maity, 2020). It can be transmitted through being in a personal contact with the infected person or indirect ways like touching their noses and mouths immediately after touching contaminated objects (WHO, 2020). Till now, it has been demonstrated that COVID-19 includes some specific symptoms such as losing the ability of smell and taste, cough, shortness of breath, headache, muscle and joint pain, and so on. Furthermore, its symptoms may be diverged from mild to severe, even resulting in death (Turkish Ministry of Health, 2021; Pathak, 2021). It is estimated as the most prominent health catastrophe that has led to the far-reaching health, financial, environmental and societal problems among individuals worldwide (Chakraborty & Maity, 2020).

2.3.2 Psychological Impacts of COVID-19

Since the outbreak of a new coronavirus disease (COVID-19), there has also been a growing interest about global mental health issues. It was supposed that

psychological distress and mental illness symptoms are strongly related with COVID-19 (Torales et al., 2020; Stankovska et al., 2020). These findings were corroborated by Wang and his colleagues' (2020) study conducted on 1210 participants from 194 cities in China regarding the potential psychological impacts, such as anxiety, depression, and stress at the beginning of the COVID-19 crisis and it was revealed that 53.8% of individuals reported moderate or severe to the psychological effect of COVID-19. Also, 16.5% reported moderate to severe depressive symptoms; 28.8% reported moderate to severe anxiety symptoms; and 8.1% reported moderate to severe stress levels (Wang et al., 2020). On the other hand, people in many countries were subjected to isolation, quarantine or social distancing for long periods to prevent the spread of the coronavirus. Being in quarantine and social isolation are frequently went through as an unpleasant experience because of loss of freedom, uncertainty about the disease status, fear of infection, anger, loneliness, distress and boredom that have a huge impact on psychological well-being (Brooks et al., 2020; Serafini et al., 2020; Shah et al., 2020). In light of the recent studies, it was also indicated that the normal process of mourning and grief have also been negatively affected since COVID-19 outbreak began. During this pandemic, people are exposed to a flood of dramatic changes and losses, such as job loss, economic insecurity, limited connection with others, etc. in addition to more ambiguous losses, for instance, the loss of dreams or plans for the future (Breen, 2020), lack of social practices like funerals (Zhai & Du, 2020) and so on. Therefore, the process of grieving can become complicated for people in the society (Breen, 2020), yet Alzheimer's family caregivers have experienced abrupt changes and multiple losses related to the both Alzheimer's care and their personal life (Cohen et al., 2020). So, it is especially important to explore the experiences of family members giving care to AD patients from the various perspectives related to the grief, loss and other challenges in the midst of COVID-19.

2.3.3 COVID-19 and Being Family Caregivers of Individuals with AD

Now, in times of COVID-19, the physical and psychological health of people included in some vulnerable groups, such as elderly with AD and their carers, are deeply affected due to the outbreak. Before this pandemic, older adults living with AD and other dementias are already recognised as one of the most fragile groups in society

because of their special needs and health conditions (Brown et al., 2020). During this period, governments usually make some recommendations related to staying at home and limiting social contact, which can restrict AD patients' accessibility to special care from health system, home care assistance or their relatives. Further, COVID-19 pandemic might increase the risk of morbidity and mortality for older patients, and also for those having AD or other dementias (Cohen et al., 2020). Along with AD patients, health and well-being of caregivers are also tend to profoundly damaged by negative affects of the COVID-19 outbreak. It is estimated by recent studies that family caregivers of people living with Alzheimer's have a high risk to suffer from mental illnesses amidst COVID-19 pandemic (Brown et al., 2020). While trying to cope with many difficulties due to the caregiving role, they can also necessarily make a great effort for explaining COVID-19 or reminding the infection preventive practices such as wearing masks, washing hands or physical distancing since AD patients potentially have impaired reasoning and depend on others for their care needs (Wang et al., 2020). Further, people who have a responsibility to give care for their relatives with AD might feel anxiety because of the risk of COVID-19 transmission. If they have to stay at home due to the lockdown, they are also likely to encounter some potential threats to their mental health, for instance, the restriction of face-to-face interactions (Dinç & Erdoğan, 2021; Wang et al., 2020). It can be presumed that family caregivers of AD patients might try to deal with various challenges during the COVID-19 outbreak and at this point, their experiences and needs should be evaluated to have a broader understanding for all people, particularly for vulnerable groups of people like elderly with AD and their relatives who give assistance to them.

Despite negative impacts of COVID-19 on mental health and well-being, recent research has shown that this outbreak might bring various positive impacts on people's daily lives as well. Krajewski et al. (2020) suggested that some positive aspects, including, rethinking all facets of life (i.e. relationships, occupation, etc.), living a slower pace, acquiring new knowledge and habits, having a chance to spend much more time with family members, appreciating solidarity and codependency, and recognition of positive changes in their environment such as decreasing in the air pollution (Krajewski et al., 2020). Another study conducted by Al Dhaheri et al. (2021) on 6142 adults from Middle East and North Africa region revealed that almost half of the participants perceived strengthened family support, gave more importance to their

well-being, and took more time to relax during COVID-19 pandemic (Al Dhaheri et al., 2021). Likewise, these findings are further supported by the study of Cornell et al (2021) and they found three common themes related to the positive aspects of COVID-19 outbreak: family time, work flexibility and calmer life, based on the survey from 1370 participants in Australia (Cornell et al., 2021). Thus, although this pandemic has been mostly associated with the negative consequences, several studies have revealed that it could also lead to the rewarding experiences for people around the world.

The literature on the effects of the COVID-19 pandemic on the lives of older adults with AD and their family caregivers has been increasing in these days. In a study by Cohen et al. (2020), it was revealed that COVID-19 outbreak caused drastic changes in the care of seniors with AD and had a significant impact on their carers in Argentina (Cohen et al., 2020). To illustrate, the majority of the AD caregivers preferred not to visit their relatives because of the fear about COVID-19 transmission. Furthermore, the care model for patients with AD and other dementias included some practices, such as participating in social or physical activities and receiving a plan for everyday activities, yet this model was changed with the beginning of COVID-19 pandemic and quarantine period. As a result, almost more than half of caregivers reported higher level of anxiety, stress and perceived burden that can be derived from feelings of loneliness and boredom, fear of confinement or physical inactivity during this outbreak (Cohen et al., 2020). Additionally, Vaitheswaran et al. (2020) attempted to explore the experiences and needs of family members who give care of individuals living with AD in India, and they found two specific areas of caregivers' issues: concerns having a direct association to caregiving (e.g. trying to protect their AD relatives from coronavirus, striving to cope with the changes in the daily routines for AD patients) or concerns not connected with the role of care (e.g. managing daily household chores and supplies, caregiver's health and well-being). However, it was highlighted that concerns and experiences of AD relatives might be impacted by various variables, like caregiver's feelings of competency or characteristics of the relationship between AD patients and their family carers (Vaitheswaran et al., 2020). That's why the experiences of those who give assistance to their loved ones with AD are needed to be investigated thoroughly. In concordance with the published literature from other countries, COVID-19 pandemic is a prominent issue in Turkey as well and experiences of individuals who have to look after their family members with AD

during this outbreak may remain a relatively obscured. For instance, in a study of Dinç and Erdoğan (2021), findings showed that family caregivers in Turkey might face some particular challenges, for example, about meeting the need of AD patient's special health care or giving an equal importance to both their caregiver duties and their own lives (Dinç & Erdoğan, 2021).

2.2.4 The Aim of the Study

Although this COVID-19 pandemic has been in our lives for a very short time, emerging body of literature on the experiences of family relatives who give care to people with AD has been done, but there is still limited number of studies including the holistic understanding about the experiences of AD patients' family caregivers. In other words, what family caregivers of patients with AD experience during COVID-19 outbreak and how they go through this period have not yet been fully understood. Also, these previous studies have been given little importance to the positive aspects of COVID-19 pandemic, in contrast to the negative impacts of this outbreak on individuals who give assistance to their relatives with AD. As expected, family caregivers of AD patients may not only face with numerous challenges but also potential benefits that can have a positive affect on their life. Besides, there is a paucity of research consisting of a more sophisticated understanding about both the individual and culturally-shared experiences of family caregivers of AD patients during COVID-19 outbreak, particularly in Turkey.

In this respect, the goals of this research are to investigate and deeply understand the experiences of family caregivers of AD patients during COVID-19 outbreak in Turkey. This study aims to provide a broader understanding by a detailed examination and interpretation of how individuals giving care to their family members with AD make sense of their experiences during COVID-19 pandemic within the cultural context. Hence, Interpretational Phenomenological Analysis (IPA) was preferred to provide better insight pertinent to subjective experiences along with the cultural underpinnings of Turkey.

Chapter 3

Methodology

3.1 Research Design

Qualitative research design was selected for this research to investigate personal meanings of giving care for family members with Alzheimer's disease during COVID-19 pandemic. Using qualitative research design enabled researchers to illuminate how persons perceive, interpret and attribute particular events or phenomenon. Thus, qualitative methods give an opportunity to explore unique understandings and processes rather than focusing on the objective data derived from quantitative methods (Lapan et al., 2012, pp.4). To date, there is no study regarding how Turkish family caregivers of individuals living with Alzheimer's disease experience COVID-19 period as distinct from other people. With respect to the goals of this research, qualitative methods was used to understand how family carers of Alzheimer's patients are going through caregiving processes during COVID-19 outbreak based on their personal expressions.

Interpretative Phenomenological Analysis (IPA), which is one of the qualitative research method, was preferred to use for this study since it attempts to discover how individuals give meaning to spesific life events in a given context (Smith & Osborn, 2008). In contrast to objective definitions or categorizations, IPA studies adopt phenomenological approach, originated from philosopher Edmund Husserl's phenomenology, and therefore, it's main focus is to understand what is happening based on a subjective perspective (Larkin et al., 2006). Additionally, IPA is concerned with interpretative stance since the endeavor of making sense is reflected by the accounts of participants they provide (Biggerstaff & Thompson, 2008). At the same time, researchers include their own interpretations and perceptions while making an effort to understand participants' point of view about their experiences (Willig, 2007). Thus, IPA gives prominence to two-sided sense-making, in other words, a double-hermeneutic process (Smith & Osborn, 2008). In general, IPA studies should include three main features, named as idiographic, inductive and interrogative (Larkin et al., 2006). Idiographic approach refers to the detailed analysis of cases one by one and

thereafter identification of themes by determining convergence and divergence among participants to illuminate shared and distinctive experiences within one particular context and phenomenon (Larkin et al., 2006). Also, IPA includes inductive method which allows researchers to conduct more flexible and expansive studies due to the rise of unanticipated themes while doing analysis (Love et al., 2020). As such, conducting IPA studies gives an opportunity to make contributions of the extant literature through interrogative approach in which researchers do a detailed examination of each cases and compare findings of the analysis with previous studies (Smith, 2004).

