GRIEVING SCHIZOPHRENIA: IMPACTS AND COPING WITH AMBIGUOUS

LOSS AMONG PARENTS OF ADULTS DIAGNOSED WITH

SCHIZOPHRENIA

GRADUATE SCHOOL OF SOCIAL SCIENCES

TOBB UNIVERSITY OF ECONOMICS AND TECHNOLOGY

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CLINICAL PSYCHOLOGY

MASTER OF SCIENCE

AUGUST 2023

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ABSTRACT

GRIEVING SCHIZOPHRENIA: IMPACTS AND COPING WITH AMBIGUOUS LOSS AMONG PARENTS OF ADULTS DIAGNOSED WITH SCHIZOPHRENIA

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Master of Science, Clinical Psychology

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The aim of this study is to explore in depth how parents who care for their adult child with schizophrenia experience and cope with ambiguous loss, which is seen as one of the caregiver burdens experienced by caregivers. For this purpose, in-depth interviews were conducted with 10 participants, all members of the schizophrenia solidarity associations in Ankara. The data obtained from the participants with semi-structured interviews were analyzed by reflexive theme analysis, one of the qualitative methodology methods. As a result of the analysis, four superordinate themes were identified: *objective burdens, subjective burdens, family & social burdens* and *coping*. The findings showed that the participants experienced ambiguous loss and grief regarding their children and burdens in different dimensions of their own lives. In this sense, the findings are generally consistent with the relevant literature. The findings related to coping revealed the importance of functional coping strategies used by parents caring for their children in coping with ambiguous loss. The results are discussed and clinical implications and directions for future research are provided.

Keywords: Schizophrenia, Caregiver Burden, Ambiguous Loss, Grief, Coping

ÖZ

ŞİZOFRENİ TANISI OLAN YETİŞKİNLERİN EBEVEYNLERİNDE BELİRSİZ
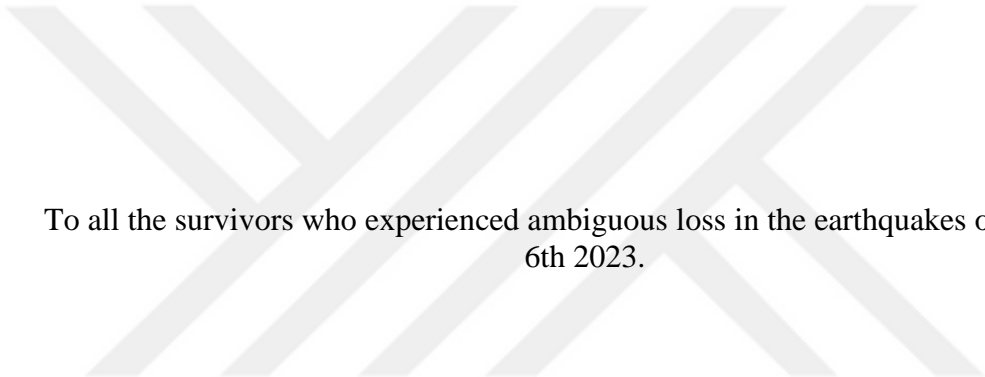KAYIP SÜREÇLERİ, ETKİLERİ VE BAŞA ÇIKMA YOLLARI

KADİROĞLU, İrem

Yüksek Lisans, Klinik Psikoloji

Tez Danışmanı: Prof. Dr. A. Nuray KARANCI

Bu çalışmanın amacı, şizofreni hastası yetişkin çocuğuna bakım veren ebeveynlerin, yaşadığı bakım verme yüklerinden biri olarak görülen belirsiz kaybı nasıl deneyimlediklerini ve bununla nasıl başa çıktıklarını derinlemesine araştırmaktır. Bu amaçla, Ankara'daki şizofreni dayanışma dernekleri aracılığıyla 10 katılımcı ile derinlemesine görüşmeler gerçekleştirilmiştir. Katılımcılarla yapılan yarı yapılandırılmış görüşmelerle elde edilen veriler, nitel metodoloji yöntemlerinden biri olan refleksif tema analizi ile analiz edilmiştir. Analiz sonucunda dört üst tema belirlenmiştir*: nesnel yükler, öznel yükler, aile ve sosyal yaşama ilişkin yükler ve başa çıkma.* Bulgular, katılımcıların çocuklarına ve kendi yaşamlarının farklı boyutlarına ilişkin belirsiz kayıp ve yas duygularını yaşadıklarını göstermiştir. Bu anlamda bulgular genel olarak ilgili literatürle tutarlıdır. Başa çıkma ile ilgili bulgular ise, çocuklarına bakım veren ebeveynlerin belirsiz kayıpla başa çıkmada kullandıkları işlevsel başa çıkma stratejilerinin önemini ortaya koymuştur.

Anahtar Kelimeler: Şizofreni, Bakım Veren Yükü, Belirsiz Kayıp, Yas, Başa Çıkma

To all the survivors who experienced ambiguous loss in the earthquakes of February 6th 2023.

ACKNOWLEDGEMENTS

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CHAPTER I

INTRODUCTION

This study aims to understand the burdens faced by parents caring for their children with schizophrenia, the ambiguous processes of loss, and how families cope with all these challenges. For this purpose, in-depth interviews were conducted with 8 mothers and 2 fathers who care for their children diagnosed with schizophrenia through Schizophrenia Solidarity Associations in Ankara.

In order to better understand the challenges faced by families, it seems important to first understand the definition, epidemiology and etiology of schizophrenia. Therefore, under the heading of theoretical background, the definition, epidemiology and etiology of schizophrenia will be examined first. Afterwards, the findings obtained from the literature on caregiver burdens of schizophrenia will be presented. The sense of loss is seen as one of the burdens experienced by families. Within the scope of this research, the sense of loss will be discussed from the perspective of ambiguous loss theory. Ambiguous loss can bring with it frozen grief, but this grief experienced by families may not be recognized by the society since there is no physical loss. This concept will be examined under the title of disenfranchised grief. Finally, the aims of the research will be presented at the end of the theoretical background chapter.

CHAPTER II

THEORETICAL BACKGROUND

2.1. Definition of Schizophrenia

Schizophrenia is a chronic mental illness that affects an individual's thoughts, emotions, functioning, perception of the world, and quality of life (Eack & Newhill, 2007; NICE, 2014). Despite its low prevalence in society, schizophrenia ranks 9th among illnesses causing life years lost in Turkey (Ministry of Health, 2009). According to the diagnostic criteria in DSM-5, schizophrenia is defined by the following criteria (American Psychiatric Association, 2013, pp. 99-100):

"A. Characteristics: Two or more of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated). At least one of these must be (1), (2), or (3):

1. Delusions

2. Hallucinations

3. Disorganised speech

4. Grossly disorganised or catatonic behaviour

5. Negative symptoms (i.e., diminished emotional expression or avolition)

B. Social/occupational dysfunction: For a significant portion of the time since the onset of the disturbance, level of functioning in one or more major areas, such as work, interpersonal relations, or self-care, is markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, there is failure to achieve expected level of interpersonal, academic or occupational functioning).

C. Duration: Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meets Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or by two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. Ruling out of other disorders: schizoaffective disorder and depressive or bipolar disorder with psychotic features have been ruled out because either.

1) no depressive or manic episodes have occurred concurrently with the active-phase symptoms, or

2) if mood episodes have occurred during active-phase symptoms, they have been present for a minority of the total duration of the active and residual periods of the illness.

E. Attributes: The disturbance is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition.

F. History: If there is a history of autism spectrum disorder or a communication disorder of childhood onset, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations, in addition to the other required symptoms of schizophrenia, are also present for at least a month (or less if successfully treated)."

The symptoms of schizophrenia can be divided into positive and negative symptoms. Positive symptoms include hallucinations, delusions and disorganized speech that people experience. Conversely, negative symptoms encompass diminished aspects seen in individuals with schizophrenia, such as lack of motivation, social withdrawal, and difficulties in expressing emotions (Buchanan & Carpenter, 1997). These symptoms significantly hinder functionality and disrupt various cognitive processes, including attention, memory, and executive functioning (Gold & Green, 2005). Consequently, as it can seen as Figure 2.1. individuals diagnosed with schizophrenia face difficulties in maintaining employment or academic pursuits, establishing interpersonal relationships, and achieving independence in their lives.

Figure 2.1. Effects of Schizophrenia (Maguire, 2002)

Positive Symptoms
Delusions
Hallucinations
Disorganized speech
Catatonia

Negative Symptoms
Affective flattening
Alogia
Avolition
Anhedonia
Social withdrawal

Social/Occupational Dysfunction
Work
Interpersonal relationships
Self-care

Cognitive Deficits
Attention
Memory
Executive functions
(e.g., abstraction)

Comorbid Substance Abuse

Mood Symptoms
Depression
Hopelessness
Suicidality
Anxiety
Agitation
Hostility

In the next section, literature findings on the epidemiology and etiology of schizophrenia will be presented.

2.2. Epidemiology of Schizophrenia

According to data from the World Health Organization, on average, 24 million people worldwide are affected by schizophrenia; one in every 222 adults has schizophrenia. In other words, according to the World Health Organization, the prevalence of schizophrenia is calculated as 0.45%. (World Health Organization, 2022). However, in a recent review conducted in Turkey, the lifetime prevalence of schizophrenia was found to be 8.9 per 1000 individuals (Binbay et al., 2011). The accepted prevalence rate in the general population is 1% according to the literature (Lauriello et.al., 2005; St. Clair & Lang, 2021). There is no significant difference in the incidence between men and women (Maguire, 2002; Karakuş et al., 2017). The age of onset of the illness is observed to be around 15-25 years for men and 25-35 years for women (Maguire, 2002). There are studies indicating a higher prevalence of schizophrenia in developing countries compared to developed countries (Jablensky et al., 1992). However, since general causality cannot be established, it would be more appropriate to focus on risk factors instead of these studies. The next section will discuss the risk factors and etiology of schizophrenia.

2.3. Etiology of Schizophrenia

When exploring etiological investigations in the scholarly literature, it becomes evident that the factors contributing to the onset of schizophrenia are extensively discussed within the framework of nature and nurture. The prevailing consensus emphasizes the interplay between genetic predisposition (nature) and environmental influences (nurture). Similar to other human experiences, the development of schizophrenia is shaped by specific biological predispositions, alongside

psychological and social factors. Therefore, it is appropriate to adopt the biopsychosocial model when examining the origins of schizophrenia (Shean, 2009). However, it is important to acknowledge the uniqueness of each individual's experience, as some people with a diagnosis of schizophrenia may be more influenced by biological predispositions, while others may be more susceptible to psychological or social risk factors. In essence, the etiology of schizophrenia emerges from the intricate interplay of nature and nurture, with varying combinations of risks manifesting in different individuals. The subsequent section will provide a comprehensive analysis of the biological and environmental causes of schizophrenia.

2.3.a. Biological Factors (Nature)

2.3.a.i. Genetics

Scholarly investigations have provided evidence suggesting a hereditary component in the etiology of schizophrenia. However, it would be inaccurate to assert that genetic transmission alone determines its occurrence. Notably, twin studies have been instrumental in illuminating this matter. For instance, research involving monochorionic (MZ) twins, who share a more extensive intrauterine environment during pregnancy, has shown a 60% concordance rate for schizophrenia development, whereas this rate drops to 11% for dichorionic (DZ) twins (Davis et al., 1995). Thus, even within MZ twin pairs, these findings support the involvement of environmental factors in schizophrenia development. Such evidence suggests that genes act as code providers for protein synthesis rather than sole determinants of experiences. It is plausible that a gene responsible for producing a specific protein may exhibit hypo- or hyperactivity in an individual, and the production of this

protein can vary under different environmental circumstances (Cooke & British Psychological Society, Division Of Clinical Psychology, 2017). In summary, while genetic transmission can present a substantial risk factor for certain individuals, it operates within an interactive network of risk factors that collectively contribute to the manifestation of the schizophrenia phenomenon.

2.3.a.ii. Neurochemical Theories

The manifestation of psychotic symptoms resulting from the alteration of neurotransmitter activation levels suggests the potential involvement of neurotransmitters in the development of schizophrenia (Brown & Lau, 2016). Although the brain contains numerous neurotransmitters, dopamine, serotonin, and glutamate are recognized as playing a more prominent role in the etiology of schizophrenia (Cooke & British Psychological Society, Division of Clinical Psychology, 2017). These three neurotransmitters hold significance as they are fundamental components targeted by antipsychotic medications used in the treatment of schizophrenia. However, limited evidence exists concerning the neurochemistry of psychotic experiences, preventing the establishment of a causal relationship between neurochemical factors and schizophrenia. When discussing neurochemical theories, it is essential to acknowledge the potential impact of environmental and other biological factors (Cooke & British Psychological Society, Division of Clinical Psychology, 2017).

2.3.a.iii. Brain Structure and Function

Certain studies comparing individuals with a schizophrenia diagnosis to those without have identified potential structural disparities in the brain (Shenton et al., 2010). Notably, variations in gray matter volume have been observed between these two groups. Additionally, functional differences in specific brain regions, characterized by decreased or increased neural activity, have been reported (Kubicki et al., 2007). Comparisons of brain images taken before and after the diagnosis of schizophrenia have revealed alterations in the size of structures like the hippocampus and amygdala (Keshavan et al., 2002). However, these findings are subject to multiple interpretations (Cooke & British Psychological Society, Division of Clinical Psychology, 2017). Firstly, it should be acknowledged that there is significant overlap in brain structures and functioning among individuals with different disorders and those diagnosed with schizophrenia. Thus, solely relying on brain imaging is insufficient to determine the presence of psychosis. Secondly, comparing individuals with and without a diagnosis of schizophrenia poses challenges due to issues related to diagnostic criteria and the diagnostic process itself. Considering psychotic disorders as a spectrum, it becomes apparent that comparing diagnosed and undiagnosed groups may not yield conclusive outcomes. Furthermore, long-term use of antipsychotic medication by diagnosed individuals introduces complexities, as it can lead to certain brain changes, such as overall brain shrinkage (Moncrieff & Leo, 2010). Lastly, it is established that trauma and stress can contribute to brain differences (Read & Bentall, 2012). Therefore, similar to other biological risk factors, environmental factors can also influence brain structure and function.