In this thesis study, the main focus is to understand subjective experiences of six women who have a responsibility of giving care to their family members with AD during COVID-19 through an in depth analysis in relation to IPA.

3.2. Setting and Participants

Due to the COVID-19 risk, this study was carried out via internet in the time intervals of November 2021 and June 2022. Therefore, it was possible to comfortably meet with the participants from different locations through online platforms, such as Skype or Zoom. The interviews, which lasted between 60 and 90 minutes, were completed through these platforms.

Participants of this study were comprised of eight Turkish female adults ($n = 8$) who give care at home to their relatives with AD in Turkey. To clearly understand shared experiences of these eight family carers, purposive sampling method was used and thus, a more specific group with similar characteristics was described in accordance with the principles of IPA (Smith & Osborn, 2007, pp.56). Furthermore, a total of eight family caregivers of Alzheimer's patients were included in this study because it was recommended for providing more heterogeneous sample that six to eight interviews should be done with participants in qualitative studies (Kuzel, 1992). By doing this, people were also excluded if they didn't meet following criterias: (1) Being over 18 years, (2) Having a kinship with people clinically diagnosed with AD, (3) Describing themselves as being an informal caregiver, and (4) Giving care for a family member diagnosed with AD for at least one year during COVID-19 outbreak. Although two male and eight female participants met inclusion criterias, it was decided

to conduct this study based on interviews of only female participants, and thus, more homogenous sample were formed. Importantly, all of participants were daughters of the care recipient with Alzheimer's disease, whose ages were ranged from 43 to 62 ($M = 55$, $SD = 5.15$). The employment status of three participants were retired, three of them were unemployed and the remaining two were still working during COVID-19 pandemic. More than half of them ($n = 5$) were not married, but two of them were married and only one was widowed. Also, majority of participants ($n = 5$) didn't infect with coronavirus, and three of them had COVID-19 infection with mild to moderate symptoms. Pseudonyms were used in place of participants' real names in order to protect confidentiality and the right of privacy. The descriptive information of all participants were figured out in Table 1.

Table 1.

Descriptive Information of Participants

Pseudonyms	Age	Occupation	Relationship Status	COVID-19 Status
Buket	56	Retired	Single	Not infected
Burçak	55	Unemployed	Single	Not infected
Defne	55	Retired	Single	Infected
Kardelen	62	Unemployed	Married	Infected
Lale	43	Employed	Single	Not infected
Nilüfer	59	Unemployed	Widowed	Not infected
Yasemin	54	Retired	Married	Not infected
Yonca	56	Employed	Single	Infected

In addition to the descriptive information of family caregivers; some information was obtained about the duration of care, Alzheimer's stage, and the covid status of care recipients. It can be seen in Table 2 that three of care recipients were provided assistance between one to five years, the other three received care more than ten years and two of them were cared for five to ten years. Considering stages of Alzheimer's disease, half of care recipients suffered from middle stage of Alzheimer's disease and three of those were living with severe stage of Alzheimer's disease, but only one care recipient had mild stage of Alzheimer's disease. Likewise research participants, most of care recipients ($n = 5$) didn't contract coronavirus, yet three of

them infected with COVID-19. Information regarding care recipients was reflected below in Table 2.

Table 2.

Information about Care Recipients

Duration of care	Stage of Alzheimer's disease	COVID-19 status of care recipient
1-5 years	Moderate Stage	Not infected
>10 years	Moderate Stage	Not infected
>10 years	Severe Stage	Infected
>10 years	Severe Stage	Infected
1-5 years	Severe Stage	Not infected
5-10 years	Moderate Stage	Not infected
1-5 years	Mild Stage	Not infected
5-10 years	Moderate Stage	Infected

3.3. Data Collection

3.3.1. Data Collection Instruments

In line with the IPA guidelines, data was collected through one-to-one, semi-structured interviews with participants. First of all, the informed consent were requested from all participants through orally and written form (Appendix A). Through the informed consent form, it was aimed to clearly understand the purpose of the study and the procedure by the participants. It was also stated that the participant has the right to withdraw from interview at any time in case of discomfort. Participants were supposed to sign informed consent form if they agreed that they would participate voluntarily and give a permission for audio-recording of interviews to transform them into written form and analyse in verbatim. In the following step, participants were asked to fill in the demographic information form (Appendix B), which included some questions of information about care recipient, as an example, the duration of care, stage of Alzheimer's disease and COVID-19 status of care recipient in addition to participants' descriptive information such as age, occupation, relationship status and COVID-19 status. After that, in-depth semi-structured interviews (Appendix C), included prearranged but flexible open-ended questions were enabled participants to

freely express their personal experiences of caring for a loved one with Alzheimer's disease during COVID-19. In interviewing part, there were ten open-ended questions, and participants were initially asked a warm up question about introducing themselves and care recipients in order to draw a detailed picture regarding participants' lives. After that, following open-ended questions were aimed at deeply understand the caregiving experiences of participants before and after COVID-19 outbreak to figure out the unique sides of the caregiving process in the midst of pandemic. According to the flow of semi-structured interviews, additional questions were also raised to shed light on the emerging critical points and clarify some statements of participants.

3.3.2. Data Collection Procedures

Before interviews, ethical approval of Ethics Committee for Social Sciences of Bahcesehir University was obtained. Subsequently, individuals were orally reached through acquaintances or non-profit Facebook groups of Alzheimer's relatives. A brief information text about the inclusion criteria and the purpose of the study was shared in these platforms and verbally informed. After the voluntary participants who fulfil the meeting criteria's were determined, interviews were planned with eight female family carers of Alzheimer's disease.

Firstly, every participant was supposed to sign informed consent form to ensure that they fully understood the scope and process of this study and also give a permission to use the information they gave. Yet, pseudonyms were used instead of participants' real names in an attempt to protect confidentiality. After that, demographic information forms were given to fulfil the questions about caregivers' age, gender, economic status and marital status. In addition to sociodemographic information, detailed questions about the disease progression of care recipient were expected to be answered by family caregivers. Specifically, there were some questions including COVID-19 pandemic such as "Have you had the coronavirus (COVID-19) illness?", "After coronavirus (COVID-19) pandemic, have you felt the need to seek psychological support?", and so on. The interviews lasted between 60 to 90 minutes. These interviews were designed for 10 open-ended questions which were developed based on the IPA principles to freely express their experiences with their own words. At the beginning of interviews, participants were asked to an open-ended question

“Can you tell us about yourself and your relative with Alzheimer's?” to give general information about themselves and feel more comfortable before moving on other questions regarding caregiving experiences during COVID-19 pandemic. In order not to fall into repetition, some questions were passed if the necessary information was already obtained. During the interviews, extra information was provided when there were points that could not be clearly understood.

3.3.3. Data Analysis Procedures

Semi-structured interviews were conducted on eight female participants according to the principles of IPA. To transcribe what the participants said verbatim, all interviews were audio-recorded and they were analyzed by an idiographic method which implies unique personal experiences with avoiding any generalizations. In order to gain overall understanding about a specific phenomena, it is supposed to examine all similarities and convergences at an individual and then group level (Smith et al., 2009). So, the first step of the IPA analysis was immersing oneself in the data through re-reading each transcript at multiple times and scrutinizing carefully to the other cases after elaborating on the first data in detail. After that, researcher has an attempt to detect similar patterns and sub-ordinate themes which creates super-ordinate themes (Cheng et al., 2010). With the consultation of the thesis supervisor, all themes were rectified repeatedly and thus, final list of super-ordinate themes were emerged. Before the analytic process, all information that may reveal the identity of participants were altered and instead of real names, using pseudonyms for each participants were preferred so as to preserve their privacy (McGeechan et al., 2018).

3.3.4. Trustworthiness

It has been ongoing argument that two essential components, reliability and validity, for the quality research studies were deficient or blurred in qualitative methods (Noble and Smith, 2015). While the reliability and validity of quantitative research is depend on the observable and measurable data, qualitative analysis can be achieved these notions with different, which is defined as ‘‘trustworthiness’’ (Morrow,

2005). Since IPA is also one of the qualitative research approach, it is possible to provide trustworthiness with such strategies such as reflexivity (Yardley, 2000).

Reflexivity, which reflects the impact of researcher's own subjectivity or pre-existing information on the analytic process of individual experiences, is a crucial component of IPA (Yardley, 2000; Clarke, 2008). As aforementioned above, IPA study also includes double hermeneutics, so it implies how researcher interpret participants' narratives through the lens of both participants' and researcher's point of view during meaning-making process (Reid et al., 2005). Furthermore, it puts emphasis on the demographic characteristics, preconceptions and emotions of researchers while investigating specific topic (Pietkiewicz & Smith, 2012).

My grandfather was diagnosed with Alzheimer's onset in 2010 and lived with this disease more than ten years. In the last three years of the disease, he has reached the final stage and has completely lost his vital functions such as walking, eating and drinking. While continuing to fulfill the requirements of the caregiving role for my grandfather during the pandemic, my relatives had many positive and negative experiences, and thus, I had the chance to closely observe the experiences of my family members who give care for him before and during COVID-19 outbreak. Since the beginning of this period; my father, my grandmother, my aunt and my uncle had taken responsibilities for giving care to my grandfather. I had clearly noticed the change in the caregiving processes for each of them after the pandemic entered our lives. The coronavirus outbreak has brought many difficulties and some advantages to the caregiving process and the daily life of my relatives. Although I was not involved in the caregiving process, as a result of all these observations and awareness, I wanted to understand how the caregiving processes of other family carers for Alzheimer's patients changed after the pandemic from their subjective perspectives.

In order to take into consideration my personal experiences related to the caregiving of patients with Alzheimer's disease during COVID-19 pandemics, I kept a diary reflecting my own feelings and experiences on the recommendation of my thesis supervisor. When I started the thesis, I felt that I had a very difficult time because my own compelling emotions were triggered. While writing the thesis in the midst of COVID-19 pandemic, I had to mourn after the death of my grandfather for a while. I was able to do my own inner work with the help of my psychotherapy process, and tried to notice my sentiment and attitudes that could be reflected in the thesis study as

much as possible. Bracketing, commonly named as epoché in Husserl's terminology, has a crucial importance for IPA studies as an endeavor to prevent the tendency of participants to enlighten participants' subjective living experiences based on the researcher's own personal experience (Yüksel & Yıldırım, 2015). Therefore, I made a great effort to bracket my subjective experience and knowledge to stay closer to participants' meaning-making process.

In addition to these steps, to increase the validity of data findings and conclusions, the method of member checking was used. Indeed, this method can enable researchers to obtain beneficial feedbacks from participants about what extent the final results and themes reflect their "lived" experience? (Birt et al., 2016). In this direction, member checking method were implemented by the fact that two participants were contacted again and feedback was obtained by the researcher. After that, both two participants stated that the main and subordinate themes related to their caregiving experience for their loved ones with AD during pandemic comprehensively reflected their experiences.

3.4. Limitations

It was hypothesized by the researcher that this thesis study may include a few potential limitations. First of all, research topic was decided in pandemic's first year, yet the research process spanned over three years and the data collection process took longer than planned. One to two participants stated that it has been a long time since the beginning of the pandemic and that they sometimes had difficulty in remembering what they've been through in those days. In fact, participants may express recall bias, which reflects to have a difficulty in reminding old experiences or memories while engaging in self-report studies (Jager et al., 2020). The possibility of recall bias can be considered as two sides of the coin: the deficiency or falsehood of participants' expressions may affect the credibility of data obtained from interviews, but also spread of the process over a long period of time might enable researcher to illuminate participants' whole process of caregiving during pandemic.

Second potential limitation may be related to the country in which one participant live. In fact, although she is Turkish, she is living at Northern Cyprus and gave care for her father in there during the pandemic. Heidegger, one of the important

figures for phenomenology, stated that individuals should be understood by the "person-in-context" notion, which highlights that the reality can be created with the interaction of the outer world and of course, the place they live in (Larkin et al., 2006). For IPA studies, choosing people with common characteristics as much as possible plays a important role in order to thoroughly understand the common experiences of all participants. In this study, all of the participants were Turkish and seven of them are living in Bursa, so these features were considered as a common feature. Nevertheless, the perception of a participant's own subjective world in a relation with the living context was also considered as a point to be taken into account for the analysis of that person's caregiving experiences during pandemic.

Another potential limitation was considered to include the content of the interview questions. In line with the existing literature and preliminary information, onespecific questions were asked to the participants that may be a part of their experiences. For instance, participants were supposed to respond this question: "What has changed in your relative's medical needs/needs or access to healthcare services after the pandemic? How did these changes affect you?" Practically, it was asserted that it may not be possible to fully implement the method of bracketing (Smith et al., 2009, pp.28). Even so, thesis advisor was consulted about the appropriateness of the questions and the questions were reviewed again. Thus, it was aimed that personal insights and prior knowledge do not overshadow on the commitment of figuring out the lived experiences of participants.

Finally, it may be a limitation that seven of the interviews are conducted online and 1 of them is face-to-face due to technical problems and the same interview conditions with all participants could not be provided online, except for one participant. According to preliminary studies, it is thought that being in front of a screen during online interviews may prevent the person from reflecting his more sincere and natural state during face-to-face meetings (Hallett & Barber, 2014). Yet, the potential advantages of conducting online interviews are stated to be much more cost-effective than face-to-face interviews (Davies et al., 2020). However, face-to-face interview can be counted as a limitation since one of the participants reside in Northern Cyprus.

Chapter 4

Results

The data obtained from the written transcripts of the interviews with eight female participants who care for their relatives with Alzheimer's were analyzed in accordance with the principles of the Interpretive Phenomenological Analysis. As a result of the detailed analysis, three master themes were emerged: I) Forced proximity; II) Riding through the waves of emotions; and III) Turning crisis into opportunity. Detailed explanations related to the master themes and subordinate themes, in addition to the narratives of the participants, which provide the basis for the extraction of the themes, will be demonstrated in this section. Also, each three master themes and ten subordinate themes were revealed in Table 4. 1.

Table 4.1.

List of master and superordinate themes

Master themes	Subordinate themes	Number of contributing participants
1. Forced proximity:		
	a. Providing intensive care	6
	b. Psychological closeness	8
	c. Need for respite	6
	d. Overprotection	8
2. Riding through the waves of emotions		
	a. Living in fears	8
	b. Under the burden of caregiving	7
	c. Away from the outside world	7
3. Turning crisis into opportunity		
	a. Adapting to constant changes	8
	b. It's a learning period	5
	c. Vitality of social support	8

For organizing main themes and subordinate themes, the coding system were implemented and thus some connections were established between common

experiences indicated by important passages from the statements of the participants, and certain concepts, namely themes, came to the fore. In this direction, it was noticed that all eight participants entered a “forced proximity” process with care recipient with AD since the beginning of the COVID-19 outbreak. Afterwards, they mentioned that while they were continuing to care for their relatives with Alzheimer's during COVID-19, they felt mixed feelings together and, so to speak, they were “riding through the waves of emotions”. Finally, they talked about the fact that they learned to live with the COVID-19 pandemic and naturally developed a resilience, and on the other hand, they experienced some situations where the “crisis was turned into an opportunity” for them. These emerging main themes and their sub-themes will be defined in detail.

4.1. Forced Proximity

This first main theme, defined as “Forced proximity”, came to light when participants talked about their relationships with care recipients suffering from Alzheimer's disease after the pandemic began. Due to COVID-19 restrictions and quarantine times, all participants mentioned about that they had to spend most of their time together with their relatives with AD relatively more than before the pandemic. In respect of this obliged proximity with their care recipients at home in consequence of COVID-19 pandemic, they mentioned about the intense care they give to their relatives with AD, their closer relationships with their loved ones living with AD, their own breathing needs and trying to protect their relatives more. That's why four subthemes, defined as providing “intensive care”, “more than physical closeness”, need for respite, and “overprotection” were created.

4.1.1. Providing Intensive Care

Participants commonly reported that the increase in the time spent at home and being physically closer to the person who received care gave an opportunity for these caregivers to make a greater effort for the duties of caregiving. And thus, their priority in their life became meeting their responsibilities of caregiving the caregiver. As an example, they explained how taking care of care recipient with AD more often affected

to them and how it turned into being center of their life during the pandemic process with the following statements:

Researcher: How has it affected you to take care of your father more often during the pandemic?

Defne: "When the process is long, it's like it's all your business now. Housework is secondary, so the main thing is your father, the rest seems like a formality. It becomes your life. How should I explain now? When you open your eyes, you have your father in your mind and you run to him. Before going to bed, you are the last to take care of your father and go to bed like that. The others are in the second place, so they are completely focused on your father..."

Nilüfer: "Well, I wake up my mother twice a day. I feed her, leave her on the chair, and at the same time, when I was going to do the housework, I didn't do the housework. I was interested in her."

In a similar direction, participants described that in addition to the importance of trying to protect her mother from possible dangers while giving care, according to their perspective, they almost devoted themselves to protecting their relative living with AD, especially during the pandemic period, and watched over them meticulously. Furthermore, they mentioned how they made a great effort and how demanding work was for them to devote most of their time to extra and detailed care. Another participant Yonca portrayed this intensive care as like a mother protects her child:

Yonca: "Because you cannot leave a child at any time, because anything can happen at any moment, so you are observing in that sense. And you say something to her, the child understands after a while, you know, she doesn't understand. You said "Wash, give the towel in my hand, hang the towel, go ahead.", but she is confused where to go. You hold her, you change direction, so you are always with her step by step. This kills a serious day, frankly. You dedicate all your time to her."

Participants stated that they made sacrifices to many important things in their own lives, such as their relationship and intimacy with the outside world, for protecting those who care for, and that they prioritized the lives of care recipients with AD for over their own life.

Defne: ‘‘Both my brother and I isolated ourselves too much and our daughter-in-law and my brother's wife were working so she tried not to come near us as much as possible so we were sitting on top of each other. Without talking too much... Here, my brother was very careful because he talked to his wife a lot. We did not have any problems with my father in terms of the disease, but somehow we got caught with this disease. Maybe it's what we got vaccinated for, I don't know. We got over it quickly. My father had fever for 3 days. By the way, I got sick too, but I couldn't understand myself while I was dealing with it so much...’’

Lale: ‘‘Most people accepted it as a single dose, plus it was the school endorsed vaccine. I couldn't do it because the vaccine is experienced like a little covid, it causes severe weakness, pain and chills for about 2 days. Therefore, it was not possible for me to do my caregiving under those conditions, even if the lady was with me because when she was with me, at least I was dealing with procurement even if I never touched my father. You skip the supply, what will you do with the others? So I had to be Sinovac, the traditional vaccine, the one that feels nothing.’’

4.1.2. Psychological closeness

While talking about the increased proximity with their relatives with AD in accordance with some obligations because of pandemic, all participants reflected the share notion of affective intimacy, in other words, they experienced this nearness as "more than physical closeness". For instance, Defne described their affinity with her father as "being two halves of an apple", which reflected the escalation of her commitment, and even dependence, to her father while giving care and the dominance over other parts of her life:

Defne: "Due to the confinement at home brought on by these conditions, we have become like two halves of an apple, spending time together 24/7, being in touch with my father all the time. I don't know what will happen when something happens to one of us in the future. Spending a lot of time together... It's all in the center of my life now, so I don't know what will happen next. The worst part of this process was that we became very dependent on us. So I have become completely dependent on him now, for the reason that I am at home."

In addition to spending more time with her relatives living with AD, Nilüfer expressed that her sense of guilt decreased and she felt more relaxed because she could find an opportunity to complete what she wanted to do about caregiving, and thus she could feel a sense of completion with those statements:

Nilüfer: "Spending a lot more time with my mother made me feel more comfortable psychologically. She has reached a certain age. When a person loses something from her/his hand, she/he realizes its value. This is coming towards the end. I'll take my enthusiasm for it, I'll do all the things I'm going to do with it. Do not miss anything. That's why I did what I would do against my mother during the pandemic period. That's why I'm very comfortable in conscience."

Similarly, Lale who had both responsibilities of going to work and also give care to her father with AD at home, stated experiencing less caregiver guilt and being quite satisfied in this period.

Lale: "Now, during the pandemic period, I actually had the opportunity to do this with peace of mind and without feeling guilty, so I did it until the end, because that's what I wanted to do. I mean, trying to find out for myself by looking, enjoying every moment of everything and thinking that he couldn't say it in every problem. You are solving a puzzle, it has a logical side, it has a reading side, and it has a very emotional side. This is what I call literally caregiving. That's why I was like this before covid, but what could we do, we could take a walk in that vicinity, we were going out in a wheelchair, or something like two times a day, if the weather permits. We were

able to look around, and it provided this type of opportunity. It provided what I couldn't do during office hours."

Yonca also implies that she felt joy and companionship with her mother since they were able to spend more time for engaging in spare time activities during home confinement period.

Yonca: "As I was alone with my mother, my relationship became even better. I was more interested. We had more fun together. We spent more time together. We gathered lots of flowers in the garden. We planted and harvested all our flowers and carried them to the garden. It was a pleasant time, a process."