<u>2.3.b. Environmental Factors (Nurture)</u>

<u>2.3.b.i. Prenatal Environmental Factors</u>

Prenatal factors thought to play an active role in the etiology of schizophrenia can be categorized under three headings. Firstly, there are studies investigating the likelihood of developing schizophrenia in individuals born to mothers who experienced infections during pregnancy (Brown & Lau, 2016). Particularly, it has been observed that the risk of developing schizophrenia may increase in children born during the winter and spring months when infections are prevalent (Brown & Derkits, 2010). Davies et al., (2003) reported that individuals with schizophrenia have a 5-8% higher occurrence of being born in the winter and spring compared to the general population.

Secondly, there are studies indicating that inadequate nutrition, particularly during early stages of pregnancy, can lead to serious disorders such as schizophrenia and schizoid personality disorder (Hoek et al., 1998). Furthermore, research has shown that low levels of Vitamin A, D, B12, B6, and iron in mothers are associated with an increased risk of developing schizophrenia in their offspring (Brown & Lau, 2016). The mother's dietary patterns can affect gene expression and the baby's brain development. Once again, the significance of the interaction between biological and environmental factors is evident in this context.

Lastly, when examining the literature, it is evident that advanced paternal age is a factor that increases the risk of schizophrenia (Ek et al., 2015; Malaspina et al., 2001). However, there is no clear data regarding the influence of maternal age (St Clair & Lang, 2021).

2.3.b.ii. Postnatal Environmental Factors

There are some postnatal environmental factors thought to increase the risk of developing schizophrenia. First one is cannabis use. There are numerous studies examining the relationship between cannabis use and psychosis and schizophrenia. Di Forti et al. (2019) proposed that daily marijuana use increases the risk of developing psychosis by five times. Although the extent to which cannabis use alone poses a risk for psychosis is not clear (St Clair & Lang, 2021), it can be considered an important modifiable environmental factor.

Secondly, when examining the literature in the field, findings suggesting a relationship between migration status and the risk of developing schizophrenia can be found (Cantor-Grae, 2013; Tarricone et al., 2016). These findings indicate that individuals from rural areas who migrate to developed cities and belong to lower socioeconomic levels are predisposed to developing schizophrenia from the first or second generation onwards. The common risk factor identified in all of these studies can be interpreted as the stress resulting from decreasing social status (St Clair & Lang, 2021).

Thirdly, birthplace and residence are one of the postnatal environmental factors. When comparing the risk of developing schizophrenia between individuals who grew up in rural areas and those living in urban environments, it is observed that individuals who were born and raised in urban areas have a higher risk (Brown & Lau, 2016). When examining the reasons behind this, it is thought that the social inequality and stress created by urban living may play a role (Selten et al., 2016). However, a meta-analysis conducted by Vassos et al. (2012) suggested that there is no relationship between exposure to urban living and the risk of developing

schizophrenia. Instead, they proposed that factors such as family stress, infections, inadequate nutrition, pollution, and social inequality determine the level of risk.

Fourthly, research has focused on the effects of socioeconomic status on the risk of developing schizophrenia. There are two hypotheses regarding the perspective that low socioeconomic status constitutes a risk factor for schizophrenia. The first hypothesis suggests that individuals with low socioeconomic status who grow up in disadvantaged conditions from birth (such as inadequate nutrition, exposure to pollution, exposure to social inequality, and the environment in which the child is raised) are at risk of developing schizophrenia and psychosis. The second hypothesis argues that individuals diagnosed with schizophrenia experience a decline in their functionality after diagnosis, resulting in a transition from higher to lower social statuses (Dohrenwend et al., 1992). According to the findings of a study examining the relationship between social difficulties and schizophrenia conducted by Wicks et al. (2010), individuals with four indicators of low social status (those who grew up in rented housing, those who grew up in single-parent households, those who grew up in households experiencing unemployment, and those who grew up in households receiving social assistance) had a 2.7 times higher risk of developing schizophrenia compared to those who did not experience these social indicators. Considering the prenatal factors and biological risk factors discussed in the previous section, it appears that socioeconomic status may be a factor that increases the likelihood of developing schizophrenia. However, further research in this field is needed.

Lastly, early childhood traumas emerge as one of the most frequently studied risk factors in the field of schizophrenia. Examples of these early traumas include physical, sexual, and emotional abuse, as well as parental loss. While these traumas

specifically increase the risk of schizophrenia, they also influence the development of trauma-related psychotic symptoms (Bebbington et al., 2011).

2.4. Treatment of Schizophrenia

2.4.a. Antipsychotics

Antipsychotic medications are used specifically in the treatment of schizophrenia to reduce positive symptoms (such as hearing non-existent voices). Especially during acute episodes, the use of antipsychotic medications helps decrease the intensity of the patient's experiences and makes them more manageable (Cooke & British Psychological Society. Division Of Clinical Psychology, 2017). However, in addition to reducing symptoms, antipsychotic drugs also have side effects such as diabetes, cataracts, weight gain, sleep problems and sexual disorders (Üçok & Gaebel, 2008). More recently developed psychotics, called second generation or atypical, seem to be more successful in reducing side effects (Üçok & Gaebel, 2008). While medication treatment was once considered the cornerstone of schizophrenia treatment, conflicting results have emerged in recent years. Freeman & Garety (2006), in their meta-analysis suggested that the overall effectiveness of antipsychotic medications, which are claimed to particularly prevent relapses in schizophrenia, may have been overestimated, with only about 20% of patients experiencing significant improvement or prevention of relapse. Other studies indicate that atypical antipsychotics, which have become popular in recent years and promise to reduce adverse effects, reduce hospitalization rates (Lafeuille et al., 2014) and reduce the risk of relapse (Tiihonen et al., 2017). It should be noted that, like psychotherapies, individuals can have different experiences with medication use.

Professionals working in this field should meticulously work on reducing potential unwanted side effects, finding the right medication and dosage for everyone.

2.4.b. Psychotherapy as a treatment of Schizophrenia

Psychotherapy provides individuals with the opportunity to work on their life experiences in a calm, non-judgmental, and supportive environment. Talking about and exploring the experiences of individuals with psychotic experiences, including schizophrenia patients, and establishing a relationship with a psychotherapist can be healing. Cognitive Behavioral Therapy (CBT) is among the most researched therapy approaches for the treatment of schizophrenia in the literature. Studies and meta-analyses have shown that patients benefit from CBT as much as they benefit from psychiatric medication treatment (Cooke & British Psychological Society. Division Of Clinical Psychology, 2017). Additionally, the NICE Guideline for Psychosis and Schizophrenia (2015) recommends cognitive behavioral therapy for psychosis (CBTp) that includes at least 16 sessions. Furthermore, trauma-focused therapies, psychodynamic therapies, Acceptance and Commitment Therapy (ACT) and mindfulness, narrative and systemic therapies, Cognitive Adaptation Training, Assertive Community Treatment, and voice dialoguing can be listed as therapeutic approaches that have been found beneficial in the treatment of schizophrenia (Cooke & British Psychological Society. Division Of Clinical Psychology, 2017; *Treatments | Society of Clinical Psychology*, n.d.).

2.5. Burdens of Schizophrenia

Schizophrenia is a mental disorder that carries a significant burden for the individual with the illness and their immediate surroundings. When considering the direct burden, it is evident that schizophrenia, being a condition requiring ongoing chronic treatment, poses a financial burden on both individuals and the society (Millier et al., 2014). Indirect burdens encompass the challenges faced not only by individuals with the illness but also by their caregivers, relatives, friends, and other social circles. A review study conducted by Millier et al. (2014) identified twelve themes that can be categorized under the humanistic burden of schizophrenia. Some of these themes include quality of life, depression, treatment side effects, burden on the family, homelessness, cognitive and social dysfunction, and stigmatization. These themes are interconnected. For example, a decline in cognitive abilities of the affected individual can lead to unemployment, and unemployment, in turn, can result in homelessness. Since this thesis focuses on the experiences of families of individuals with schizophrenia, the topic of caregiver burden will be addressed in detail in the next section.

2.5.a. Caregiver Burden

The phrase "caregiver burden" is utilized to express the challenges encountered by family members who take care of individuals with mental illness. In the present study, caregivers were the parents of children diagnosed with schizophrenia; therefore, the term family burden was sometimes used instead of caregiver burden. The burden on families encompasses the stress of changing family relationships, emotional reactions to the illness, coping with the individual's changing behaviors,

the restriction of social activities, stigma from society and self-stigma, as well as economic difficulties (Rössler et al., 2005). Hoenig and Hamilton (1966) have distinguished this burden into two dimensions: objective burden and subjective burden (Hoenig & Hamilton, 1966). Objective burden refers to the practical challenges encountered in family relationships, as well as the constraints on social, work, and leisure activities. For instance, the financial difficulties that families face due to caregiving responsibilities can be one of the objective burdens. On the other hand, subjective burden encompasses the psychological processes experienced individually by family members (Magliano et al., 2005). An example of subjective burden can be seen in a mother caring for a child with schizophrenia who experiences feelings of helplessness, depression, and anxiety.

"Mental illness is, by its very nature, a familial experience" (Kinsella et al., 1996, p. 24). The term "family" refers to a group of individuals who are emotionally and socially connected and engage in regular interactions with each other (*APA Dictionary of Psychology*, 2023). In the case of individuals with schizophrenia, their primary caregivers are usually their family members. Approximately 41% of individuals with schizophrenia live with their parents (Jungbauer et al., 2004), 12% receive care from their siblings, and 7% receive care from their partners (Millier et al., 2014). A similar trend can be seen in Turkey, where most individuals diagnosed with schizophrenia reside with their families (Bastug & Karanci, 2015; Karanci & İnandılar, 2002).

A survey conducted by the National Alliance on Mental Illness in the United States among caregivers of individuals diagnosed with schizophrenia revealed noteworthy findings. The results indicated that 41% of caregivers had been providing care for over a decade, with 19% of them dedicating more than 40 hours per week to

caregiving responsibilities. A significant proportion of caregivers, approximately 55%, encountered difficulties in finding time to attend to their own healthcare needs. Moreover, a substantial 90% of caregivers expressed concerns regarding the future well-being of their child or loved one diagnosed with schizophrenia (*2008 / NAMI: National Alliance on Mental Illness*, 2008) Studies conducted with samples from Turkey show that families living in Turkey also bear a high burden of caregiving (Attepe Özden & Tuncay, 2018; Durmaz & Okanlı, 2014).

In the following sections under this heading, the effects of gender, ethnicity and symptoms on the caregiver, the consequences of caregiver burden and the concept of expressed emotions, which are considered important to address in family burden, will be emphasized.

2.5.b. Effects of Gender, Ethnicity and Symptoms on Caregiver Burden

Studying the impact of sociodemographic predictors and the effect of symptoms on the caregiver burden is important for understanding the dynamics of this burden. Studies focusing on the gender of caregivers show that the majority of the caregiving burden falls on women (mothers, sisters, or wives) (Scazufca & Kuipers, 1996; Yusuf & Nuhu, 2009). An analysis conducted on 697 caregivers by the US Community Survey reported that female caregivers constituted 82% of the total sample, and 90% of these women were mothers of the care recipients (as cited in Awad & Voruganti, 2008). The same survey also indicated that 70% of caregivers were aged 60 or above.

When examining the conducted studies, it is observed that cultural factors influence both the perceived caregiver burden and the attitudes of family members towards the care recipient (Awad & Voruganti, 2008). For example, it is known that

white caregivers experience greater family burden compared to African Americans and exhibit more rejecting attitudes towards the care recipient (Rosenfarb et al., 2006). However, it is noted in the literature that more detailed longitudinal studies are needed regarding culture and family burden (Awad & Voruganti, 2008).

Another important factor affecting the family burden is the nature of the symptoms experienced by the care recipient. Different findings exist in the literature on this subject. Some studies indicate that negative symptoms such as social and emotional withdrawal observed in schizophrenia increases the family burden (Dyck et al., 1999), while other studies state that positive symptoms such as hallucinations and delusions contribute more to the family burden (Wolthaus et al., 2002, Magliano & Fiorillo, 2007). Despite the varying results, it is commonly accepted that as the symptomatology of the family member with schizophrenia increases, the perceived family burden also increases (Awad & Voruganti, 2008).

In conclusion, when the literature is examined, it is seen that some sociodemographic variables such as gender, ethnic background and the symptomatology of the ill person affect the factors affecting caregiver burden. Therefore, it will be important to consider these factors when discussing family burden.

2.5.c. Consequences of Family Burden

After the diagnosis of schizophrenia, the family journey undergoes significant changes (Teschinsky, 2000). In most cases of schizophrenia, parents are required to provide 24-hour care for their child. The responsibilities of the caregiving parent, such as the inability to have personal time, monitoring the medication regimen of

their child, maintaining meal schedules, and overseeing the individual's self-care, can lead to caregiver burnout (Millier et al., 2014). Research has revealed that parents who serve as caregivers for individuals diagnosed with schizophrenia are affected physically, psychologically, emotionally, and economically by this illness (Rafiyah, 2011). At the same time, families experience a change in the dimension of social relations.

This section will focus on the consequences of caregiver burden in the dimensions of physical, financial, psychological, emotional and social relationships. When the literature is examined, it is seen that these outcomes are related to each other in different ways. The common emotion in the changes experienced in physical, financial, psychological, emotional and social aspects, which are also investigated in this thesis, is the feeling of loss. Therefore, the feeling of loss will be discussed in a broader and more detailed manner in the following chapters.

Based on data from a study comparing randomly selected participants living with people with mental illness and those not living with someone with mental illness using data from the National Health Interview Survey, it was reported that living with someone with a mental illness was associated with poorer physical health compared to the control group (Gallagher & Mechanic, 1996). In addition to this finding, considering that the onset of schizophrenia occurs in young adulthood, it can be said that caregivers, especially parents, are disadvantaged in terms of physical health due to their advanced age.

Factors such as the chronic course of schizophrenia, early onset, the need for hospital treatment, and a high rate of disability are predictors of the financial burden on the family (Rössler et al., 2005). Furthermore, in cases requiring intensive care for individuals with schizophrenia, family members may have to reduce their working

hours or quit their jobs altogether (Millier et al., 2014), which can be considered as one of the reasons that increase the financial burden experienced by families.

While it is possible to quantify and express elements such as basic needs expenses, healthcare expenses, and time loss, it is difficult to numerically represent the psychological and emotional losses experienced by families (Awad & Voruganti, 2008). The feelings that caregivers experience while providing care for the care recipient, such as pain, distress, stigma, loss of life role, and loss of their child, are highly unique. According to the results of a survey conducted with families and individuals with schizophrenia aimed at identifying the negative effects of schizophrenia, individuals ranked the negative effects of the illness as follows: reduced family activities, increased conflicts within the family, family members exhibiting depressive symptoms, family members feeling ashamed of the care recipient, economic difficulties, postponement or cancellation of plans, decreased self-esteem of family members, decline in work and school performance of family members, increased alcohol consumption, and family breakdown due to divorce (Awad &Wallace, 1999). The distress caused by these life experiences has a negative impact on the psychological well-being of families (Gupta et al., 2015). In parallel, numerous studies demonstrated that caregiving for individuals with schizophrenia is psychologically and emotionally demanding (Magliano et al., 2005). Parents have the belief that as their children grow up, caregiving responsibilities will lessen and over time, their children will take care of them. In addition to the emotional investment in raising their children, parents also have expectations that develop towards their children. Many parents have dreams that their children will complete their education, have a successful marriage, have children of their own, and find a good job. However, when a chronic mental illness diagnosis is received, these expectations and

hopes may be damaged or lost (Williams-Wengerd & Solheim, 2021). The challenges of long-term caregiving and the loss of expectations can increase the psychological strain experienced by families.

Another significant aspect of family burden for current study is changes in social relationships. As mentioned earlier, caregivers' time is largely occupied by attending to the needs of the affected individual, which can disrupt their social interactions outside the family (Millier et al., 2014). A study comparing the burden experienced by caregivers of individuals with schizophrenia to those caring for individuals with long-term physical diseases found that caregivers of individuals with schizophrenia had significantly weaker social networks compared to the other group. Seventeen percent of relatives of patients with schizophrenia reported difficulties in inviting people to their homes. Furthermore, in the same study, it was reported that as social interaction decreased within the caregiver group of individuals with schizophrenia, the burden on the family increased (Magliano et al., 2005). When considering the relationship between reduced family burden and the provision of professional support and social support to the family (Magliano et al., 2002), the importance of these supports becomes evident. Therefore, it is recommended to involve the family in the treatment process and support them in coping with the illness, which is why professionals working in this field are advised to do so (Rössler et al., 2005).

When examining social support, it is evident from the literature that the greatest barrier to receiving support is stigma. Negative attitudes towards patients with schizophrenia are widespread in the society. These negative attitudes, accompanied by negative media portrayals, create a perception in the society that individuals with schizophrenia are dangerous (Angermeyer & Matschinger, 2003).

Negative attitudes and the stigma associated with the illness leads to social isolation, unemployment, homelessness, substance use, and other consequences for individuals and their families. At this point, a vicious cycle is formed, as individuals are stigmatized, they are exposed to challenging life experiences, and as a result of these experiences, they become even more stigmatized (Rössler et al., 2005). Research indicates that stigma contributes to an increase in the symptoms of individuals (Ertugrul & Ugur, 2004) and is a factor that lowers their quality of life (Sibitz et al., 2011). High levels of social stigma can lead to internalized stigma of the individual which is an internalization of the stigmatizing attituedes of the society, like believing "I am dangerous to the society" (Karanci et al., 2019). Internalized stigma can be developed by both the individuals with schizophrenia and their caregiving families. Therefore, combating stigma related to schizophrenia emerges as an important issue (Gumber & Stein, 2013). It is believed that this stigma is even more prevalent in countries like Turkey where accessible information and education about psychiatric disorders are limited (Karanci et al., 2017).

As mentioned above, schizophrenia creates many changes within families. These changes arouse certain emotions in both the caregiver and the person with schizophrenia. The effect of the way these emotions are expressed in the family on the course of the illness is related to the concept of expressed emotions. The next section is devoted to the concept of expressed emotions, which examines the relationship between the emotional climate within the family and the course of the illness.

<u>2.5.d. Expressed Emotion</u>

The concept of expressed emotion is defined as a qualitative measure of emotions expressed within the family. However, these expressed emotions are also believed to play a significant role in the relapse of positive symptoms (Kavanagh, 1992). Expressed emotion is classified as low expressed emotion or high expressed emotion based on the scores obtained from assessment tools administered to families. In follow-up studies, the concepts of criticism, hostility, and emotional over-involvement, which fall under the category of high expressed emotion, have been identified as factors influencing the relapse rate. The employment status of the patient, the level of cognitive functioning, the knowledge level of the caregiver about schizophrenia, and the number of hospitalizations of the patient have been found to affect criticism and hostility (Bentsen et al., 1998; Boye et al., 1999; as cited in Karanci & İnandılar, 2002). On the other hand, the substance use status of the patient, the level of communication with the family, and being a single parent or a female parent have been found to be associated with emotional over-involvement (Bentsen et al., 1996; Kavanagh, 1992; as cited in Karanci & İnandılar, 2002). The concept of expressed emotions demonstrates that within the family system, an emotional climate is formed through mutual interactions. The attitudes of individuals who are part of this emotional climate can lead to the formation of certain vicious cycles within the family (high levels of expressed emotions may lead to relapse). It is important for professionals to approach the problem from the perspectives of both caregiving parents and patients in order to find solutions to these vicious cycles.

This study focuses on the dynamics related to the burdens of schizophrenia on the family. Under the heading of burdens on the family, the possible predictors of family burden (gender, ethnicity, symptomatology) and the consequences of family

burden on caregivers in the dimensions of physical, financial, psychological, and social relationships are focused. Finally, the current findings in the literature on expressed emotions within the family are presented in this section. As mentioned in the section on the consequences of family burden, families are affected in many ways after their child is diagnosed with schizophrenia. The emotion associated with all of these consequences is the feeling of loss due to mental illness. For this reason, the next section is devoted to the feeling of loss as it is directly related to the research question of the current study.

2.6. Feeling of Loss Related to Mental Illness

As mentioned in the previous section, caring for a child with a mental illness has many financial, social and emotional burdens on families. It is thought that part of this burden is the sense of loss experienced by families (Miller, 1996). Parents of adult children with schizophrenia may experience feelings of loss and grief. However, the impact of a loved one's mental illness on parents and family members, specifically the loss and grief associated with it, has been studied less than other emotional consequences, like depression, anxiety, guilt etc., (Richardson et al., 2012).

According to study, it has been found that family members often feel that they have lost the previous or idealized version of their loved one (Jones, 2004). This psychological loss of a loved one brings with it many other losses. For instance, family members may experience disruptions in their expectations and plans (Ozgul, 2004), may go through a sense of loss in various aspects such as loss of their former child's potentials, loss certainty about the future, loss of parental confidence, loss of financial stability (Richardson et al., 2012) or loss of hopes one had for their children

(Osborne &Coyle, 2002). Understanding this experience can be challenging since the person they love is still physically present but has undergone big changes. This type of loss is referred to as "psychic" (Miller, 1996), "nonfinite" (Bruce & Schultz, 2001), or "ambiguous" loss (Boss, 1999). While these concepts share similarities, this thesis will specifically focus on the Ambiguous Loss theory developed by Pauline Boss (1999). Therefore, in the next section this theory will be discussed in greater detail.

2.7. Ambiguous Loss Theory

Ambiguous loss describes situations where the presence or absence of a loved one cannot be confirmed. The loved one may be physically absent but psychologically still alive; or the loved one may be physically present but psychologically unreachable (Boss & Couden, 2002). This type of loss describes a relational difficulty rather than qualifying as a psychopathology. The loved one is lost with ambiguity due to an environmental factor (such as illness or war). Ambiguous loss is described as inexplicable, confusing, and mysterious (Boss, 2009). Therefore, an ambiguous loss becomes a traumatic experience for those who experience it (Boss, 2009). Boss has developed the theory of ambiguous loss based on the family stress model; therefore, the theory seeks to understand the experiences of family members (parents, children, spouses, siblings) in the face of ambiguous loss. This thesis study also focused on how the mother/father of an adult with schizophrenia experiences this kind of loss.

In losses associated with death, individuals experiencing the loss obtain direct information about the certainty of the loss upon receiving the news of the death. Religious and social rituals following the death help individuals in grief to make

sense of their loss and accept the absence of the deceased. However, in the case ambiguous loss, the loss becomes confusing (Boss, 1999). The ambiguity about the physical or psychological presence of the loved one prevents the process of making sense of the loss. Typically, family members of the deceased are the primary individuals facing this ambiguous loss situation. When family members cannot find clarity regarding the ambiguous loss of the loved one, they may feel paralyzed and unable to act (Boss, 1999). Decision-making can be delayed, family roles can become complex, and relationship boundaries can become ambiguous (Boss & Couden, 2002). To be able to move forward and continue life, the meaning of the uncertainty created by the presence or absence of the loved one needs to be restructured by families (Boss & Couden, 2002).

Boss has stated that ambiguous loss can occur in two types (Boss, 1999). The first type is physical ambiguous loss, where the loved one is physically absent, but there is no definitive information about their presence or absence, leading the individual to continue to exist psychologically. In other words, the loved one has said goodbye without farewell (Boss, 1999). This type of loss occurs in situations where it is unknown whether the loved one is dead or alive, such as disappearance or abduction. Examples of this type of loss include when a person who went to war does not return and the family does not receive any news about their death or when the body of a person is lost in a natural disaster and cannot be found. In such losses, even though the loved one is not physically present, the lack of definite information about their death creates the possibility that they might return one day. Therefore, the loved one can still be psychologically felt as existing by the individuals experiencing the loss (Boss, 1999).

The second type of ambiguous loss is psychological ambiguous loss, where the loved one is physically present but is inaccessible cognitively and psychologically (Boss, 1999). The loved one has said goodbye without physically leaving. Examples of this type of psychological loss include the loved one developing diseases like Alzheimer's, autism, traumatic brain injury, chronic mental illnesses, or being in a coma (Boss, 2009). The type of ambiguous loss that will be addressed in this research is psychological ambiguous loss.

Ambiguous loss is a traumatic experience characterized by pain, incomprehensibility, and immobilization, making coping challenging (Boss, 2009). It shares similarities with traumatic experiences that lead to posttraumatic stress disorder (PTSD); however, unlike PTSD, the experience of ambiguity persists in the present and can last for years or even generations (Boss, 2009). Due to the lack of social visibility of this loss, individuals experiencing ambiguous loss often find themselves isolated which impedes their ability to cope effectively (Boss, 2009).

The timing of closure and when the ambiguity will end remains unknown for those experiencing the loss. In society, there is an expectation for families facing loss to overcome it quickly. The reactions of families to loss are often perceived by society as a failure after a certain period (Boss, 2009). In this regard, Boss (2009) emphasizes the need for clinical interventions that embrace the paradoxical nature of uncertainty, where individuals and families learn to tolerate ambiguity. It is crucial to focus on increasing their tolerance towards uncertainty. Boss also highlights the unique nature of accepting and grieving the loss, emphasizing the prioritization of individual variables such as subjectivity and culture in interventions. Based on her clinical observations and interventions, Boss (2009) proposes the following guidelines for professionals working with ambiguous loss: (a) finding meaning, (b)

tempering mastery, (c) reconstructing identity, (d) normalizing the paradox, (e) revising attachment, and (f) discovering hope.

2.7.a. Psychological Ambigous Loss and Schizophrenia

Psychological ambiguous loss defines a type of loss where the loved one is physically present but not present cognitively and psychologically. The loved one has changed due to an environmental factor (chronic illness, traumatic brain injury, etc.) and has become cognitively unreachable or intermittently reachable. Boss has described this type of loss as "saying goodbye without leaving." (Boss, 1999).

The diagnosis and treatment process of a persistent mental illness like schizophrenia is also filled with various ambiguities. The course of the illness, coping abilities, response to treatment, all these processes are influenced by individual, environmental, and genetic factors (Boss & Couden, 2002). The individual's abilities can also vary from day to day, and they may struggle to perform daily activities they used to do, which leads to a change in their relationship with their social environment. The individual is no longer the same person known by their family. The fact that a person is still physically alive but being 'like a new person' makes it difficult to adapt to this situation (Young et al., 2004). At times, however, the individual may appear functional as they were before the illness (Boss & Couden, 2002). Nevertheless, obtaining definitive information about the progression of the illness can be impossible. In addition to all these, family members who care for the person with schizophrenia also lose their own priorities, independence, and future expectations of their child with schizophrenia (marriage, job, education, having grandchildren) (Wiens & Daniluk, 2017).

The ambiguity brought by these changes are as confusing for the individual and their family as the illness itself (Boss & Couden, 2002). Individuals facing this type of loss find themselves fluctuating between hope and despair, and Boss has likened this experience to a roller-coaster (Boss & Couden, 2002). In parallel with Boss's theory of ambiguous loss, the common themes found in the qualitative research conducted by Wiens and Daniluk (2017) with families with children with schizophrenia are: enduring and pervasive sense of sadness, distress and struggle, fluctuations in their levels of hope, feelings of regret and guilt, ongoing concern about their child's future, concern about the impact of their child's mental illness on their other children, commitment to helping and taking action and personal and relational changes.

Family members facing this ambiguity may experience inertia, helplessness, depression, role confusion, and other situations (Boss & Couden, 2002). Furthermore, the physical presence of the ill person makes it challenging to label the situation as a "loss" for everyone involved, freezing the coping and grieving processes (Boss,1999).

2.7.b. Understaning the Psychological Impacts of Ambigious Loss in terms of Chronic Illnesses

When faced with an ambiguous loss, the greatest challenge lies in how to cope with the ambiguity. As a loved one battles with a chronic illness, their family finds themselves in a conflicting and challenging situation: the person is not here as they used to be, yet they are still present in my life (Boss & Couden, 2002). Changes in their children caused by illness make parents worry about how to support and care for their children (Johansson et al., 2012; Landon et al., 2016; Wiens & Daniluk,

2017). This conflict brings about a state of freezing, which is a normal response to ambiguity. Individuals who experience loss struggle to cope and adapt behaviorally to this ambiguity (Boss & Couden, 2002)

Boss (1999) examined psychological reactions to ambiguity, such as depression, helplessness, anxiety, and relationship conflicts, from the perspective of the family stress model. She explained the formation of these symptoms in five points:

1. Family members experience confusion regarding how to behave, make decisions, and distribute new roles within the family after the illness. This cognitive confusion can be highly challenging. Family members who are unsure about how to cope with this confusion may choose different strategies. For example, they may exclude the ill person from the family and act as if they have already passed away, or they may deny the existence of the illness and interact with the ill person as they did before the illness, ignoring its presence.

2. The ambiguity brought about by the illness hinders the continuation or restructuring of family roles, rules, and rituals. Family members may remain stagnant, waiting for the illness to disappear.

3. The loss experienced by the family is not a result of death but rather an ambiguous and psychological loss. Therefore, the family's loss is not validated by the social environment or even by themselves. Consequently, the family system may become frozen.