4.1.3. Need for respite

As well as the increasing enjoyment intimacy of spending time together at home, the participants frequently talked about the other side of the coin, namely the need for respite. To give an example, Buket occasionally needed to move away from the caregiving role and to maintain her well-being:

Buket: "You feel psychological pressure. Sometimes I leave her (her mother she cares for) to my son, I say come on, let's go to a market, I want to get some air, really, not in the sense of getting bored. It's really hard to take a breath to clear my head a little bit like that. It is really hard."

In similar lines, inability to leave the house and increased care responsibilities with the pandemic outbreak would lead to increase of her need for catching an opportunity to make a rest and she longed to relinquish her caregiving responsibilities for a while, as Yonca said:

Yonca : "As I said from the beginning, the greatest need is to create spaces that will make me relax and breathe, rather than social solidarity and the mother, that is, someone will take those responsibilities, I will rest that day or rest for a few days. I'll

be able to get away for a few days from time to time. Because I used to be able to escape for a few days.”

Yasemin also reflected the need to breathe as the need to get away from her permanent environment, in other words, her house. She mentioned that she cannot feel free because she cannot go out whenever she wants and cannot get away from the caregiving responsibilities, and this limitation negatively affects her well-being.

Yasemin: ‘‘Prohibitions were bad... Restrictions were bad, we were bored and overwhelmed. We wanted to travel, but we were afraid, as I said, although we went, we did not go freely.’’

Another participant Nilüfer implied that her approach to her mother could come from a much more positive and compassionate position when she could meet her own self-care and time-out needs, and thus the quality of her relationship with her loved one with AD would increase if she met her need for breathing.

Nilüfer: "Of course there are times when I'm tired. Here I am leaving the house in the afternoon. I am coming, when I come, I become more compassionate, I become more fit. This is how our relationship continues.”

4.1.4. Overprotection

In general, all of eight female family caregivers of individuals with Alzheimer’s disease shared the feelings of responsibility for protecting their relatives’ health. Especially, caregivers stated that they felt responsible for ensuring that their caregivers did not contract with coronavirus. One of the participants, with the pseudonym Buket, gave a vivid descriptions of her worries and had a sense of excessive guilt she felt about the possibility of her mother living with AD being infected with COVID-19 because of her potential fault, and then, she believed that the health of the person she cares for was "entrusted to her":

Buket: 'I don't take anyone home, only one of my friend comes and goes. I say I'm afraid, I'm afraid, it's entrusted to me... Well, if something happens to me now, or if it's something that comes from me, if my mother gets sick from something that I missed, I will have a lifetime of guilt. I say not to go out, I say not to go out, I say not to meet, but I say to be healthy and live.'

With concordance to the intense guilt, Defne's accounts pointed out that her own life was constrained by making some sacrifices to protect her mother. She claimed that as a caregiver, she made an extra effort to prevent her father from contracting with coronavirus. Additionally, she tried to protect herself too, because of preventing her mother to get COVID-19.

Defne: 'Something happened, because my father went to bed, we didn't deal with people too much, you know, because he might get sick. What do I know, the plague of this is very heavy. And we were more careful before the at-risk groups got the vaccines first. We haven't been out for a very long time. Both my brother and I isolated ourselves too much and our daughter-in-law and my brother's wife were working so she tried not to come near us as much as possible so we were sitting on top of each other.'

In addition, Burçak stated that she made an extra effort to protect her mother because she was the only caregiver and she assumed many responsibilities on her own. Thus, with the responsibility she felt, she tried to meticulously provide complete protection for both herself and her mother living with AD, by putting her mother's health first:

Burçak: 'Because I'm the only one taking care of her drinking, dressing, everything. We had to do everything together, mouth to mouth. I took care of my vaccines. When I went out, I meticulously changed my clothes and entered the house. I don't take my mother out, I go to my normal shopping, I go to the market, I go to the market for example.'

From another perspective, Lale explained the heaviness of burden about her every decision regarding her father and the guilt she felt for the probability of serious outcomes from her resolutions. Yet, she said that when she learned her caring staff was infected with COVID-19, she felt that this responsibility was gone and she felt a great relief. Therefore, she was relieved to think that she probably wouldn't be the only one responsible for contracting COVID-19 to her father. She maybe felt exhausted by reason of trying to constantly review her decisions and always being on the alert. Interestingly, she described herself as having a relaxation of a "dead person" who could not bear any responsibility to anyone.

Lale: "I have been making all kinds of decisions for 3 years, I have to control it and therefore I am responsible. Since I have all responsibility, I do everything meticulously. This is the first time something like this is beyond me. I don't have a decision to make now, because if we are covid, they will take us all to the hospital. If we are not, we are at home, so I am no longer the decision maker, in something very traumatic for 1 hour, such a relief came to me. It was also a very strange feeling, I mean, I had a "moment of peace" from something terrible almost something like this. I guess such a moment of peace can be experienced when a person dies."

4.2. Riding through the waves of emotions

Along with the uncertainties and challenges brought by the COVID-19 pandemic, all participants stated that they experienced many diverse emotions together in this process. While trying to balance between coping with caregiving-related issues and sustaining their own lives in the midst of the pandemic, they strived hard to "riding through the waves of emotions". From this perspective, three common unpleasant emotions commonly experienced by all eight participants can be characterized as three sub-ordinate themes: a) Living in fears; b) Emotional strain: "Under the burden of caregiving"; c) "Away from the outside world".

4.2.1. Living in fears

With the onset of the COVID-19 pandemic, it was widely explained by all participants that this outbreak caused a rise of caregivers' sense of fear, and in other words, the adverse effects of the pandemic had contributed to all participants who care for their relatives with Alzheimer's disease "living in fear". First of all, since the pandemic process started, it was not fully understood what the pandemic was and what its consequences might be, and it was a new situation and quite outside the routine we were used to in our lives. Thus, the participants may have experienced a deep fear due to this obscurity. Specifically, due to restrictions and social distancing rules at the beginning of COVID-19 pandemic, being physically close to other people may have been a frightening and panicked situation for caregivers.

Defne explained that she inevitably faced a situation that was contrary to her own perception of herself, as being extravert and sociable, in a dramatic way and that her socialization opportunities were cut, maybe "like a knife" at the beginning of COVID-19 pandemic. She also stated that the onset of the incomprehensible pandemic brought a shock, and with increased fear:

Defne: "Well, there was something like this, for a moment, I am someone who likes to communicate with people very much. All of a sudden, everything stopped, everyone became afraid of each other, you don't approach your neighbors... At first, people were more distant because they couldn't figure out what exactly happened, they were more in a panic. They were in a state of fear."

Furthermore, the fear of contracting coronavirus and infecting their loved ones living with AD was stated as a common feeling experienced by all participants during the caregiving process during COVID-19 pandemic. They perceived contracting the coronavirus as highly dangerous, and even deadly, particularly in the onset of pandemic. In response to the one of the questions asked by the researcher, Burçak said that she was very afraid of infected with coronavirus and transmitting to her mother, especially after the death of her relatives due to COVID-19. It has been stated by the participants that the fear of losing a loved one with AD whom they cared for

hadelevated, and that the fear of causing the possibility of their death by spreading from caregiver to their parents living with AD was also felt very much.

Researcher: "What fears? Can you explain a little more about these fears?"

Burçak: "Well, just because the disease will pass. My uncle passed away from coronavirus. I still do. So those fears God forbid. Especially when it was at their head when they passed away, and of course we were scared too. You know, I'll pass it on to my mother, something happens. I'm scared, God forbid. It goes to me, it gets infected, something happens."

Buket also highlighted her feeling of dread when there was a possibility of the care recipient with AD keeping touch with other people indoor at close range, that is, when she is directly confronted with the life threat. She could feel desperate and insecure when she was afraid of the threat from fatality of coronavirus:

Buket: "I can't get it out. Her brothers are very close here, we go out in the summer. I take them in the summer because they have gardens and we live far away in the gardens. I do not see a problem there, but when it comes cold, winter, and indoor environment. One day, the weather was sunny, she could only meet with her siblings once in 1.5 months, and we sat in the garden. We couldn't do anything, so I can't take it because I'm so afraid. I read an article that the virus goes directly to the brain in Alzheimer's patients. It's eating your brain. After reading that article about him, I don't accept him as a neighbor anymore, when my mother is with me."

Some of the participants talked about the fear and apprehension when their relatives suffering from AD contracted with COVID-19. She stated that she felt increased worry and frightened while considering the possibility of her mother's death was ambiguous, and also quite close, but afterwards she felt quite relieved when she recovered.

Kardelen: "I was worried, I was very worried, I just didn't know how my mother would get over it, whether she would get over it because it was a very risky situation."

After two or three days, but I saw that his fever went down, she started to eat, she started to react while changing her diapers as before. After that, I was relieved."

Likewise, another participant Nilüfer experienced a strong fear when she felt about the uncertainty related to the probability of her mother's death as "the end of the world", that could reflect as a destructive emotion for her own inner world.

Nilüfer: "With that fear, I was very afraid that my mother would be sick. I was incredibly afraid. We even stayed in the hospital once in a pandemic. I said it's the end of the world, I'm losing my mother. Because we have to go to the hospital, we went, we slept for 20 days. I was so scared."

4.2.2. Under the burden of caregiving

Participants, along with the intense emotions they experience in addition to the effort to fulfill their caregiving responsibilities, described that they experienced an emotional strain and distress from time to time, and they have felt almost "under the burden of caregiving". Majority of eight female caregivers explained that the feelings of fatigue and burnout increased in direct proportion with the rise in caregiving burden after COVID-19 restrictions. For example, Lale told about the stress and fatigue of caregiving when she had to give care alone without getting support due to limited opportunities:

Lale: "Oh, is it true, is it true that your caregiving stress is increasing, as the exposure increases, there is an opportunity to find a solution, while there is a possibility that you can find people who can take care of it better than me, you cannot find it due to the circumstances. It's putting you in your head even more so no one can look at it but me. These are always such side effects. Caregiver stress, let alone physical fatigue, I don't know, things that increase with the rise of the exposure of caregiving duration, but you also find a solutions for them."

Nilüfer also described a similar situation and tried to make sense of the fatigue and strain she experienced. As a way of relieving the tiredness and strain she

experienced, she brought up the option of taking a vacation, to alleviate the burden of caregiving and maintain her well-being and health:

Nilüfer: ‘‘What I needed, or as I said, I’m tired now, maybe we’re 60 years old because of it. It’s not easy for a 60 year old person to download and remove it alone, I needed some help. Secondly, once a year, I need a month’s vacation. I always need this while taking care of my mother, but I never had that opportunity. I need to be undisclosed. For my mother, for me. If we go like this, I’ll be choked, instead of my mother, I’ll get sick.’’