4. The ambiguity caused by the illness shakes the core beliefs of even the strongest family members regarding fairness and justice in the world.

5. The duration of such an ambiguous loss is also uncertain. Therefore, caregivers or accompanying family members of the ill person may experience psychological and

physiological exhaustion. The symptoms that arise may be attributed more to fatigue than psychological vulnerability.

As emphasized in the above items, the confusing nature of ambiguous loss is quite challenging for the caregiver family members. Family members trying to cope with the feeling of loss may sometimes experience conflicting emotions (Richardson et al., 2012). For example, while feeling anger towards the sick person, they may also feel guilty and ashamed for being angry (Jones, 2004) or they may experience survivor guilt (Miller, 1996).

2.7.c. Ambiguous Loss and Frozen (Unresolved) Grief

Grief is a process that consists of cognitive, behavioral and emotional reactions of people to loss (Godress et al., 2005). Most of the studies focusing on the grieving process after the loss focus on the reactions to the mourning of a physical loss, that is, the death of a loved one (Kübler-Ross & Kessler, 2005). Young et al. (2004) reported that among the thousands of articles there are only 26 articles focusing on grief and mental illness. However, with the emergence of theories such as the ambiguous loss theory, it has been revealed that the feeling of loss can be experienced not only after real death but also after some relational changes. As mentioned in previous parts, one of the relational changes comes from psychological ambiguous loss. Serious mental illnesses like schizophrenia, autism, Alzheimer can be example for this loss.

According to the results of a recent systematic review study that examined 12 articles published in the field of "serious mental illness" and "grief", families with a child diagnosed with serious mental illness mourn the loss of both their lost expectations regarding their child and the previous states of their child and their

previous relationships (Williams-Wengerd & Solheim, 2021). Despite participants coming from different locations, representing different fields of study, different research designs, these researchers observed that parents generally undergo similar intense grief when faced with the mental illness of their adult child (Williams-Wengerd & Solheim, 2021). These experiences include a sense of losing their expectations for both their child and them, feelings of guilt and uncertainty regarding their losses, and the wide-ranging impacts that a diagnosis of severe mental illness has on family relationships.

Ambiguous loss theory centers on the aspects of loss, such as what is lost, the uncertainty of when the loss will cease, and the impact the loss will have on family roles and relationships (Boss & Carnes, 2012). The literature shows that parents experience significant ambiguity about a variety of issues related to illness, their children, and their future (Darmi et al., 2017; Johansson et al., 2010; Landon et al., 2016; White & Unruh, 2013). What's more, parents grieve the loss of a previous relationship with their child and find it difficult to understand what their child is like because of the changes associated with serious mental illness (Darmi et al., 2017; Johansson et al., 2010) These ambiguous losses increase feelings of grief and make it harder for parents to process their grief, creating increased stress and a kind of "frozen grieving" feeling. This situation is difficult to make sense of and process, as the psychologically lost and grieving person is still here.

There are many religious and social rituals that help make sense of the loss after a physical loss. Certain circumstances, such as a funeral, a death certificate for the disappeared person, facilitate the process of acknowledging and re-meaning the loss. As Freud mentioned in his book "Mourning and Melancholy", a normal grieving process results in the person being able to break their ties with the loved

object and connect with new objects (Freud, 1922). However, in ambiguous loss, the loss is far from clear, it is confusing (Boss, 1999). Unlike grieving after the death of a loved one, in this type of ambiguous loss the person is still physically present. For this reason, people who experience the loss cannot break their ties with the loved object and move on to the process of re-meaning, the mourning process that comes after an uncertain loss is frozen due to the uncertainty of the situation. In particular, people who experience a psychologically uncertain loss may not even be aware that they are experiencing a loss. "Naming exactly what has been lost is in itself difficult but an important task" (Young et al., 2004, p. 189). In order to make sense of and facilitate coping with the confusing situation experienced, it is important to first bring visibility to this type of ambiguous loss. The inability to fully confirm the loss prevents the onset of grief. Moreover, people who have experienced loss are far from getting support from the society on how to cope. Because the ambiguity of the loss is invisible to the society, the experienced loss may not be recognized by the society.

According to a study conducted by Godress et al. (2005), parents whose children were diagnosed with a mental illness experienced intrusive thoughts, avoidance tendencies, challenges in coping, and prolonged grief as a result of their child's condition. Additionally, parents often experience a variety of emotions such as sadness, guilt, blame, and anger (Williams-Wengerd& Solheim, 2021). Prior studies have demonstrated that the sorrow felt by parents of adult children with psychosis is similar to the grief experienced by parents who have lost a loved one to death (Mulligan et al., 2012). However, grief connected to mental illness possesses unique characteristics. Unlike the grief following the death of a loved one, parents of adult children with mental illness tend to encounter higher levels of uncertainty and guilt (Johansson et al., 2010). All these symptoms are seen as normal parts of the

grief process, but the society does not acknowledge this type of grief and its symptoms because there is no physical loss (Worden, 2009). The fact that the grief of the families is not visible or that they do not find a response in the society is one of the factors that increase the difficulty of the process they experience. This phenomenon has been described in the literature as "disenfranchised grief "and will be discussed in detail in the next section.

2.8. Disenfranchised Grief

Grief, although appearing as an individual process, is actually a process with social dimensions as well (Cesur Soysal, 2021). The recognition of the loss by society and the initiation of mourning rituals with the support of the community facilitates the processing of the experienced loss. Therefore, the grieving process cannot be separated from cultural and social characteristics (Cesur Soysal, 2021). Particularly in the Turkish culture, relatives, friends, and neighbors emerge as important sources of social support during the mourning process; grieving individuals find the opportunity to share their feelings and process their loss with the support of their social environment (Cesur Soysal, 2021). However, at this point, the norms of societies regarding grieving appear to be quite significant (Romanoff, 1998). Different types of losses are perceived differently by the society. Factors such as who the lost person was, how they were lost, and how the grieving should be experienced influence the support that individuals involved in the mourning process will receive (Cesur Soysal, 2021).

Compared to losses resulting from death, ambiguous losses are more perplexing, intangible, and invisible. As a result, society may not recognize the loss of individuals in mourning. For example, a family whose child has been diagnosed

with a chronic mental illness may not have their loss acknowledged, their pain may be underestimated, or they may lack support. These individuals, whose grieving rights have been taken away, experience invisible losses that are not socially validated. They find themselves in a state of uncertainty, where both the loss itself and the grieving process are ambiguous and difficult to make sense of. This phenomenon has been defined by Doka (1989) as "disenfranchised grief." Disenfranchised grief refers to "the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported" (Doka, 1999, p. 37). Individuals experiencing disenfranchised grief may be deprived of expressing their emotions, receiving support, and understanding (Cesur Soysal, 2021). The person who has experienced the loss may also deprive themselves of the grieving process, which is known as self-disenfranchisement. They may suppress their own grieving reactions and fail to recognize their right to grieve. Undoubtedly, this situation cannot be considered independent of the individual's social environment. Disenfranchised grief is, in fact, a result of the social environment's failure to establish an empathetic relationship with the bereaved individual (Neimeyer, 2002). Individuals in such a social environment may not believe that it is valid or justified to experience their own grief. Consequently, they may avoid seeking social support due to feelings of shame and guilt (Attig, 2004). In such a situation, the grieving process following an already ambiguous loss becomes frozen and unsupported by society, making it difficult to be processed. In addition, the stigma attached to mental disorders makes things even more difficult for families. They often feel shame and therefore avoid seeking social support or help (Jones, 2004).

Doka (1989) in his initial study categorized disenfranchised grief into three categories, later adding two more categories (Doka, 2002). These categories are as follows: a) conditions where the relationship is not recognized, b) conditions where the loss is not recognized, c) conditions where the griever is not recognized, d) conditions where the grief is not recognized, e) conditions where the grief responses are not recognized. Within the scope of this thesis, the psychological ambiguity of families whose children have been diagnosed with schizophrenia can be considered as a loss that is not recognized. Since the loss is not death-related, it remains invisible to the society as it is indefinite and confusing. Other examples of conditions where such losses are not recognized include the loss of elderly and ill individuals, loss of self due to dementia, perinatal losses, pet losses, losses in romantic relationships, financial losses, and loss of trust in the world due to sexual abuse (Cesur Soysal, 2021). Individuals experiencing an unrecognized loss by the social environment may experience helplessness, disappointment, and social isolation due to the lack of understanding from their surroundings (Pillai-Friedman, 2014).

When examining the psychological consequences of disenfranchised grief, it can be said that individuals who experience loss find themselves in a profound sense of loneliness, accompanied by intense and complex emotions. In a study conducted by Cohen in 1996, the focus was on how individuals distinguish between their experiences of grief in losses related to death and losses unrelated to death. The results indicated that losses unrelated to death could elicit strong emotions similar to those experienced in response to death-related losses (Cohen, 1996). The invisibility of individuals' grief processes creates a gap in terms of social support. The literature shows that social support reduces the stress experienced during the grieving process, facilitates the process of finding meaning, and has effects such as enabling

individuals to have a positive outlook for the future (Vanderwerker & Prigerson, 2004). However, individuals who are deprived of social support during the grieving process are left alone with difficult emotions, which can prolong the grieving process and lead to an extended state of mourning (Doka, 1989). Moreover, the findings also revealed that despite experiencing distressing symptoms, individuals were less inclined to seek formal counseling for losses unrelated to death (Cohen, 1996).

2.9. Aims of the Study

After receiving a diagnosis of a chronic mental illness such as schizophrenia, life becomes challenging for the family of the affected individual, and these challenges are commonly referred to as "family burden" or "caregiver burden." The physical, emotional, financial, and psychological effects of caregiver burden on families have been frequently addressed in the literature. Although one of the burdens that parents face during caregiving is the feeling of loss, there is a gap in the literature on loss and grief. Osborne & Coyle (2002) emphasized the need for further studies on the topics of "loss" and "grief" in this sample to gain a deeper understanding of the emotional reactions experienced by families with a child diagnosed with schizophrenia. A recent systematic review also revealed the limited number of studies that specifically target the dimensions of "grief" and "loss" in the context of chronic mental illnesses (Williams-Wengerd & Solheim, 2021)

The physical absence of the affected individual is clear, but their psychological absence (not being in their previous, healthy state) is highly confusing. Boss (1999) referred to this situation as ambiguous loss. As a result of this type of ambiguous loss, families not only experience psychological losses regarding their child and their expectations for the child, but also lose their own life expectations or priorities due to

the challenges of caregiving. Some families may exhibit grieving responses following these losses. The ambiguity of the loss and the stigma surrounding schizophrenia can make coping with grief and loss more difficult. This is because the loss is not socially visible, and families may hesitate to seek social support due to the stigma associated with it.

This study specifically aims to understand the burden experiences of loss and grieving among parents who have a child diagnosed with schizophrenia, as well as how they cope with these experiences. In line with this aim, in-depth interviews were conducted with parents who are the primary caregivers of their children diagnosed with schizophrenia. Throughout the paper, the term "child" will be used in general, regardless of their age, but it should be noted that these children are referred to as "adult children." In this regard, the study includes three research question:

1. What are the burdens of caregiving experienced by parents of children diagnosed with schizophrenia?

2. How do individuals whose children are diagnosed with schizophrenia experience ambiguous loss?

3. How do individuals whose children are diagnosed with schizophrenia cope with ambiguous loss?

To interpret and analyze the results of the current research questions, the framework outlined by the theory of ambiguous loss has been utilized. Williams-Wengerd & Solheim (2021) have stated that there is a lack of theoretical foundation in the field of loss and grief studies related to serious mental disorders. They further emphasized that this theoretical gap diminishes the conceptual consistency of studies in this field, makes it challenging to compare findings, and limits support for future

research. The researchers also added that the theory of ambiguous loss is a suitable framework to establish a conceptual foundation in this field. It should be noted that developing a theoretical foundation not only benefits academic research but also serves as a guiding light for professionals working in the field and provides support to families living with schizophrenia.

CHAPTER III

METHOD

3.1. Ontological and Epistemological Position of the Researcher

In order for readers to better understand and interpret the current study, it would be useful to mention the ontological and epistemological stance of the researcher.

Ontology tries to answer the question of what is real, and it is possible to take different positions according to the answer given (Willig, 2013). In the evaluation of the data collected for this study, the "critical realist" ontological position was adopted. According to this perspective, people are only a small part of the existing reality (Howitt, 2010), therefore, individuals' interpretations of the world are only a part of the existing reality. The conclusions drawn from people's interpretations of a situation are related to the interpreter's perception of reality rather than reflecting the concrete reality. The benefit of adopting such a position in research is that, while acknowledging the subjectivity of participants' statements, it goes beyond the text to consider their discourse in its historical, cultural, and social context (Harper & Thompson, 2012). To summarize, the critical realist position emphasizes that what is outside the discourse affects the meaning possibilities of the discourse. In the present study, cultural and social elements that are beyond the subjective perspectives of the participants and sometimes affect this subjective perspective seem to be important (e.g., stigma related to mental illness).

Epistemology is a concept related to the philosophy of knowledge; it tries to make sense of what we know and how we can know (Willig, 2013). The researcher

adopted "contextual constructionism" in the current study. Contextual constructionism states that meanings and experience emerge through the interaction of subjective and mutual subjective construction (Byrne, 2021). During the research, both the participants and the researcher constantly try to make sense of their environment; thus, each individual constructs a unique reality. Therefore, the data obtained should not be considered independent from the subjectivity of the participants, the subjectivity of the researcher and the general context. As the subjectivity of the researcher is also of great importance in how the findings of the study will be interpreted, the researcher's knowledge construction process.

In studies using reflexive thematic analysis, it is thought that a constructionist epistemological stance can be useful both because it prioritizes the subjectivity of individuals and because it focuses on the meaning of data rather than the importance of repetition (Byrne, 2021). For a theme to emerge, it needs to be repeated in the data, but it is wrong to say that every repeated discourse is an important finding for the research. Instead, in a constructivist perspective, subjectivity and meaningfulness are important (Byrne, 2021).

3.2. Methodology

A qualitative analysis design was considered to be the most appropriate method to work with the research questions of the current study. Qualitative research methods offer the opportunity to understand the personal perspective of an event or experience (Baker & Graham, 2004). In doing so, it does not aim to hypothesize pre-existing theories, but to provide a rich and in-depth understanding of events or experiences (Willig, 2013). Especially in cases where the research question seeks to examine a complex concept, or where the sample is limited and requires in-depth

understanding; qualitative research designs can provide important information about the subject. As stated in the previous chapter, this study focuses on how parents whose adult child has been diagnosed with schizophrenia experience and cope with ambiguous concepts of loss and grief, and therefore, a qualitative design was the most appropriate choice when analyzing this research question to explore and understand experiences. Within the scope of the qualitative design, Reflexive Thematic Analysis was used as the qualitative data analysis method. This method was preferred because it is a method of analysis in which the researcher plays an active role in the analysis process, supports creativity and offers theoretical flexibility. A more detailed explanation about Reflexive Thematic Analysis and the analysis process will be given in the "Analysis" section.

3.3. Participants

The participants of this research project were selected on the basis of purposive sampling method. The participants were reached through two different schizophrenia solidarity associations in Ankara which are Schizophrenia Patients and Their Relatives Solidarity Association and AŞDER (Ankara Association for Learning and Supporting Living with Schizophrenia).

Determining the number of samples is an issue that has been discussed in the field of qualitative research methods in recent years. The general concept used to determine the number of samples in the research is called data saturation. Data saturation is achieved by accepting participants and conducting interviews until a new information, code or theme is not obtained in the interviews (Braun & Clarke, 2019). When the literature is examined, it is seen that there are different methods to ensure data saturation in qualitative research. According to Guest et al. (2006) reported that 94% of

the codes related to the analysis were obtained at the end of the first 6 interviews and 97% at the end of the 12th interview. Constantinou et al., (2017) reported that all possible themes were finalized after the 7th Interview; Francis et al. (2010), on the other hand, stated that data saturation was reached when the interviews were conducted as 10+3 to determine the sample size. However, Braun & Clarke (2019) stated that whether or not to work according to the data saturation criterion for theme analysis depends on the nature of the selected sample group and factors such as the ontological and epistemological stance of the researcher. In addition, they added that the concept of data saturation is not a useful or theoretically consistent concept, and the findings of the data saturation experiment studies are far from certainty. Therefore, the current study did not use a definitive guide to determine sample size for data saturation, instead focused on the information power model (Malterud et al., 2015), as suggested by Braun & Clarke (2019). The information power model argues that factors such as the purpose of the study, the originality of the sample, the theoretical basis, the quality of the dialogue and the analysis strategy affect the number of people to be sampled and therefore determine the sufficient information power to be taken (Malterud et al., 2015). The interaction of the factors in this model is effective in reducing or increasing the number of people to be recruited. The logic of the model is explained in the figure below (Figure 3.1.) However, the model was designed as a set of suggestions that should be considered in the process of recruiting participants rather than a numerical calculation (Malterud et al., 2015). With the proposal of this model, the factors that would increase the power of knowledge were taken into account throughout the research process, and the transcripts were examined in detail, one in every three participants during the participant recruitment process, and possible codes and themes that could arise were noted. With the suggested five influencing factors, the number of

interviews was cut off at 10, since also no different themes and codes were observed in

the last two participants interviewed after the 8th participant.

Figure 3.1. Information Power (Malterud et al., 2015)
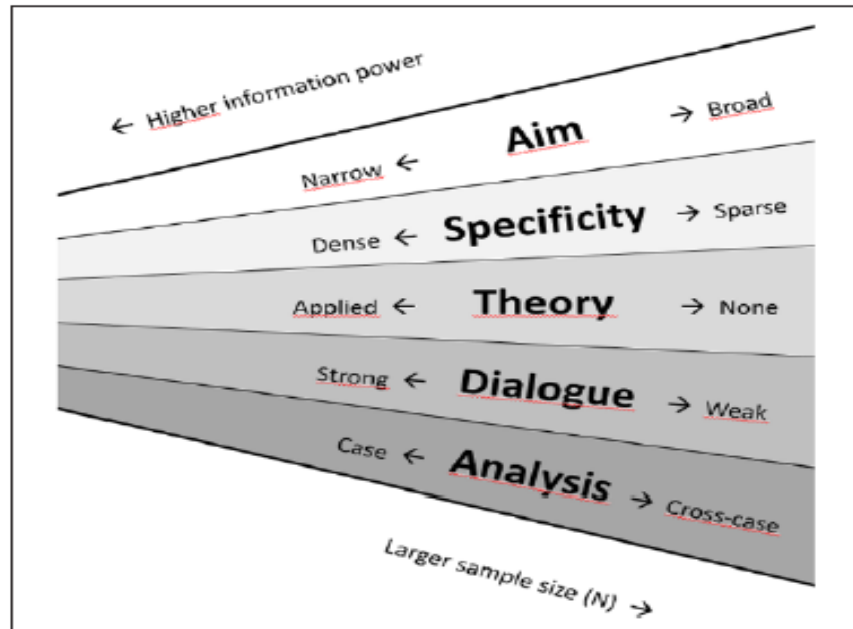
Of the 10 participants who were interviewed in-depth, 8 were mothers and 2 were

fathers. The age ranges are 52-80. Except for 1 participant, all participants reported living

in the same house with their adult children. Detailed sociodemographic information is

given in the table below.

Participant Number	1	2	3	4	5	6	7	8	9	10
Age	63	70	74	52	58	80	64	79	62	80
Gender	Female	Female	Female	Female	Female	Male	Female	Male	Female	Female
Marital Status	Widow	Married	Divorced	Divorced	Married	Married	Divorced	Widow	Married	Widow
Educational Status	Secondary School	University	Primary School	Master	University	Doctarate	High School	Master	High School	University
Work Status	Not working	Not working	Not working	Working	Not working	Not working	Not working	Not working	Not working	Not working
Socioeconomic Status (1-10)	1	7	4	7	5	10	5	8	4	6
Number of people living in the household	3	3	2	1	3	3	2	2	4	2
Number of children living in the house	2	1	1	0	1	1	1	1	2	1
Psychiatric or psychological help	None	Using medication	Using medication	Using medication and going to psychotherapy	Using medication	None	Using medication	None	Using medication	Using medication

Table 3.1. Demographic Information about the Participants

Participant Number	1	2	3	4	5	6	7	8	9	10
Child's Age	46	50	52	29	31	53	30	44	45	59
Gender	Male	Male	Female	Male	Male	Male	Female	Male	Male	Male
Marital Status	Single	Single	Single	Single	Single	Single	Single	Single	Single	Single
Educational Status	Primary school	University	University	University	University	High School	High School	High School	University	University
Work Status	Not working	Not working	Not working	Working	Working	Not working	Working	Not working	Working	Not working
Age of the child at diagnosis	30	28	32	21	24	18	16	20s	33	20s
Number of hospitalizations	2	2	More than 2	2	0	3	5	0	0	2
Does he/she live with his/her parents?	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes

Table 3.2. Demographic Information about the Children of the Participants

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3.4. Inclusion and Exclusion Criteria

Two inclusion criteria were determined for the inclusion of participants in the study:

1. The child being cared for by the mother/father has been diagnosed with schizophrenia.

2. Parents who will participate are the primary caregivers of the child diagnosed with schizophrenia.

Although it was stated at the beginning of the interview, the participant in the 3rd interview said that her child was not diagnosed with schizophrenia by the doctor, but only showed psychotic symptoms in the later parts of the interview. Since the study did not meet the inclusion criteria, the data of the interview with this participant excluded in the analysis and were not included in the conclusion of the study. Similarly, the participant in the 5th interview also stated that her child was not diagnosed with schizophrenia at the end of the study. The data on this participant was also not analyzed and added to the result. As a result, although 12 participants were interviewed in total, 2 participants did not meet the inclusion criteria, so the interviews with these participants were not included in the analysis. Interviews with 10 participants who met the inclusion criteria were analyzed.

3.5. Materials

As stated above, this study was designed to include individual interviews and to use a qualitative analysis method. For this reason, individual interviews were conducted with the participants (mother or father of a person diagnosed with schizophrenia) who agreed to participate in the study as participants. Individual interviews consisted of two stages: sharing the informed consent form with the participant and sharing the demographic form and interview questions with the participant.

<u>3.5.a. Sociodemographic Information Form</u>

The sociodemographic information form starts with question in which the participant is specified as the mother/father of the child diagnosed with schizophrenia. In the remaining part of the form, parents' age, education status, employment status, marital status, number of people living in the household, how many children they have, number of children living in the household, whether there is another person they care for, socio-economic level, chronic disease status, psychiatric diagnose and, if any, treatment history were questioned. These questions are important in terms of seeing the sociodemographic characteristics of the participants. In the second part of the demographic information form, information about the child diagnosed with schizophrenia was requested. These questions questioned the child's age, gender, educational status, employment status, marital status, at what age she/he was diagnosed with schizophrenia, how many times she/he was hospitalized after the diagnosis, how many years the parents took care of their child, and whether they lived in the same house or not (see Appendix C).

<u>3.5.b. Interview Questions</u>

Interview questions consisted of 16 open-ended questions (see Appendix D). These questions, in parallel with the research questions of the study, aimed to examine in depth how parents were affected by caregiver burdens and ambiguous loss related to the diagnosis of schizophrenia of their child and how they coped with these processes. Probing questions were used in order to better understand the participant's life experience at points deemed necessary by the researcher. Interview questions were prepared in line with "The Interview Protocol Refinement Framework-IPR" developed by Castillo-Montaya (2016). According

to this protocol, the questions to be used in individual interviews should be determined through a preparation phase consisting of 4 stages:

Stage 1: This phase particularly emphasizes the importance of matching key questions (questions that are important to the study) and research questions. In order to ensure this harmony, it is recommended to prepare an interview protocol matrix (see Appendix E). In this way, the distribution of question types and which question will be asked in response to which research question can be seen. According to the protocol, the questions most relevant to the research question should be asked in the middle of the interview, the prepared line provides the opportunity to see this distribution.

Stage 2: At this stage, it is important to prepare the interview questions in the form of an "Inquiry-Based Interview" according to the protocol framework and to establish a balance between the interview and the question. There are several important steps to follow to achieve this balance:

a) Interview questions should be different from research questions. Interview questions should be designed in accordance with everyday language, away from academic language.

b) Again, in terms of adopting the rules of daily speech, interview questions should be compatible with social norms. For example, not interrupting; expressions of appreciation; asking only one question at a time; it is suggested that there should be factors such as not asking questions that may evoke judgment and using transitional expressions when necessary.

c) It is recommended to ask various questions that can establish the balance of inquiry and interview and are not only aimed at answering research questions. For example, initial questions can put participants at ease and build a relationship with the participant. Again, by using transition questions, participants can be guided by linking the initial questions and key questions directly related to the research questions. With the closing questions, the

participants can be prepared for the end of the interview. These features will help to make the interview more like a conversation. On the other hand, having many key questions can also enable the questioning, which is the main purpose of the interview.

Apart from these steps, it is recommended to ask drilling questions where necessary so that the answers to the questions can be understood in depth. However, when asking these sounding questions, care should be taken to ask only one question at a time.

Stage 3: This stage explains what needs to be done during the preparation of interview questions. It is necessary to receive feedback from people and colleagues who will not participate in the actual research on the questions prepared for the interview. In this framework, techniques such as "close reading" and "thinking around activity" are suggested. In this phase, unlike pilot interviews, only questions are read and evaluated.

Stage 4: At this stage, it is recommended to pilot the interview protocol before the main study with people who have similar characteristics with the research sample.

Adhering to the stated interview protocol stages, an interview protocol matrix was created in order to see the connection between the interview questions and the research questions more clearly. This matrix showed which interview questions were related to which research question and showed the balance of how questions were distributed. Care was taken to form the questions in a language that the participants could understand, drifted apart from the academic language. While preparing the questions and during the interview, care was taken to ask the questions in accordance with social norms, and to establish a relationship with the participant in the process with the beginning, transition and closing questions. Finally, the questions prepared also provided the condition of reading the questions to which the 3rd phase drew attention and receiving feedback many times. Due to the nature of the study, it was not possible to conduct the pilot study specified in Stage 4, since it was studied with a sample that is rare in the society. Castillo-Montaya (2016) stated

that the 3rd phase gains great importance in such cases, the 3rd phase was meticulously emphasized. The interview questions were finalized by evaluating the feedback received from the colleagues from TOBB ETÜ Clinical Psychology Master Program.

3.6. Procedure

Various measures have been taken to ensure that group member participants in this study are treated appropriately and that their personal information is kept confidential. First, the proposal, individual interview questions and informed consent form were submitted to the TOBB ETU Human Studies Evaluation Board. After obtaining the ethical approval from the committee (see Appendix A), the study started, and the participants were announced through the two solidarity associations for schizophrenia: Schizophrenia Patients and Their Relatives Solidarity Association (Ankara) and AŞDER (Ankara Association for Learning and Supporting Living with Schizophrenia).

The announcement of the study was conveyed by the associations to the parents of individuals diagnosed with schizophrenia, who are the members of the association. The contact information of the parents who agreed to participate in the study was conveyed to the researcher, and the researcher contacted the parents. The researcher contacted the participants who volunteered to participate in the study over the phone. On this occasion, the aim and scope of the research were introduced to the participants. After this speech, an appointment was made with the participants who definitely agreed to participate in the study by setting the appropriate day, time and place for the interview. Most of the interviews were held in empty and noise-free rooms in the associations for the comfort of the participants. However, since two of the participants were unable to leave the house, the researcher went to the house of two participants and conducted the interview.

When the interviewer and participants met, the interviewer first talked about the purpose and structure of the study and shared the informed consent form (see Appendix B) with the participants. The purpose of the study, the characteristics of the interview, ethical precautions and confidentiality were emphasized in the informed consent form. A copy of the form was also given to the participant. After the participants gave their consent to participate in the study and to be audio recorded, the voice recorder was started to be used. At this stage, firstly, sociodemographic information collection questions about the participant and their child were asked. These questions were asked verbally to establish a relationship before the interview questions (see Appendix C).

After gathering that demographical information, interview questions (see Appendix D) were asked in accordance with The Interview Protocol Refinement Framework-IPR (Castillo-Montaya, 2016). For instance, the researcher encouraged the participants to explain the points they found important and took care to make the interview in an atmosphere where the participants could freely share their experiences rather than an interrogation. Individual interviews lasted approximately 30 minutes to 1 hour.

At the end of the interviews, the interviewer made a summary of what they talked about in the interview and thanked the participant. Then, it was discussed how the participants felt after the questions in the interview. In general, the participants stated that this interview was good for them, and they felt relieved. After the interview, it was reminded that the participants who needed support or had questions could reach the researcher through the contact information on the informed consent form.