On the one hand, Kardelen explained that in addition to the responsibilities of caring for her relative with Alzheimer’s, there are responsibilities brought by the role of grandmother. Thereby, she could experience role engulfment and burdensome, rooted in constantly trying to perform these tasks alone and these may cause her to feel suffocated and try to distract herself from compelling the part of her experience in order to preserve her inner peace:

Kardelen: ‘‘Now that there is a baby in the house, of course, I realize that I am really tired now, but still, when it comes to my mother, she is my red line. I don’t have any um or uff about her. I don’t feel any discomfort yet. I’m just tired.’’

4.2.3. Away from the outside world

All participants drastically emphasized that they had perceived feelings of isolation and talked about their sense of ‘‘being away from the outside world’’ due to spending much more time at home while adhering to ‘‘stay-at-home’’ orders. This feeling of isolation was experienced in different ways by this eight female caregivers of individuals with AD. As one of the participant, Buket shared, the way people relate with each other was starting to change after social distancing protocols due to the COVID-19 pandemic. She declared that people were ‘‘withdrawing’’ to themselves, or in other words, they embarked on living a more individual and separate life. Moreover, she underlined with the resentment she feels for this relational deprivation, the lack of

close and affectionate relationships and manifested her deep longing for this kind of relations she was accustomed to before the pandemic:

Researcher: "What has changed in your life in general with the pandemic? How did these changes affect your caregiving process?"

Buket: "What has changed in our lives? Either we shut ourselves up... I'm saying that the worst thing that this pandemic has done to us is that we learned that we can live alone. You know, we don't need anyone else, look, we can live alone. For example, I love communicating with people, I love being together. But what happened now? We're off, you're afraid of everyone. You don't know who has what, or my son works at the hospital, I'm afraid of myself sometimes. What if I have it, what if I take it?"

According to Yasemin, the way she relate with others underwent significantly alteration with the pandemic and expressed ever- increasing depressive feelings and sadness due to lack of connectedness and physical closeness.

Yasemin: "Our social life has definitely changed. We couldn't see anyone, our friends, I couldn't see any of my relatives, I couldn't see my friend. We got depressed at home, we were always at home. You know, our social life was over, we were always at home in winter, cook all the time, wash the dishes, even they tired us."

In the similar vein, Nilüfer mentioned that she experienced a forced loneliness against her will because of social distancing obligations in the onset of COVID-19 and that she could not enjoy her life in this way. She depicted her perception of intensified sense of isolation with this epic analogy:

Nilüfer: "You can't go anywhere. It kind of pushed me into such loneliness that loneliness is not for me at all... Of course, it seemed to me that I was cut off from society, as if life became a weed, I was leading an emotionless life. So what can I tell you, life is not just about eating and drinking. In other words, it gives meaning to human life by experiencing beauty, culture, good and bad."

Defne explained her sense of relational deprivation with cutting off from her relatives and family members. In fact, she expressed the dramatic changes in the way of interaction she could rely on from others and represented her feeling of social alienation, especially in the first time of COVID-19 pandemic.

Defne: "Our communication with people was a little less. Contact has been reduced. Everyone had preferred our house to breathe, since we live in many villages than in our house. Our relatives, nephews, cousins... It was a little bit zero, even for a long time."

Unlike feeling lonely in her daily life, participants also stated that they expressed not receiving tangible social support due to people's fear about infecting with coronavirus and the pandemic restrictions if they have a need for the care of their loved ones with AD or they personally felt requisition for receiving social support during their caregiving process. To illustrate, Lale talked about her feelings of loneliness and relational deprivation were deepened and she was state of being in great psychological strain during her father's stay in the hospital.

Lale: "Maybe it should be said that the people here also closed as they said that if we had came to the hospital, we would have been covid. I got very lonely when I went there. It turned out that "We couldn't come to the hospital to avoid getting covid, we can't support you." Those parts were really hard."

4.3. Turning crisis into opportunity

When the early days of the pandemic were over, all participants mentioned that they could jointly achieve get through and overcome hardship due to COVID-19. It was demonstrated that participants were able to counterbalance challenging situations and negative emotions mentioned in former themes, while making a great effort to balance between negative outcomes of pandemic to positive experiences in the caregiving context. So, this theme included the caregivers' ability of resilience and how they could make "turning crisis into opportunity". Ultimately, three shared notions

regarding resilience were described and they were named as: a) Adapting to constant changes, b) It's a learning period, and c) Vitality of social support.

4.3.1. Adapting to constant changes

Participants mentioned that they used many coping strategies to cope with the feeling of strain and stress while giving care to their loved ones with AD during the COVID-19 period, and reconstruct their daily routines according to ever-changing context of pandemic. When physical intimacy and socialization could not be achieved, coping skills would be an attempt to get through the feeling of suffocation and distress.

If possible, using distracting methods such as sharing with a relative or friend about their experiences, or watching TV to get out of the feeling of difficulty, may indicate the caregiver's ability to cope with difficulties, as seen in this example.

Buket: "Since we can't interact with people, that pressure is a big weight on us. You can't breathe like this. You can't breathe. Dilara's mother is sitting with her [laughing]. Here's what I do, I give myself to television, books. I'm knitting a little bit, that's it."

Sometimes, using coping skills and dealing with hobbies may not replace the emptiness and lack created by not being able to meet other people. Still, doing simple habits and engaging in the loved things can help bounce back from crises, as one of the participant, Nilüfer said:

Nilüfer: "What should I do, you're always in the house, but here's what I could do in this period, I love music so much, I fell into music again, I listen to music to get rid of it, but of course it never replaces a friend."

On the other hand, during the pandemic period, caregivers were able to use their sense of humor as a coping skill to cope with difficult emotions such as boredom and burnout while performing their caregiving duties in the house. Thanks to making jokes and finding a way to enjoy, it was possible for caregivers to feel much more

comfortable and enjoyable during the caregiving process and the caregiving experience could become a fun and positive experience for them. For example, Defne stated that getting support from someone while giving care and having fun together while giving care can reduce the burden of caregiving and make it easier to cope with stress. Moreover, having a positive perspective on caregiving and seeing it as an enjoyable experience may also make it easier to cope with unpleasant feelings and negative situations, even in the midst of COVID-19 crisis:

Defne: "We are people who can amuse ourselves while looking at my father. My brother and I have such a relationship. You know, we look at my father like that, both lovingly and having fun. We do not have such big problems."

On the other hand, caregivers said that they were able to deal with caregiver stress by spending more time with their hobbies that they did not have the opportunity to do in the time left after caregiving responsibilities even before pandemic outbreak. Therefore, they could adapt more successfully to the difficulties they experienced with the life events and rapid changes since COVID-19 pandemics began, and felt much better.

Lale: "I had a lot of fun, so let alone caregiving, being with my father, specializing in my care, I had time to wrap my caregiving with things that will reduce stress. He was so amazing, especially before this hospitalization, I did incredible gardening. I grew innumerable flowers."

Along with the mandatory isolation applied during the COVID-19 pandemic, people who received care were able to spend time with various pursuits, apart from the hobbies and coping methods acquired by the caregivers. Thus, thanks to the hobbies and leisure activities that the care recipients acquired during this period, the short intervals that the caregivers needed to get away from the caregiving role were formed and they were able to use these breaks efficiently to breathe and rest. In addition, they were able to control their strenuous situation and feel much more comfortable.

Yonca: "I will say gardening, the most obvious subject that makes my life easier is the gardening. The greenery of my garden because these older people were very involved with the soil, the moment they see the nature and the soil, his mood changes. She is very happy, she is scratching for hours, cleaning, so she is doing it with great love. It also gave me some serious time, it created moments of breathing. Such an environment has been one of the greatest conveniences for me."

4.3.2. It's a learning period

Most of participants stated that their belief in their own abilities to achieve a particular goal, in other words, their self-efficacy, increased as they overcome the difficulties they faced during the COVID-19 process by finding coping ways and were able to get things done. They said that when they encountered difficulties in the process, they learned to cope with those difficulties by experiencing and learning from their experiences. Lale emphasized that even though she had to struggle with challenging situations with COVID-19, she said that spending more time with her father and being able to learn what to do with her during the care process made her feel as if she had achieved a final goal. Then, she emphasized that she feels very lucky and grateful while being capable of managing problems regarding her father's health.

Lale: "It's as if I had time to acquire the technical equipment that would enable me to put the brakes on my ultimate goal from the very beginning, that is, to be able to save this process even for a day. I was able to work, so I was able to work my father. Let alone studying, I had the chance to learn how a patient reacts to this disease, by observing and standing next to you. You know, people learned how to make bread in covid, they became pasta makers, I became a nurse."

She also stated that learning to cope with the difficult experiences she had during the pandemic and the strengthening of her own self-efficacy perception gave her motivation and strength to fulfill her meeting the care duties and other life tasks during the caregiving process.

Lale: ‘‘In other words, I was also proud that I was able to maintain within the conditions. This gives you strength and gives you the chance to carry it even further.’’

In the similar vein, another participant Nilüfer provided exemplars of her great effort for her mother with AD as much as she can and the more her belief about being successful when performing a caregiving task got stronger, the more she feel inner power to continue without giving up despite any hardships.

Nilüfer: ‘‘In the pandemic, I have listened to psychologists a lot before, I listen to it on the internet, so I follow a lot of how these patients should be treated. They say don't give up. Love and attention. It was as valuable to them as medicine. As I said right now, he has no reaction, but even raising a hand makes me very hopeful and happy. It's like I'm getting paid for my hard work. That's why we continue.’’

Yonca, one of the participants, implied that she felt inadequate and self-doubtful in fulfilling her care duties, especially when she was left alone with her mother living with AD due to the restrictions in the early stages of the pandemic. However, as mentioned earlier, the fact that the caregiver could provide care alone, albeit being obliged, may have resulted in enhanced self-efficacy beliefs and handling of caregiving related issues more easily.

Yonca: ‘‘There were processes in which I received support in my caregiving process, from the family circle, if necessary, from relatives. These processes are completely over, especially in the first periods of the pandemic, everything was left to me, but when it comes to the end, they say that it will be done. When you accept it, you become able to do anything about this subject. You make it routine and it happens, so it takes time, of course, we were looking at both housework and taking care of the mother, it was 4 o'clock. All the workload is on you, but you know, you can do it when you have to.’’

4.3.3. Vitality of social support

All eight participants had a great emphasis on the strong need of social support in the COVID-19 pandemic. A great majority of them pointed out the importance of receiving assistance from other people while trying to cope with the intensive care and stress required by the care recipient. As an example, Burçak reported that the existence and availability of social support from her brothers helped her to overcome hardship and feel comfort.