3.7. Data Analysis

Thematic analysis is a qualitative data analysis approach that offers theoretical flexibility to the researcher, which facilitates the creation of patterns/themes in the data set.

This approach involves a process in which researchers immerse themselves in the data, repeatedly read and question the data, imagine, wonder, write down what comes to mind, step back from time to time, and continue the analysis as they develop insights or appropriate mind space (Braun & Clarke 2020). In this process, researchers begin to create codes after sufficient exposure to the data. Braun et al. (2019) stated that the coding and thematization process is a flexible and organic process and that codes and themes may change during the process. Codes are defined as entities that reflect at least one observation in the data (Braun & Clarke, 2020); as codes are created, researchers bring these codes together to form themes that reflect multiple aspects of the data. Braun & Clarke (2020) stated that themes are multifaceted and tell a story about the data.

A review of the literature reveals that there are three different versions of thematic analysis: coding reliability, codebook, and reflexive thematic analysis (Braun et al., 2019). Within the scope of this research, it was determined that the most appropriate version for the research questions and the epistemological and ontological position of the researcher was reflexive thematic analysis. Reflexive thematic analysis describes a more inductive (bottom-up reasoning approach) and more situational interpretative process that supports the subjective skills of the researcher (Braun & Clarke, 2020). In this approach, the analysis is the interaction of the data obtained in the interviews, the theoretical assumptions used in the analysis process and the skills of the researcher (Braun & Clarke, 2019). A six-stage process is proposed to guide researchers and facilitate a theme analysis (Braun & Clarke, 2012, 2013, 2020). However, it is not necessary to proceed linearly in these stages, the researcher can move back and forth between the stages (Braun & Clarke, 2020). Thus, it is stated that it is normal to be flexible between these stages and to repeat some stages. The stages followed in the analysis process and the processes the researchers went through can be listed as follows:

3.7.a. Phase 1: Familiarization with the Data

At this stage, the researcher listened to each interview recording once before transcribing it with "active listening" in order to understand the issues discussed in the interview. After active listening to each interview, the interviews were transcribed. At this stage, extra nonverbal information observed during the interview was also noted.

3.7.b. Phase 2: Generating Initial Codes

At this stage, the transcripts were read again, and the coding stage was started. The information related to the research question was coded briefly and concisely. MAXQDA 2022 (VERBI Software, 2021), a qualitative research software, was utilized during the coding phase. The coded interviews were reviewed every three interviews, and some codes were renamed, or new codes were added during this process.

3.7.c. Phase 3: Generating Themes

After coding all the interview data, the stage of determining the themes was started. According to the common meanings between the coded data, the codes were brought together and tried to be reduced to a single code and possible themes and sub-themes were determined. At this point, rather than the frequency of the codes within a theme, the importance was given to the extent to which the themes/subthemes formed by combining the codes were related to the research question.

3.7.d. Phase 4: Reviewing Potential Themes

At this stage, the researcher needs to review all codes and possible themes/subthemes in the data. Thus, themes/sub-themes that are not related to the research question or that

may be related to each other can be reorganized. Again, at this stage, some codes can be revised and assigned to new themes, or completely removed if they are not considered to be related to the research question. Therefore, it may be necessary to return to the second and third stages of analysis during or after this stage (Byrne, 2021).

Braun & Clarke (2012) suggested that researchers at this stage should conduct the review in two stages. First, the relationships between all themes, sub-themes and codes should be reviewed. Secondly, after making the necessary adjustments, the researcher should check how far the themes and sub-themes reflect the codes in the data and the general narrative in the data. It is recommended to observe the internal homogeneity between themes in the first stage and the external heterogeneity between themes in the second stage (Byrne, 2021).

At this stage, the researcher reviewed possible themes, merged some themes because they were related to each other, or changed some themes into sub-themes. When necessary, the data set was returned to, and changes were made in the coding dimension.

3.7.e. Phase 5: Defining and Naming Theme

At this stage, the researcher should review the final themes and the names of the themes one last time. All themes and sub-themes should be consistent with both the interview data and the research questions (Byrne, 2021). Each theme should describe a new data that the other themes do not describe, and the ways in which the themes differ from each other should be explained consistently (Patton, 1990).

Again, at this stage, the researcher should determine the quotations to be used while explaining the themes and sub-themes. These quotations should provide a clear and coherent narrative about the relevant theme/subtheme. It is important that the quotations to

be used are taken from different interviews in order for the themes/subthemes to be convincing and the importance of the research question to be seen. At this stage, the researcher benefited from the opinions of the thesis advisor Prof. Dr. A. Nuray Karanci; the themes, the names of the themes and the quotations to be used were determined together with the thesis advisor.

3.7.f. Phase 6: Producing the Report

As with the other stages, this is a stage that requires revision (Byrne, 2021). After the first five steps were meticulously followed, the findings of the current study were obtained and reported. These findings will be discussed in the result section.

3.8. Trustworthiness of the Study

When the literature is examined, it is seen that there are some criteria that help to obtain reliable and robust results in qualitative research (Lincoln & Guba, 1985; Morrow, 2005). In the current study, the criteria introduced by Lincoln & Guba (1985) were followed in order to ensure trustworthiness in thematic analysis with the suggestion of Novell et al. (2017). During the study, the researcher tried to apply the standards indicated by these criteria. These criteria and the position taken by the researcher regarding these criteria are listed as follows:

3.8.a. Credibility

Credibility addresses the extent to which the information reported by the participants in the interviews is represented by the researcher as "congruent" (Tobin & Begley, 2004).

Lincoln & Guba (1985) suggested that in order to ensure and increase reliability, researchers should make continuous observations, ensure a long-term attachment to the research topic, and use peer review to provide an external control. At this stage, feedback on the findings was received from Prof. Dr. A. Nuray Karancı, the advisor of the study, and peers in the TOBB ETU Clinical Psychology Master Program.

3.8.b. Transferability

Transferability refers to the generalizability of research results. In qualitative studies, this generalizability can only be achieved from case to case. However, the researcher needs to provide a detailed explanation for readers who want to transfer the findings to their own fields (Lincoln & Guba, 1985)

3.8.c. Dependability

In order for the reliability of a research result to be controllable, the process needs to be controllable. For readers to make a better evaluation, notes about the process are as important as the research findings (Lincoln & Guba, 1985).

3.8.d. Confirmability

Confirmability focuses on how the researcher makes which inferences from which data. Lincoln & Guba (1985) stated that confirmability can be realized by meeting the standards of credibility, transferability and dependability.

3.8.e. Audit Trail

Audit trail refers to the steps followed by the researcher in the research process and the methodological decisions taken by the researcher, recorded and documented throughout the study to provide evidence to the readers. Recording these documents is important to ensure auditability. For example, documents such as transcripts, the researcher's observation notes, and the research diary may be necessary for both the researcher's process and the readers' follow-up.

3.8.f. Reflexivity Is Central to the Audit Trail

In qualitative research, the subjectivity of the researcher also plays an important role in interpreting the research findings. For this reason, researchers are advised to keep a diary in which they convey their internal and external subjectivity, reflect their decision-making stages, and reflect their feelings and thoughts about the process (Lincoln & Guba, 1985).

During the research, the researcher tried to take a position in accordance with these criteria. After the research data were collected, the researcher reviewed the trustworthiness of the process with Morrow's (2005) four-step suggestion to double check the trustworthiness of the study with another guideline. The first of these four steps emphasize the subjectivity of the researcher. Therefore, the interpretations of the findings in the research cannot be separated from the subjectivity of the researcher and the importance of the researcher's stance in accessing information should not be ignored (Fischer, 2009). The second step states that the researcher should be transparent and report their own processes (self-regulation) (Fischer, 2009). During the process, the researcher should put the effects of his/her personal background and assumptions in the background as much as possible so that they do not affect the current analysis. However, he/she should still question the

possible effects of his/her personality on the study and report this. This report is shared in the reflexivity section in the next chapter. The third standard emphasizes the importance of adequate data collection. Both interview content, interview observation notes and feedback from participants were used to meet this standard. The last standard states that the researcher should have a good understanding of the participants' inner world in order to make inferences about the interviews. To achieve this standard, the researcher read and re-read the interview transcripts, interview notes and notes on her own reflexivity.

The researcher questioned the reliability of the study from a broader perspective, following both Lincoln & Guba's (1985) trustworthiness standards and Morrow's (2005) trustworthiness standards, although they have parallel aspects.

3.9. Reflexivity

Reflexivity involves the researcher's effort to understand his/her own position within the research topic and the research process and to reflect on how this position may have affected the findings (Berger, 2015). In other words, it is a very important section for qualitative analysis that tries to explain the place of the researcher's subjectivity in the research process. In order for readers to interpret the current research process and findings from my position, I would like to explain how I decided on the research topic, my feelings and thoughts during the interview process with the participants, and my analysis process.

When I turned to clinical psychology in the last years of my undergraduate education, there were some topics that were exciting for me and that I was very eager to read and learn. Schizophrenia and other psychotic disorders were one of these topics. I remember being very interested in films and books on schizophrenia during my undergraduate years, and when I was trying to find a topic for my master's thesis, the first thing that came to my

mind was how I could study schizophrenia as a thesis topic. On the other hand, the topic of ambiguous loss was a concept I had never heard of before. During the process of deciding on the topic, I researched and adopted the theory of ambiguous loss after a colleague with whom I shared my thoughts mentioned the concept of "ambiguous loss". When I thought about why I absorbed this topic so quickly, I came to some conclusions about myself. In my own life, I have never experienced a death-related loss that affected me deeply. However, after learning about ambiguous loss, I realized that there were actually things I had lost in my life, but I did not see them as losses because they were not death-related losses. Moreover, the things I lost ambiguously were not seen by my social circle. I was told that I had to get over my grief immediately. When I was introduced to the concept of ambiguous loss, it was a comforting experience for me to know that there was a counterpart to what I had experienced before. When I realized that my curiosity about schizophrenia, which I mentioned at the beginning of this paragraph, and the topic of ambiguous loss were actually very suitable for working together, I felt that I had found the ideal research question for myself. I was familiar with the fact that socially invisible losses, which are not even recognized by those who experience them, sometimes bring a long grief process behind them. Working on this topic with mothers and fathers whose adult children have been diagnosed with schizophrenia has been a very new and instructive experience for me. I had the opportunity to experience live that every loss is unique.

During the interviews, I felt that I was going back and forth in quite different states of emotion and thought. First of all, even setting the date and time of the interview was a challenging experience. Then, during the interviews, I realized that it was difficult to bring my participants back to the interview questions when they strayed from the topic, because my target participants did not belong to an age group that I have worked with in my social life or clinical experience. They were all over the age of 50, so when I look back now, I see

that I learned a lot about myself and communication with people of advanced age in this process. I felt that I was struggling at times, but as the process progressed, I began to realize that I had learned the dynamics of communicating with this age group. For example, I realized that it was necessary and useful to draw a temporal framework at the beginning of the interview.

During the interviews, the participants were describing a new world that I had not known before. Many of them talked about their traumatic experiences in the family. For this reason, I felt emotionally down after some of the interviews and needed time to process, but what gave me hope was to see the participants' willingness to hold on to life, no matter how traumatic and impressive events they were talking about. Since I reached the participants through the associations, I realized how the associations provided hope in their lives and opened a space for them to make sense of their experiences. This increased my belief that growth can occur after traumatic events. The analysis process was another challenge for me, first the transcription process and then the constant exposure to the data for analysis. At times, I felt that I could not cope with the emotional intensity of the interviews. At these stages, I sometimes felt the need to distance myself from the data, but I always forced myself to return. It was very instructive for me to realize something different about the data and myself every time I returned. However, the flexibility and creativity provided by reflexive theme analysis, the qualitative analysis method I chose, helped me in this process.

As a result, I went through a bumpy process in my thesis writing process, alternating between sadness, despair, anxiety and hope. While I was going back and forth between hope and despair, which is also part of the ambiguous process of loss, I felt a great relief at the point where I accepted this as a part of the process. This process, in which I had the

opportunity to meet brand new people and try to understand the nature of human beings, created the research you are reading now.

CHAPTER IV

RESULTS

This section presents the results of the analysis of the interviews conducted with ten participants. In line with the literature, the findings show that parents face different types of caregiver burdens. One of these burdens is the ambiguous loss experienced by individuals. It is thought that the feeling of ambiguous loss may be closely related to all the burden types identified as the main theme.

In order for the reader to better understand the main themes and sub-themes obtained from the interviews, quotations from the interviews will be used. Pseudonyms will be used instead of the names of the participants and their children. Four main themes were drawn from the ten interviews. The main themes and sub-themes are summarized in the table below.

Main Themes	Sub-themes
1. Objective Burdens	Financial Loss
	Disruption of Personal Life Priorities
	Challenges in Caregiving
	Challenges with the Health System
2. Subjective Burdens	Unfulfilled Expectations from the Child
	Difficulty in the Understanding Illness and Confusion
	Emotional Distress
3. Family and Social Burdens	Challenges with the Family
	Challenges with the Social Network
4. Coping	Cognitive Coping
	Behavioral Coping
	Coping through Social Support
	Coping through Psychiatric/Psychological Support

Table 4.1. Main Themes and Subthemes

4.1. Objective Burdens

The main theme of Objective Burdens focuses on the concrete, observable, objective burdens experienced by families. Based on the information provided by the participants, the sub-themes within this main theme are (4.1.a) Financial Loss, (4.1.b) Disruption of Personal Life Priorities, (4.1.c.) Challenges in Caregiving, and (4.1. d) Challenges with Health System and are explained in detail in the following sections.

Figure 4.1. Objective Burdens Code Map
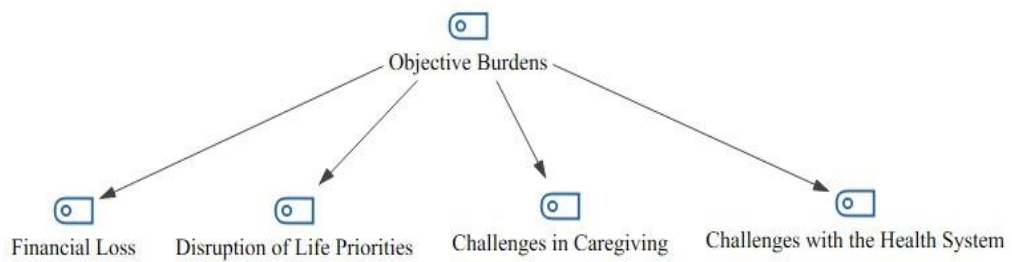
4.1.a. Financial Loss

The treatment process of a long course illness such as schizophrenia can be very economically challenging for families. The sub- theme of financial loss focuses on the financial loss experienced by families during the illness process. It is seen that this financial loss is sometimes due to the difficulties experienced due to the caregiver participant having to leave the job, sometimes due to treatment costs, and sometimes due to the difficulties related to family's socioeconomic status.

Participant 5 explained the financial loss they experienced during the treatment process as follows:

> *"That one year passed like that, but we found a doctor psychologist in Istanbul. We were both going to the doctor and the psychologist. We sold a house, believe me, our house is gone. I'm glad we had it, it's gone."*

The same participant stated that they had to live close to their child's school due to their child's illness, which was challenging for the family:

> *"Because Istanbul was also difficult for us, both financially and emotionally, we could not live far away because my son has commuting*

problems. If we were to live somewhere close, the place where ITU is located is already one of the most expensive places in Istanbul."

Participant 9 stated that she was going through difficult times financially, but she tried to ensure the continuity of activities that were good for her child by cutting back on other expenses:

"I went through a very bad period financially. I became a member here, would you believe it, maybe I would cut my shopping money and pay my dues here (to the association). Why? Because these children need it. This place needs to stay open. I cut back on my vacation, I cut my pants from my clothes, I lengthened and narrowed them. I can do that, I have a tailor, I'll try."

4.1.b. Disruption of Personal Life Priorities

This sub-theme focuses on the plans, wishes and expectations that the participants wanted to make in their personal lives after the illness but could not fulfill due to the responsibility of caring for their children. Almost all the participants stated that they were "deprived" of some things because they had to care for their children. Some pointed out that they had to end their work life early, some pointed out their disrupted dreams for the future, and some pointed out that they lost their social life. Some participants said that they were "devoted to their children" and that they shaped their personal priorities completely according to their children.

Participant 2 stated that she quit her job after her child's diagnosis in order to take more care of her child:

"For example, I retired immediately, at the age of 50. My son was diagnosed with this illness in 2001 and I retired in January 2002. After that, I started dealing with hospitals and so on. I was still an assistant general manager, I could have worked my way up, but I retired immediately."

Participant 8 explained that as a father who has the responsibility to care for his child alone, he shapes his social life according to his child and sacrifices his personal activities:

"Well, there was a situation like this: I used to go to Istanbul from time to time as a speaker for various channels. When my wife got worse, I couldn't leave anyway. If I had too much difficulty going somewhere, one of our relatives would come and wait for me until I arrived. I mean, there are already women in the evening and daytime. She was needed in the evening. We had such a life. Two, even now, for example, I have to be at home at 5 pm because she comes from the association. Events and social activities always take place after 5 p.m. I can't go to them, I have nothing, I mean, I left politics, I left those things."

Similarly, Participant 9 stated that she quit her job after her child was diagnosed and devoted herself to her child. She stated that she determined the places she would go and the decisions she would make by prioritizing her child as follows:

"My trips, friends, I mean, when I say trips, I mean vacations or... Let me put it this way, my son received the diagnosis and I focused on him in that difficult situation, bad process. Do I have a job? Am I going somewhere? My traveling friend says let's go on these tours or let's go there. No, I don't. I can't go anywhere right now. My child is sick, his

diagnosis is clear, I have to take care of him, always with him, traveling with him. Because I was looking at him and he was unhappy, I tried a few times, I can't say a few, maybe once. I immediately withdrew myself. I was looking at him and he was not happy, he was upset. I realized that these things trigger it. I became aware of it and deprived myself of most things as much as possible."

Participant 7 talked about the expectations that she thought she could fulfill after his retirement but could not be realized and that these expectations remained as "nagging" inside her. It was observed that she was quite emotional while talking about these:

"Because I worked for a long time, there were many things I wanted to do but couldn't do. I mean, I would like to go to a different city after I retired, I would like to go on tours, I mean, I would like to do everything that I have been holding on to with my daughter or if my daughter had not been diagnosed with this illness... But now I can't do anything, I mean I can't always be with her...and I don't want her to be alone. So, some things I want to do are always postponed. If I want to go somewhere with her, she doesn't come. It is like that."

Participant 5 stated that the focus in her life was taking care of her child: *"Especially as a mother, you are a mother, so now your whole life is spent every minute and every second trying to figure out what I can do for her, what is right for her and doing that."*

<u>4.1.c. Challenges of Caregiving</u>

This sub-theme deals with the caregiving responsibilities of the participants who care for their children and the difficulties they experience during these responsibilities. The factors that increase the difficulty of these responsibilities can be summarized as the child's being an adult in age, changing skills and behaviors during periods of attacks, lack of knowledge about schizophrenia and not knowing how to treat the person being cared for due to all these.

Some of the participants emphasized the fact that they took care of their children even though they were adults. For example, Participant 1 stated that she took care of her child's self-care with the following words:

> *"... For two years I've kept him in bed like a baby. He can't wash himself, he's scared, he's afraid to go to the bathroom, he locks up. He says they give me pain. What do we do? He lies in the bed, you wash him half and half, support him with a towel, don't move him, he says there will be pain. If you don't wash him, he will smell, I make two buckets of water, I use one to wash him, one to shave him... He is my son, I clean him all over, it takes us two hours to clean him. Turn on your side, back, arms, neck, neck, head, washcloth, and for two years he slept in pants and a shirt in bed."*

Participant 2 mentioned that her child exhibited aggressive attitudes towards her from time to time: *"One day I went there, and he wouldn't come out of the bathroom and the men there said we will go in too. Ali, can you come out, Ali, come out, Ali, come out...He opened the door and hit me, and they hardly took me away from him.".* Some participants stated that one of the factors that made caregiving responsibility difficult was their ignorance about schizophrenia. Some of the

participants stated that they did not have any information about schizophrenia until their children were diagnosed, while some of them had very superficial and actually wrong information, and therefore had prejudices about the disease. Lack of knowledge about the disease seems to be a situation that makes the process experienced by individuals ambiguous. Participant 3 stated that she had no information about the disease until she was diagnosed as follows: *"I don't know schizophrenia. I don't know the name of the diseases. For example, they used to call them crazy. It has only one name, crazy. It's like this, dear.".* Another participant stated that he thought that schizophrenia would be a temporary illness because he was ignorant about the nature and course of schizophrenia, and that he did not have information about the scope of the disease at the beginning: *"We said okay, but since we didn't know what schizophrenia was either, it is a mental illness, but we didn't know whether it was temporary or not, back then in the 80s. Therefore, we did not panic too much, as if it would be temporary."*

Participants who had heard some information about the illness before pointed out that what they heard were prejudiced expressions. They stated that they were under the influence of stigmatization related to mental illnesses, and therefore they had difficulty in accepting and feared when they heard the name of the illness. Participant 4 summarized this situation as follows: *"...I even had a few prejudices. Schizophrenia patients are dangerous, they cause harm, schizophrenia patients are completely mentally ill, they cannot think anything, they cannot do anything. I had so many prejudices. This scared me a lot."*

<u>4.1.d. Challenges with the Health System</u>

In this sub-theme, participants mentioned the difficulties they experienced due to the health system. Difficulties in finding a bed in the hospital, difficulties in communicating with healthcare professionals, difficulties in obtaining a report that their children have schizophrenia, and the lack of an institutions supporting schizophrenia patients within the state are among the issues mentioned by the participants within the scope of this sub-theme.

Participant 1 seems to be one of the participants who experienced the most difficulties in this regard. Stating that her child's condition was severe, the participant expressed the difficulty she experienced during the hospitalization process of her child as follows:

> *"The most difficult thing was that I couldn't admit him to the hospital, that killed me. You will ask why, the child is melting in front of your eyes, you are very helpless. If there was a fracture or a dislocation, the ambulance would come. You call an ambulance, I've been through a lot of bad things, like the court thing. He says I can't take him; he says I can't take him, I call the police, he says they'll ask him. They ask the patient if they want to go to bed, and they don't want to go to bed. It is a problem to arrange a bed, it is a problem to bring it. What upset me the most were the court cases. It's exhausting, I'll take him to the hospital, but if I can't, what will I do with him, these are the things that upset me the most. Other than that, there is no problem when he goes voluntarily."*

The same participant also mentioned the difficulties she experienced in communicating with health workers:

"When I was in such a board, I mean, the authorized professor there, I asked them to hear our voice. I said where to report such difficult patients. I said if you could be an intermediary, I said at least at home when we can't get them out when they don't go, I said at least at home, I said if their blood was taken or something, I said if they were looked at. When I said that our work would be easier for us and the hospitals, the woman shouted at me, she said get out, she said don't occupy like this, she said to the board. What else should I say, I mean, who should I tell my problem to." (participant1)

Participants stated that their children need to have a health report in order to be exempt from military service and to work in the disabled quota within the state. Participant 2 expressed difficulties in the bureaucratic process and communication problems with doctors before obtaining a health report for her child:

"I mean, I'm trying to say that he was diagnosed in 2001, but I've been dealing with it since '85. In the meantime, there was the military service. Soldiers came to pick him up from home one day. We found someone from the air force, this psychiatrist soldier in the first year. He said Ali could do military service, but he said it was dangerous for the first two months of training. That year they gave Ali a leave of absence. The next year they gave him a reprieve again. After 3 times, he was exempt from military service. What I went through, what sadness, how hard we tried, we go there. If it's schizophrenia, you get a report and it's over. There's a guy called C.G. I take him to a psychiatrist and pay a lot of money. Mr. C. I say let's do some therapy or something. He says, "What are we going to do?" He says, "Look at his hands, they're all red." The guy almost

beat us up. I'm crying, I'm asking you to guide us, please write something heavy so we can get a reprieve. I mean, the devil says, get up and give this guy a punch. Anyway. He tells me that I wrote something a bit too heavy, don't read this and cry."

Participant 8 stated that he thought that individuals diagnosed with schizophrenia should be adequately supported by the state and that different centers should be established for these patients:

"I am sad about only one thing. The constitution says social state, but there are no serious institutions for such patients. For example, as an association, we went to the state ministry responsible for the family on the Eskişehir road. I looked of out the window and the land was empty. For example, wouldn't it be better if they gathered these children and took them to plant vegetables and fruits, so that they could learn by working in life? No one thinks about that. There is a bureaucracy, and they think they have done something. For example, if you go to Sakarya Street, there is something under Çankaya Municipality, the Çengel Café, for example, they gave that place to people with Down Syndrome and they work there. I wish something like this could happen to them. They can do such non-hazardous work. Not cutting and mowing. Because their attention is distracted. They can do some things. There are no such places in Turkey. I mean, that's what I feel sad about. Everyone has a duty here, parents, the environment, the state, as well as us."

4.2. Subjective Burdens

Subjective burden encompasses the difficulties experienced in the world of emotions, attitudes and feelings of parents who are caring for a child. Therefore, subjective burden includes a more personal assessment of the caregiver. Subjective difficulties perceived by the participants about the illness and the caregiving process are included in this theme which are (4.2.a.) Unfulfilled Expectations from the Child, (4.2.b.) Difficulty in Understanding the Illness and Confusion, (4.2.c.) Emotional Distress.

Figure 4.2. Subjective Burdens Code Map
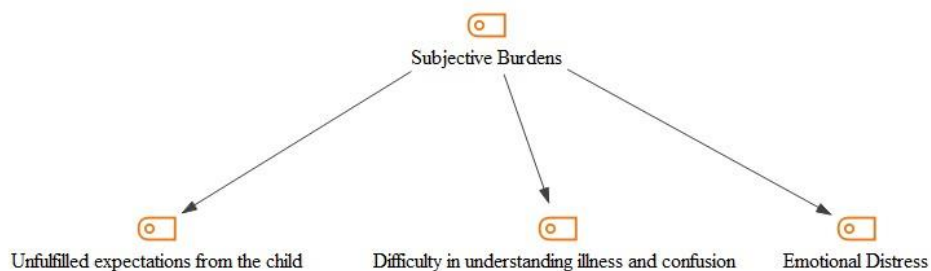
4.2.a. Unfulfilled Expectations from the Child

This sub-theme deals with the participants' unmet expectations they had about their children's future. All but one of the participants stated that they live with their children. Three participants stated that their children worked as a civil servant, and all participants stated that their children were single in terms of marital status. All participants in the research stated that their dreams for their children's future were not fulfilled and their expectations were not met. However, some of these participants also emphasized that currently they had low expectations from their children, stating

that they now only expected their children to be able to perform their daily activities (e.g., self-care).

Participant 5 stated that her child had a very successful educational life before the symptoms of schizophrenia appeared and that both her child and her expectations for the future were different. She explained this situation as follows:

"After that, unfortunately, we learned that he had schizophrenia. Of course, I mean, how can I explain it, it's so difficult. I mean, imagine you have a very smart child, someone who entered a high school in the 7th thousands rank in Turkey, then entered ITU, then METU. He has completely different dreams, never mind our sadness, but he is going to a place where his dreams will not come true. It is very sad to see him. There are thousands and thousands of painful things that happened."

Participant 9 expressed her unmet expectations regarding her child's education and marriage: *"I wanted them all to be university graduates. I wanted them to have good marriages. It didn't happen."*. Participant 4 drew attention to a different point from the other participants and stated that she lost the expectation that her child would play a role in her life in different ways and that this situation made her feel lonely:

"Of course, I had great expectations. I mean, he will study and have much better professions. Maybe he will come back and help us in another way. He will play a role in our lives and so on. But now when I cry, I cry alone. I solve my problems alone. I don't get any support from him."

Participant 3 emphasized the expectation of her child to establish an independent life: *"If there was no disease, Beril could stand on her feet. For*

example, Beril may not get married now, but if only she could manage her own life

on her own.".

4.2.b. Difficulty in Understand Illness and Confusion

This sub-theme includes the situations that the participants had difficulty in making sense of the process their children went through and the confusion they experienced.