Burçak: "My right arm who helped me is my brother. I have 2 brothers, both of them are pharmacists. If one could not come, the other would come; if one could not come, the other would come. So I didn't have any trouble. Well, let me say mashallah, as I said, thank goodness that we were always at home, so I did not have any difficulties in its care. You know, no one from outside comes to take care of my mother, I take care of it. That's why I didn't feel strained, but I have right arms, I have brothers."

Nilüfer, a participant who felt that she could not receive this social support, stated that she felt alone and having diminished energy in caregiving. It was learned that when she could not get required social support, she tried to continue with the sense of exhaustion and more suffering.

Nilüfer: "During the pandemic process, I needed a helper especially for the last year because my back got a little sick because I was constantly taking care of it. I still need it, I even tried to get someone at one time. The person I bought came twice, after that he got corona so we canceled it. I needed help physically."

Apart from the situations in which caregivers expressed frustrations about lacking of social support, Defne stated that being able to talk transparently about her feelings and experiences with her relatives and the unconditional interest shown to her felt being in "like a therapy", which made her feel supported and gave a huge motivation to better manage difficult emotions and stressful situations.

Defne: "They help me, at least morally. I don't feel alone, I don't feel tired. They somehow come to me. Where I can't get out of the job, someone in the house is holding the end of a job. So that's how I get help."

Due to their relatives being at home while complying with covid restrictions, Kardelen expressed a sense of belonging and togetherness with her family members. Additionally, emotional closeness and support gives her strength, and the social support she can receive from her loved ones play a critical role in feeling less burdensome and have a buffering impact on serious disturbance.

Kardelen: "I was already at home as much as possible, taking care of my patient. My time out was very limited anyway. Therefore, it didn't bother me much when it was Covid, but I can say that it was good for everyone to be at home. I did not feel alone, I did not feel alone with my relative who take care."

Chapter 5

Discussion and Conclusion

The COVID-19 pandemic has extraordinarily changed people's lives in many ways since the day it started (WHO, 2020). In particular, especially those who care for the elderly and vulnerable groups faced with unknowns and a lot of difficulties (Borges-Machado et al., 2020; Brown et al., 2020). In the literature, it has been emphasized that caregivers have a higher risk of experiencing psychological problems such as burden, anxiety and depression during this time (Altieri & Santangelo, 2021; Li et al., 2021; Pongan et al., 2021). However, as before the pandemic, the experience of each caregiver is unique, and along with the pandemic outbreak, caregivers have gone through a multi-layered and sophisticated process while giving care to their loved ones living with Alzheimer's disease. For this reason, it is important to understand considering the versatility and richness of their caregiving experiences, especially in unprecedented times as COVID-19 .

The goal of this study is to understand the experiences of family caregivers of individuals with Alzheimer's disease during COVID-19 pandemic at a broader level with scrutinizing the potential impact of coronavirus outbreak on caregiving process of AD caregivers. Also, it aims at contributing to the literature in this area by attempting to inquire both the idiosyncratic and shared nature of all participants' experiences related to giving care to AD relatives in unprecented times of COVID-19. In the current study, the experiences of family relatives who take responsibility for giving care to indiviuals living with AD was investigated through the Interpretative Phenomenological Analysis (IPA), which enables to gain deeper insight and more multifaceted accounts regarding the spesific phenomenon. For this reason, participants were asked to some open-ended questions, in which they can express themselves freely, regarding the impact of the pandemic on the caregiving process, the changes in caregiving process since the pandemic began, and their needs while giving care during COVID-19.

In the subsequent section, findings will be discussed in view of existing literature. After that; conclusions, recommendations and clinical implications will be demonstrated in this part.

5.1. Discussion of Findings

In line with the rich answers given, three main themes that reflect common experiences were appeared: I. Forced proximity; II. Riding through the waves of emotions; and III. Turning crisis into opportunity. Apart from main themes, ten superordinate themes, defined as I. a. Providing intensive care, I. b. Psychological closeness, I. c. Need for respite, I. d. Overprotection, II. a. Living in fears, II. b. Under the burden of caregiving, II. c. Away from the outside world, III. a. Adapting to constant changes, III. b. It's a learning period, and III. c. Vitality of social support, were considered as indicating the processes of eight female family caregivers they went through while giving care during the COVID-19 pandemic. In general, participants implied that the whole caregiving experience became more manageable and getting usual after struggling with quite challenging experiences and limitations at the onset of COVID-19. First of all, the contributions of the results to the literature and potential limitations will be discussed by comparing the main and superordinate themes with the results of previous studies. In the final part, some recommendations for upcoming research will be argued.

Similar with the existing studies, it was indicated that caregivers have been severely impacted by the mandatory restrictions during COVID-19 period (Altieri and Santangelo, 2020; Bergman and Wagner, 2021; Cohen et al., 2020). One of these effects is, as aforementioned, family caregivers devoted much more additional time for the caring (Bergman and Wagner, 2020; Greenberg et al., 2020; Lloyd, 2020) and thus, they began to give more intense care for their loved ones due to quarantine and restrictions of COVID-19 (Greenberg et al., 2020). According to the findings of the UK survey studies in 2020, 33 to 70 percent of caregivers reported that they started to provide extra care for their relatives much more than before the pandemic (Lloyd, 2020; CarersUK, 2020). Statistics of CarersUK survey studies revealed that caregivers gave quantitatively more care to care recipients because they provided approximately ten more hours of care than the total hours of care given before the pandemic in UK (CarersUK, 2020). Along similar lines with the previous research, participants needed to perform additional caregiving because of many reasons, such as inability to find formal care providers (Bergman and Wagner, 2020), cancellations or delay of hospital

appointments (Calabrò et al., 2020; Xiang et al., 2020), restrictions about reaching local services or unwillingness to go hospitals due to the fear and perceived high risk of infecting with coronavirus (Giebel et al., 2020). Furthermore, elderly people, especially those who aged 60 years and older were recommended that they should stay at home and limit their face-to-face communication. Participants stated that due to providing intensive care, they initially went through the process of understanding what kind of situation they are facing with the person received care and then, they began to identify the needs and things to do, adapted to the change in order brought by the COVID-19 restrictions and gained a skill set in caregiving in addition to the increasing burden of caregiving, as indicated in earlier investigations (Bergman and Wagner, 2020).

Unlike the findings to the previous research which emphasized feeling elevated burden and having tensions in their relationships between care recipient and themselves (Alzheimer's Society, 2020), it was pointed out in this study that caregivers also developed increased feeling of emotional closeness and intimacy with their loved ones with AD amid the COVID-19 pandemic. When the dynamics of the relationships of caregivers/care recipients living with dementia are examined, studies revealed the radical shift in their relations because of losing the mutual sharings, intimacy or beneficence, which can be defined this term as “relational deprivation” (Alzheimer's Society, 2020; Betts Adams et al., 2008). As dementia progressing, caregivers are likely to feel that they lost the warmth and closeness they have with the person they care for and express high level of distress and tension because of these losses (Adams, 2006; Markut & Crane, 2005).

Contrary to the extant literature, it can be said based on this current study that the COVID-19 process has some positive reflections on the relationship between the care recipient and those who give care for a loved one, in terms of providing the opportunity to spend more time and share with AD relatives despite the social distance. It might be said that this might bring about a unique opportunity for reparation in their relationships and compensation for the lost time they couldn't spend together before COVID-19 pandemic since participants declared their increased time at home and they were able to engage in pleasant and entertaining activities with their relatives with the adaptation process of COVID-19 crisis. However, studies revealed that in addition to the multiple losses of dementia caregivers in the progression of the disease, many

people were subjected to the losses in their lives, for instance, loss of relations with others, loss of social support, or loss of enjoyment (Serafini et al., 2020; Tam et al., 2021; Zhai & Du, 2020). Also, while trying to be obliged social distancing, people can simultaneously feel emotional distance among others together with physical distance, and as a negative consequence of it, closed relationships with their relatives started to breaking up (Chakraborty and Maity, 2020; Serafini et al., 2020; Tam et al., 2021; Zhai & Du, 2020). Although the negative impacts and deteriorated aspects of the caregiver/care recipient relationship have been widely investigated, there is still a paucity of literature regarding potential upsides of COVID-19 restrictions on the relationship between care takers and their relatives with AD. Thus, the multifaceted aspect of the changing relationships between family carers of AD individuals and care recipients might be thoroughly investigated in the light of this study.

Being demonstrated in numerous studies related to the caregivers of people living with AD, one of the most highlighted aspects about participants' caregiving experience during the COVID-19 period was their urgent need to respite and get rest. As aforementioned, participants expressed their difficulties in bearing the burden of providing constant care or caregiver overload, with pertinent to the staying at home and providing care much longer times. Research findings demonstrated that caregivers of people living with AD experienced extreme physical and/or mental fatigue as a result of taking constant care (CarersUK, 2020). According to the previous studies, as caregivers continue with their caregiving responsibilities without a rest period, they can be more likely to have a poorer physical and mental health (Masoud et al., 2022; Wagner, 2020). In fact, there was an important issue that stood out in the participants' narrative about need for respite in this study, mentioned as longing to away from their caregiver responsibilities. People who care for relatives with Alzheimer's try to fulfill wide-ranging tasks under their caregiver role, such as supporting for self-care tasks (i.e. bathing, eating, walking), constantly checking patients' behaviors, managing the pills and doctor appointments, protecting care recipients from dangerous situations, and so on, and they often have to provide 24/7 care. Aneshensel et al. (1995) argued that there are two main experiences regarding directly to the caregiving role, categorized as role captivity and role overload (Aneshensel et al., 1995). Although role captivity reflects the unwillingness of engaging in the caregiving role apart from its difficulties or stress, the feeling of emotional overwhelm due to the demands of

caregiving tasks mainly refers to role overload. Furthermore, caregivers who feel role captivity have a tendency to think that their duty of care is mandatory and unavoidable (Aneshensel et al., 1995; Liu et al., 2019). Similarly, all participants of this study, although they all experience different intensities and unique ways, they found the role of caregiving quite demanding or obligatory, concurrent with giving round-the-clock care at home, which can be result from the covid restrictions and lockdown. In addition, they inevitably feel entrapped to their caregiver role when they find themselves alone with the caregiver inside the home without providing any support from others. Thus, it was indicated that fulfill the need to breathe is highly crucial for the continuation of caregiver's daily life and caregiving duties.

People aged 60 and over, especially those who already have a chronic illness, are more likely to experience the COVID-19 more severely. Particularly, those in the vulnerable groups, such as people having dementia or Alzheimer's disease, the possibility of this process being serious and even fatal, if they contracted with coronavirus (Brown et al., 2020). In order to protect the health of people over aged 60, along with most of the individuals with AD in this group, confinement order and some additional restrictions were implemented at the beginning of COVID-19 crisis, but these have left their place over time to voluntary protective measures, as an example, using masks or being careful for social distance, to preclude transmission of the virus among individuals (Chu et al., 2020; Lebrasseur et al., 2021). Studies revealed that carers who give care for a loved one with AD constantly tried to keep their relatives safe against coronavirus and feeling elevated level of alertness. Besides, caregivers tried to carry out their care responsibilities and duties without adequate help from others or on their own (Massoud et al., 2020; Phillips et al., 2020; Vaitheswaran et al., 2020). Findings of this study on protecting care recipient confirmed the preliminary early findings and participants feel a great responsibility to eliminate all possible risks pertaining to transmission of COVID-19 to their relatives with AD. They shared internal attributions to prioritize their relatives' health conditions and needs over theirs.

In this study, female caregiver participants often emphasized that they felt a great sense of responsibility about providing care for their family relatives living with AD. Likewise, people in Eastern countries, such as Turkey, are prone to give more importance to needs and goals of the group which they feel belonged than their own personal needs (Ar & Karancı, 2019; Pan et al., 2022). With regard to filial piety,

individuals feel a necessity to accomplish giving help to older generations, represent their respect to them (Ar & Karancı, 2019; Mahoney et al., 2005), offer a self-sacrificing of their personal needs for their relative's sake (Ar & Karancı, 2019; Gallagher- Thompson et al., 2000). Based on these cultural understandings, women generally have a shared feelings of responsibility regarded to caregiving (Ar & Karancı, 2019; Ho et al., 2003; Lai, 2010). Therefore, it is highly crucial to examine the possible relations of beliefs regarding filial piety and caregivers' feelings of increased responsibility in the context of this culture and then, provide in-depth knowledge regarding the apprehension of caring responsibility.

Another issue to be considered along with cultural values is the relationship between gender roles and experiences in the care process. Generally, women are more commonly identified with adjectives such as "mother, daughter, or wife" and therefore associate themselves with more nurturing and sensuality-related qualities (Gonyea et al., 2008). Likewise, while the participants talked about their protective behaviors towards their parents living with AD, they were talking about making great effort to protect them with sensitivity just "like a baby". Furthermore, Wilson et al. (2003) mentioned the contradictory feelings of adult female carers who take responsibility to give care for their mothers: need of independence and need for interdependence. Therefore, women's trying to carry the responsibility of caring and filial piety together can make them feel great trouble and guilt (Gonyea et al., 2008; Wilson et al., 2003). Participants' protective behaviors and sense of responsibility felt by the female caregivers, may also be related to the qualities they associate with "being a woman". To comprehensively understand the dynamics of participants' feelings of responsibility and giving priority to their relatives whom they cared for, the potential impacts of cultural factors and shared beliefs might be included.

Even though caregivers of AD individuals talked about their mixed feelings throughout the COVID-19 period; there were three prominent emotions; fear, strain, and feelings of isolation, which were covered in this study. Unlike the results of this study, it was revealed that caregivers can experience mental health problems amid of COVID-19. In addition to these findings, previous studies indicated that giving care for a loved one with AD is associated with the wide range of psychological disturbances like anxiety, depression, stress, and other feelings like worry, rage, isolation, despondency or trauma-related emotions, in particular, at the beginning of

COVID-19 outbreak (Dinç & Erdoğan, 2020; Russell et al., 2022). The caregiver's mental health is negatively affected in the long term during the care giving process (Keles & Özalevli, 2018; Yılmaz & Turan, 2007). Consisted with the literature, participants were asked "Did you feel the need to receive psychological support with the coronavirus (COVID-19) pandemic?" along with the demographic information of the participants, yet no mental health problems that could meet the DSM criteria or seriously affect their daily lives were reported by the participants in the current study. However, additional research can be conducted for in-depth examination pertinent to the impact of COVID-19 outbreak on the mental health of AD caregivers.

Among all participants, fear of getting coronavirus and fear for their relatives' infection with COVID-19 became prominent during the pandemic. Akin to this study, prior literature demonstrated the scope of caregivers' fears including transmission of coronavirus to oneself or their loved ones with AD (Quadros et al., 2021; Schimmenti et al., 2020; Masoud et al., 2022). In particular, caregivers said that their biggest fear is not being able to fulfill their caregiving duties if they are infected with coronavirus (CarersUK, 2020). However, little is known concerning whether they have fears related to matters other than the covid situation. Thus, further studies can be conducted to investigate diverse sense of fear belonging to caregivers of people with AD.

Emotional strain is another important emotion discussed by the participants who have a responsibility to provide care for their relatives with AD. It has been indicated that the roots of emotional strain or the burden of caregiving was stemmed from experiencing higher level of isolation feeling or difficulty in supplying the health needs of care takers, and this cause increase in caregiving burden and a significant decline in physical and psychological health. Other studies correspondingly revealed that most of caregivers reported their concerns about being able to afford cost of caregiving or meet the expence of care personnel (CarersUK, 2020; Masoud et al., 2022). Yet, there is still little kowledge about another contributing factors of caregivers' sense of burden. (Pearlin et al., 1990). Commensurate with the emotional strain and caregiver burden, Pearlin et al. proposed that caregivers of AD individuals suffer from strain and troublesome because of some reasons: availability of social support, informations about the living context i.e. (family conflict), and other influential life events, personal factors, etc. (Judge et al., 2010; Gaugler et al., 2000). In fact, there is another possible condition that was not mentioned here but may be

important and participants of this study was also pointed out: poor prognosis of Alzheimer's disease of those who received care for their family relatives during the COVID-19 pandemic. Notably, several studies demonstrated that COVID-19 obliged restrictions could result in negative impacts on dementia patients' also neuropsychiatric symptoms (i.e. stress, anxiety) and sense of loneliness due to the COVID-19 was found as a mediator of these factors (Manca et al., 2020). Furthermore, it was supposed that burden of the caregiving role can be elevated if the prognosis of care recipient with AD gets worse, together with the potential influence of the relationship between caregiver and care recipient (Mohamed et al., 2010; Conde-Sala et al., 2010). Similar with earlier studies, participants of this study stated that they could not meet their AD relatives' need of social support due to the implementation of the restrictions and social distance rules at the first time of COVID-19, or they could only meet with others very limitedly. As a result, they thought that care recipients' Alzheimer's disease might have progressed a little because of these. Even though the participants did not mention an emotional strain they experienced due to this progression, it may have shed light on future studies to investigate the effect of the disease stage or progression of the person with Alzheimer's on the caregiver strain.

One of the most prominent emotions during the caregiving process during the COVID-19 pandemic was sense of isolation. According to the former literature, the longer the caregiving process, the greater the likelihood of caregivers' well-being (Dinç & Erdoğan, 2020) and they are likely to suffer from mental health conditions like stress, anxiety, isolation and so on (Dinç & Erdoğan, 2020). By comparing the results from preliminary studies, having a strong sense of isolation and feeling "being away from the outside world" was declared by all participants. Moreover, they perceived lack of intimate and close relations and also deprived of receiving social support for both themselves and their relatives with AD, which triggers depressive feelings and loneliness in the COVID-19 pandemic. Whereas, according to preliminary studies conducted before the COVID-19 outbreak, family caregivers of AD individuals often feel isolated from others. Individuals who take care for their relatives living with AD frequently expressed that they cannot receive social support and maintain connectedness with others. Furthermore, they are likely to deny their desire to spend their time for fun, they have limited time for their relatives or need to leave their job. It is stated that or those who feel more contentment in their relations are likely to have

less psychological problems (Brodaty and Donkin, 2009; Leong et al., 2001). Since family caregivers of AD already felt isolated before COVID-19, sense of isolation during post-covid care may be a continuation of the pre-existing emotion or an increase with covid restrictions. In order to understand comprehensively, more detailed research can be done in future studies on how caregivers feel themselves lonely during COVID-19 pandemic.

As time has passed, it has become obscure that participants in this study began to be more resistant towards adversities coming from the COVID-19 period and express more resilience (Gamble et al., 2022). In general, the term ‘resilience’ reflects the ability of adopting positive attitudes towards any difficulties or potential threats, having flexible perspective across life events and emotional strength (Masten, 2001; Dias et al., 2015). Also, it describes the unique ability to restore oneself after the traumatic phenomenon has occurred. Thanks to the ability of resilience, it can be possible to alleviate the severity of striking impacts of any changes and hardships related to caregiving and make a future plan even if exposing to traumatic events (Bonanno, 2004).

Seligman and Csikszentmihalyi (2000) mentioned that the mainstream of positive psychology has mainly focused on the positive characteristics of human beings, in other words, making emphasis on the strength, optimism, fulfillment and also, the virtue of having resilience. By implementing some positive psychology practices, including resilience, it has been seen that people's well-being is strengthened and peace is preserved, and it can provide a very important resource, especially in times of crisis that are both individually and socially damaging and compelling, such as COVID-19 (Seligman & Csikszentmihalyi, 2000).

When the pandemic started, a novel virus entered our lives and order of the life we are accustomed to was completely changed. Also, it became a serious threat, especially for those with chronic diseases and then, family caregivers had to face with many uncertainties and challenges. They experience high level of fear and struggle with a lot of limitations, such as lack of intimate relationship and social restrictions (Fajardo et al., 2021). As time progresses and we continue to live in ever-changing conditions, family carers were able to build resilience and it was shown that resilience provides a protection against depression, and as resilience increases, the probability of being depressed was increased (Altieri & Santangelo, 2021; Masoud et al., 2022).

Conversely, while people have a sense of increasingly overwhelmed or worried about COVID-19 confinement, they might experienced diminished resilience and perceived decreased capacity to give care for their relatives with compared to the pre-pandemic period. Additionally, the higher level of negative emotions, such as guilt, fear, tiredness, withdrawal might result in the rise of trauma-related stress responses (Sánchez-Teruel, 2020). One of the important findings of this study was to reveal that the participants developed their own unique ways about how they could cope with the troubles and changes they experienced over time and how they mightkeep their well-being in balance. The participants stated that they developed many different coping methods such as gardening, recreation, walking, spending time with a friend, and when they did these activities, they enjoyed life more and felt less stressed. Further, it was indicated in previous study that socio-demographic determinants and psychological factors play an important role in predicting the well-being during the COVID-19 outbreak (Sánchez-Teruel, 2020). To sum, the resilience and coping skills could be highly crutial for understanding the affect of these on well-being and psychological health of caregivers in the COVID-19 pandemic.

As some participants declared that, their self-appraisal about capability to accomplish provided adriving force of doing their caregiving tasks successfully and gave a motivation to overcome any impediments with the pandemic. In the former studies, it was revealed that a sense of resilience or self-efficacy are robustly associated with each other. Giving reference the social-cognitive theory of Bandura, self efficacy was defined as the one's perception about his/her competence for organizing and regulating a particular performance (Schunk, 1995). Importantly, self-efficacy which has been mentioned as having a strong relationship with resilience. According to Kunzler et al. (2018), people having higher level of self-efficacy are prone to have lessen negative thoughts, and it enables to stimulate enhancement in their positive emotions and also strenghten their mental health (Kunzler et al., 2018). Furthermore, it offers a function of resilience while encountering many difficulties. In the similar direction, more than half of the participants believed their capability to complete a spesific duty, especially their caregiving duties. Further, they perceived that they can successfully deal with various problems arising in the COVID-19 pandemic. They also said that learned to cope with those difficulties by learning from their caregiving experiences.

One of the most prominent needs of all participants was receiving social support while providing care, especially during this COVID-19 crisis and its restrictions. To inspect in detail, participants identified their social support needs in two ways: the need for professional care staff and their personal need for socialization and understanding from others. They strongly emphasized that the factor that both helps them and facilitates their caregiving duties during the COVID-19 was social support. They mentioned that they needed relaxation and breathing spaces by getting social support from others and sharing their responsibilities with other people. On the contrary, some participants stated that when care recipient's Alzheimer's disease progressed during this pandemic, they had experienced stressful moments because they have insufficient knowledge about caring for people in further stages, and lack of social support from anyone outside home, which would result in feeling lonely, isolated, depressed or insufficient. In general, social support is described as a fundamental component in human life as it enhances both resilience and well-being (Sánchez-Teruel et al., 2022). All these results suggest that well-being and enhancing the variables associated with it (resilience, social support and self-efficacy) may have a protective effect on the psychological state of caregivers in the COVID-19 pandemic situation.

Lastly, the most prominent need among the things that participants most, was to be 'understood by others'. Importantly, participants often emphasized how important being understood of their needs related to breathe and rest, share their feelings with and talk to others, receive support while giving care, regardless of before and after the COVID-19 pandemic. In the similar vein, previous research revealed that the great importance of the carers' needs about obtaining tangible and/or intangible support from their relatives. Moreover, family caregivers have a strong need to talk someone about their emotions, and more importantly, be understood by someone (Bressan et al., 2020; Tatangelo et al., 2018; Wawrziczny et al., 2017). The need of family carers of AD to be heard and understood by caregivers should be taken seriously and should not be ignored, especially in a stressful time, such as COVID-19 outbreak.

5.2. Recommendations for Future Studies

Using a qualitative analysis method, such as IPA, that explores detailed and personalized meanings about family carers of Alzheimer's disease experiences, it was

able to provide a comprehensive understanding of participants' experiences caring for relatives with Alzheimer's during the COVID-19 pandemic. However, since the number of participants is limited to as few as eight, generalizability of findings on the experiences of family carers who give care for AD individuals issues may arise. Contribution to the field can be made with quantitative analysis in future studies.

In this study, all participants were eight female adult daughters since there were inadequate number of male volunteering to participate in this study. In this way, more comprehensive apprehension about female adult caregivers who give care to one of their parents were able to obtain and gender impact of the caregiving experiences during COVID-19 could be eliminated. Preserving the common gender characteristics of the participants, the shared notions of caregiving experiences of female caregivers during the COVID-19 process were tried to be addressed. Even so, in terms of the generalizability of the results, what the male caregivers went through while caring for their relatives with Alzheimer's during the Covid process should be subjected in future studies.

Differences in the characteristics of the place where the participants live may be another limitation of the study because some participants live in the city center while others live in the village, and accordingly, the participants expressed certain differences in terms of some habits and experiences. For example, participants living in villages stated that, unlike those in cities, they were able to maintain their social relations and intimacy more comfortably in gardens and open spaces, especially during COVID restrictions. In future studies, the effect of the context of the participants on their caregiving experiences during the COVID-19 process can be discussed in more detail.

The positive experiences mentioned by the participants, for instance beliefs about their self-efficacy, more intimate relationship with care recipient, or having more spare time to caring only themselves may be a pioneer for further studies to contribute in this field, rather than focusing only on the negative outcomes of COVID-19 outbreak for the family carers of Alzheimer's disease.

Finally, with this study, it is better understood that while caregivers already had pre-pandemic needs, various additional needs may have been emerged in addition to existing needs since they entered the covid process. It can also be recommended to carry out in-depth studies on what family carers of AD individuals need, especially in

a very stressful period such as COVID-19 and to develop further implications according to these needs.

5.3 Implications

Firstly, family carers of individuals living with Alzheimer's disease might have paucity of knowledge regarding what is needed for implementing caregiving tasks in this COVID-19 crisis, and it was demonstrated by studies that caregivers can feel strained, despair, anxious, or depressed (Langa et al., 2001; Pinquart & Sörensen, 2007). In order to alleviate their psychological strain and strengthen their well-being, some therapeutic interventions may be done for family carers of AD individuals. To illustrate, Cognitive Behavioral Therapy and other therapy techniques such as mindfulness and/or self compassionate strategies, would be used to deal with psychological strain, depression or anxiety during COVID-19 crisis (Schulz & Sherwood, 2008).

In addition, it can be supposed that family relatives who give care for a loved one might be supported to participate online psychosocial groups during COVID-19. Especially in confinement and lockdown period, people would be able to join these groups and even in this times after vaccinations and other limited restrictions, they can gain great benefits. Research findings showed that online psychosocial groups might enable individuals, who give care for their relatives with AD, learning vital skills or develop and strengthen their coping strategies (Dinç & Erdoğan, 2021; Taşdemir et al., 2009). In addition, the importance of social support on protecting the well-being of caregivers in the COVID-19 outbreak came to the fore in this study. Along with the great accessibility and its convenience, internet-based support groups can be taken into consideration of clinicians to improve their well-being and reducing the level of depression or burden of family caregivers. Indeed, the main goal of this psychosocial support groups is to lessen the feeling of isolation and enhance having a sense of belongingness (Holmes et al., 2020). Therefore, clinicians can take into consideration managing psychosocial support groups which can be one of the effective tools for family carers of AD to get benefit for psychological well-being.

How each individual is affected by the COVID-19 pandemic and how he/she goes through the time varies a lot from person to person, and a wide variety of

experiences might be seen. This is also true for those who care for a loved one with Alzheimer's disease, and some of them experienced a number of negative emotions intensely during this outbreak and had difficulty in maintaining normal daily routines of our lives. In order to overcome the hardships of COVID-19 pandemic much more comfortably and to maintain their well-being, it may be recommended to encourage them to learn and use coping strategies in their life to deal with their caregiver stress and depressive feelings (Monteiro et al., 2018). It has been shown in many studies that while some people try to protect and strengthen their well-being by using coping strategies. Therefore, people might choose any kind of coping strategies to overcome stressful situations (Kazemi et al., 2021).

5.4 Conclusion

The aim of this study is to investigate in detail how individuals who care for their loved ones with Alzheimer's disease experience during the covid pandemic, but this study is not a fully comprehensive study of the multiple aspects of caregiving experience. Alternatively, the primary goal of this study was to provide an in-depth understanding related to giving care for people with Alzheimer's during the covid pandemic. With this study, several aspects had come to the fore that could reflect what it is like to care for people with Alzheimer's during the COVID-19 process. For instance, specific experiences such as how they react emotionally, including feelings of shock and anxiety, to changes and uncertainties in their lives at the beginning of the COVID-19 pandemic, and then their increasing fears about the health of their loved ones and making extra efforts to protect them have been noticed. In addition, processes such as how their relationships with others and the people they care for have changed during the covid process. Their feeling of isolation from the outside world had also increased in the length of staying at home, and thus, the increasing need for social support and the heavier the burden of care were emerged. Finally, as the pandemic progresses and most restrictions disappear, an adaptive process has begun for caregivers that evolves in a more positive direction.

At the onset of the coronavirus, caregivers, along with everyone, gained knowledge about the fact that that people more than 60 and older with chronic diseases were increased at risk for suffering much more severe symptoms and, even facing with

death. Therefore, they began to experience such worries and fears about future very intensely: “What if something bad, such as infected with coronavirus, happen to the person I care for? What if coronavirus caught him/her? What if he/she dies?” Even when caregivers thought about the possibility of transmitting coronavirus to the person with AD, who they have cared for, they found themselves grappling with feelings of guilt. Based on their feelings of fear, anxiety and guilt, they wanted to keep their loved ones safe by engaging in more protective behaviors, such as not to let their AD relatives out and then they felt safe and have a clear conscience.

Especially in the first two years of the pandemic period, people, and also caregivers, were heavily exposed to stay-at-home advice and home confinement policy in order to reduce COVID-19 infections. Thus, the life of caregivers was reduced to their home and they had to stay away from their social life and work environment, if they work. This may have left them feeling trapped and helpless, as well as having a sense of isolation and lonely. however, the characteristics of the context in which they live affect the feelings they feel during the caregiving process in case of confinement. For example, while caregivers living in the village have more access to meeting and socializing with each other in open spaces and gardens, for caregivers in the city, may feel more isolated and deprived of social life, because the opportunity for face-to-face socialization in open spaces is more limited. So, they shared the belief that the social support they could receive was diminishing.

caregiving burden after COVID-19 restrictions.

It has been observed the potential negative effect of limited accessing of social support may have a negative effect on the caregiver burden, because caregivers both experienced frustration because of not being able to receive professional or informal support while giving care to their AD relatives. Also, they were not being able to be taken away from their caregiving role and to meet socialization needs, albeit to a limited extent before the pandemic. Caregivers shared common feelings related to the caregiver burden were fatigue and strain. Furthermore, the most important needs that emerged when caregivers had difficulty in carrying this caregiver burden were to get away from the role of caregiver and to meet their need to breathe and have a rest. It has been said that caregiver burden and depressive feelings increase as they cannot find the opportunity to rest and take time for themselves.

With the continuation of the pandemic process, caregivers gradually started getting used to “new normal” and adapted hardships they lived in covid crisis, which lead to resist and them more effectively. Moreover, they begin to discover their unique coping skills and realize their inner power to continue despite facing difficulties over time. Thus, the experience of caregiving during the covid process has started to become a less challenging and more enjoyable for them.

To consider overall, it has been seen that there are two apparent needs that come to the fore when caring for individuals with Alzheimer's in the covid pandemic: "need of social support" and "developing resilience". In addition to these needs, we see that caring during the COVID-19 process includes not only negative but also positive situations such as feeling intimacy and togetherness with the care recipient, increasing self-efficacy belief and spending time on the hobbies she wants to do. Therefore, the importance of trying to understand the experience of caring for people with Alzheimer's during COVID, not only in black or white, but also in grayness and diversity, has been tried to be emphasized with this study.

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