Participants often mentioned difficulties in making sense of symptoms. They stated that this difficulty in making sense was higher, especially in pre-diagnosis times and when they had less knowledge about the nature of schizophrenia. Participant 2 gave the following example:

> *"I went to South Hampton, Zehra is calling, Merve Abla Ali is washing everything in the house. The quilts, pillows, it doesn't dry in the house. Playing with water...Then I went back and went to him, and he said, "Mom, I'm going to shave." I said okay, and he came in, and his head was a little shaggy here and there. I was really upset when I saw it. I immediately went to a psychiatrist, first I told him about it and then he took Ali. Ms. Merve, she said, Ali had a 50 percent transition from obsessions to schizoid symptoms. I said what are we going to do? He said we'll hospitalize him. I said, "Ali, do you want to be hospitalized?" Ali's answer was "I would be happy to."*

All of the participants who had difficulty making sense of their experiences expressed their experiences in a retrospective way of thinking. They stated that this difficulty in making sense decreased as they gained knowledge about the disease or

became accustomed to their children's behaviors. Participant 3 stated that she could not immediately make sense of what her child said, but as she thought about it, she tried to understand it by making a connection with the disease:

> *".... Before the devil, there was this thing, the woman above us, the family above us are neighbors, I mean they are newly married, it's been three years or something. My daughter says that the woman upstairs does this and that (jumps on her feet) to disturb me, she gets up at 5 o'clock at night. Until I get used to these things, I say why would she do that, the woman has a child, who would get up at five in the morning like that. She says, "You love her, you support her, I know you." No matter what I say, she doesn't believe me. Now that is forgotten. And then this devil appeared."*

Participant 5 expressed her inability to make sense of her child's changing behaviors during the attack period as follows:

> *"... The last time it was reduced to a very low dose and unfortunately it was probably the first attack. We don't know if it was an attack. It was snowing in Istanbul, and he started to go to school in a sleeveless shirt while it was snowing. I couldn't believe it, I couldn't understand what was happening, I was calling the psychologist, I was calling the doctor, what was happening to my son."*

Difficulty in making sense of the situation leads to inner confusion. The confusion focuses on the participants' reactions to their children's fluctuating moods, changing abilities, being physically present but not always psychologically available, and the fact that life goes on despite all this. This confusion creates a further complication where parents do not know how to treat their children. Participant 1

talked about the confusion created by the fact that life goes on despite the challenging experience:

"One of the children is doing his master's degree and the other is in the hospital. We're invited to a wedding; I'm crying my heart out but I'm grinning. I mean, I'll never forget it, I'm crying my heart out. We were dancing with Kerem. I say, "What kind of a situation is this? Someone's in the hospital, we're at a wedding, you can't miss it. I mean, it was very...Now it's ashes now, but it was very difficult at the time."

The fact that the children of the participants are older and look physically healthy increases the confusion experienced by the parents. There is confusion about how much responsibility their children can take, what they can and cannot do. Participant 6 stated that this was not a problem for him, but that his wife was confused about the activities his child could do. It is seen that this ambiguous situation can be interpreted differently by family members. Participant 6 stated this situation as follows:

"His mother especially has some complaints, to be honest, he does his own self-care to a great extent, but he still does things like brushing his teeth and making his bed without being told, of course, but cursory is not very good. His mother wants him to help her in the kitchen and do some chores. He doesn't do them, he can't do them, we see an extreme laziness, but of course he can't help himself. I understand him, but her mother sometimes gets angry. Like you can't do this or that. That's why sometimes there is yelling and talking loudly."

The fluctuating course of the disease was also mentioned by the participants as a challenging factor that created confusion about how to treat their children. Participant 7 stated this situation as follows:

"So, you don't know how to behave, you can't communicate. It always feels like it will pass, like it will pass. Suddenly it's like he's going to get rid of it for good. It's up and down. Sometimes good, sometimes aggressive. So, you don't know what to do. You must choose your speeches. You can't always do that either."

4.2.c. Emotional Distress

The participants stated that after their children was diagnosed with schizophrenia, they experienced many challenging life experiences such as changing relationships within the family, changes in their children's lives, difficulties related to the treatment process, and difficulties with the social environment. Emotions such as sadness, fear, guilt, hopelessness can be counted as emotions that provide the expression of emotional distress. Participants mentioned many emotional distress symptoms related to the process of caring for their children with schizophrenia. Some of these emotional distresses are similar to the emotions included in the definition of grief in the literature. For this reason, this sub-theme focuses on emotions such as sadness, guilt, helplessness, fear, loneliness, anxiety, which can also be found in the grief process mentioned by the participants.

Two of the participants directly mentioned the experiences emphasized by the phenomenon of grief. For example, participant 5 emphasized the freezing of life after the experience:

"Now he works for the state. It has been two years now, but of course it is a very, very difficult process. I mean, I always say the same thing when I am asked to describe it, there is an earthquake and you are buried under it, but you don't die. I mean, you say you want to die, but you don't die. You never live. And you live there for years. You just breathe for years. It was the same for us. I mean, I always think about that. We just breathe under the rubble, but we don't live in any way, it is very difficult."

Participant 4 seems to be describing the ambiguous loss she experienced and her grief reaction to it:

"For example, I have a son, but how much is he in my life? It's like a one-sided relationship. Yes, I love him very much and I am happy to be with him, but of course there are periods when we can't have a full mutual dialog... Because no matter how much we get used to it, there is a wound inside us that never goes away. We cover it up and walk around, we try to return to normal life, but it is very difficult to walk around with that wound inside us. "

Although other participants did not directly emphasize the phenomena of loss and grief, they talked about the effects of the experience on them and the emotions they felt. At this point, the most common emotional reaction of the participants was sadness. Participant 1 expressed the sadness she experienced after her child was diagnosed with schizophrenia as follows: *"I own the patent on these analogies: Ankara collapsed, and I was underneath it. It was like a tank ran over me. So, both of these... I can express it this way. I was ruined, I went up in smoke."*.

Another common emotion among participants was guilt. Guilt is often accompanied by the participants' belief that it was something they did wrong that

caused their child to become ill. Participant 2 stated that she and her husband had difficulty accepting the illness and were looking for a reason for the illness; they blamed themselves: *"So, it is very difficult to process it. This time we started to say with her father, is the problem with you or me, is it in your family or in my family."* Participant 7 also mentioned that after the onset of the disease, she thought that schizophrenia emerged because she could not provide adequate care to her child because she worked during the years, she was raising her child:

> *"Before that, I was working, so I couldn't understand his childhood at all. I mean, I couldn't pay too much attention because shift work is like this. If I go in the morning and come back in the evening, I pick her up and I'm always with her. But since you work the same shift for 6 days...Now, when you are a daytime worker, you come after 3pm, okay. But for a week you go at 3 and come at 11. For a week, you go at 11 and come in the morning, you will sleep in the morning so that you will go back to the shift at 11. So of course, I couldn't be very interested, to be honest. But of course, it is not enough for the elders to take care of them. Motherly affection is different. Now I think that if I had the opportunity after I retired, if I was younger, then I would have raised my child myself, but sometimes I also say that I blame myself so much, but there is no such thing that families who raise their own children will not have this disease. When I think of it like that, I say that if I had raised it myself, it would have happened. "*

Some other common emotion, helplessness, includes the belief that the person does not know how to cope with the problem and that it will not get better. Participant 1 stated that she did not know the steps to follow in the treatment process

and therefore felt helpless along with sadness*: "It upsets me a lot, it upsets me, I mean, at that time, you know, it was more like a helplessness, what am I going to do or what am I going to do. You know, I am not an educated and cultured person...".* Participant 5 mentioned that she did not know how to treat her child due to the confusion caused by the disease and that this situation made her feel helpless:

"I mean, it is such a difficult disease, there are times when you feel so helpless...Especially not knowing how to behave when he has an attack, the fear of doing him wrong in the slightest thing you experience, the fear that I shouldn't do anything wrong, I shouldn't do anything wrong...It sometimes makes you unable to move."

The feeling of fear emerged as a reaction to the changing intellectual and behavioral processes of their children. Participant 1 expressed her fear that her child would inflict physical violence on her due to her worsening symptoms:

"Since he did not receive a complete treatment, his illness became more severe and chronic. I don't have enough power, dear, if I go to them, they will hit me, they are boys, I put up with whatever they say, what can I do, this is how our life is going on."

Hopelessness, another common emotion, reflects the participants' pessimistic view of their children's future. Participant 7 and Participant 1 expressed this feeling as follows: *"... Well, none of my expectations were met, I think it is not good, I mean bad. I mean, there is no hope, there is no hope." "Well, from time to time, when these attacks are frequent, sometimes I say, I mean, how long? How long will this go on like this? Of course, there are times when I am pessimistic and unhappy. I would be lying if I said I don't."*

The feeling of loneliness describes a state of feeling abandoned by their families or social circles in the process of caring for their children. Participant 9 stated that she felt this way because of the social support she did not receive from her social environment: *"I've been through so many difficult things that if I wasn't alone, maybe if there was someone who understood me. I say maybe, but I wouldn't have experienced these things, it would have been superficial. ".* Participant 5 stated that she felt lonely because she did not know anyone else who had experienced this disease after being diagnosed with the disease:

> *"So, my biggest thing about this is that when you first meet this disease, the Mavi At Kafe or the association should be recommended. It was not recommended to us. I felt very much in need during that first earthquake. There must be someone who is going through this, with someone, at that moment you think that no one else is going through something so difficult. You can think that very few people are going through it. And you always feel like they are hiding it because you don't know. I mean, it is a very important illness that you don't know at all."*

The feeling of anxiety usually arises in response to an unfortunate situation that is expected to occur in the future. In line with this definition, participants often talked about their future worries about their children's situation. Participant 8 stated that she is worried about what would happen to her child after her death:

> *"Well, I feel like this, as long as I live, there is no problem, but I think about what will happen after I am gone. There is no proper institution to take them, to do something there, to place them, there is nothing like that. We went to some places, a special place. It is no different from a prison.*

Everything is made of iron. The bars are all iron. People get ill there anyway."

Participant 10 expressed similar feelings and thoughts as follows: *"Since life goes on, since our conditions are obvious, how can we best continue this life in these conditions? But what worries me the most is after me.".*

4.3. Family and Social Burdens

This main theme covers the difficulties experienced by the participants within the family and with their social environment. Participants stated that they were emotionally affected by these difficulties. The Family and Social Burdens theme includes two sub-themes. These sub-themes: (4.3.a.) Challenges with the Family and (4.3.b) Challenges with Social Network are presented in the sections below with quotations.

Figure 4.3. Family and Social Burdens Code Map
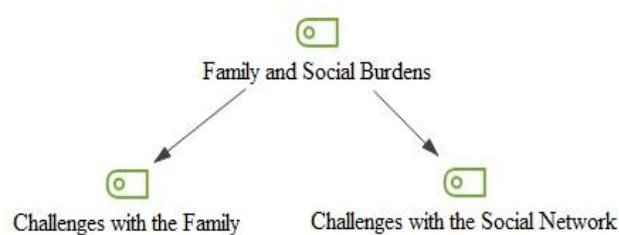
4.3.a. Challenges with the Family

This sub-theme focuses on the familial difficulties experienced by the participants after their children were diagnosed with schizophrenia. Participants

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mentioned different dimensions of the family difficulties experienced. Situations such as disagreements within the family, confusion of roles, neglect of other children, distancing or ending of the parental relationship are within the scope of this sub-theme. For example, Participant 5 stated that her husband had difficulty in accepting the disease and that they sometimes had conflicts because of this:

"From time to time, there were periods when my husband and I fought a lot. Unfortunately, I was always the one who tried to get more information on this subject. It was so, so my husband had a much more difficult time accepting it. When that happened, I was always the one who got more information. I, found the Mavi At and the association in Istanbul. I was always the one who tried to learn more information and teach my husband. I wanted to act right for my son and do the right things for him, and I also had to teach my husband about it. Because he didn't accept it, he didn't have it in his nature to be very inquisitive or to try to learn anything about health or such issues. When I saw him behaving in a wrong way, I would get very angry. We would have arguments at that moment."

Participant 4 stated that after the diagnosis of the disease, her husband could not adapt to the situation and their relationship ended:

"But I warned my husband about that, I told him not to stress and not to raise his voice. After that, he stopped, but he also stopped his dialog with us. He punished us, he acted as if we were the guilty ones, as if we were complaining about him, as if we were exposing him. Then our dialogs broke down and we are now separated."

Participant 9 mentioned that she thought that she neglected her other children while taking care of her diagnosed child and that her husband did not support her in this regard:

"My younger son got married. For example, I went to Van for Murat (the child who diagnosed with schizophrenia), I was telling their father to take care of the children in his spare time. But he doesn't. My husband always had this nature, to entertain himself with his circle of friends. They are not in the plan. Especially if a child has been diagnosed, it is necessary to get these children together. When I came back, I didn't find both of of my children well at all. What happened was that my child made a wrong marriage. The children started throwing themselves out of the house. They picked up bad habits, bad environment. Selim (brother of the diagnosed child) took drugs for a short time. But he recovered, there is nothing like that now. Melih (other brother of the diagnosed child) had a bad environment, bad friends, he dropped out of school."

When the discourses within this sub-theme were analyzed, six mothers stated that their husbands had difficulty in accepting the disease or still did not accept it; three of these mothers stated that they and their husbands separated after the diagnosis of the disease. This numerical rate shows the impact of family challenges on marriages.

4.3.b. Challenges with the Social Network

The sub-theme of challenges with the social network covers the avoidance of being involved in social relationships mentioned by the participants or the situations where contact is avoided by the social environment. Most of the participants'

statements included in this sub-theme pointed out that they preferred to remain socially isolated for certain reasons related to schizophrenia. An untidy home, the thought that the child's appearance will be considered strange by the society, the distancing of the social environment by the events experienced during the attack periods and the belief of the parents that they will not be understood by the social environment bring about social isolation. For example, Participant 4 stated that she avoided entering certain social environments with her child due to the difference in her child's physical appearance as follows:

"Well, I suddenly cut off my dialogues, I didn't want to see anyone. Sometimes, for example, I didn't go anywhere with my son at that time. For example, we didn't go to my workplace with my son, we didn't go to friends and relatives with my son. It was a bad process because there was something that was noticed from the outside without him being very aware of it. He had a difference when observed. For example, he was wearing shorts in the middle of winter. Or he wasn't combing her hair, he was growing it out, dyeing it in irrelevant colors. You know, I didn't want it like that. "

Participant 9 stated that due to her child's condition, she could not receive guests at home or go to some places, and that there were moments when this situation was not understood by the social environment:

"Family visits, visiting relatives, receiving guests. For example, I would say, "I'm sorry, I'm sorry, I can't take you, I can't accept you, I can't come." Or if my son had an outing, for example, my brother would come over, they would come to the house, my brother would come over. Murat would say what are you coming every day, every day. Actually, he's not

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like that, he's very loving, very hospitable. He said sit at home, don't come, and one day I looked, and my sister was crying. I said don't cry, you see, he's a patient, so why are you offended. If you're offended, if you're crying, I said I'm sorry. You need to understand."

Participant 6 stated that he thought that his child was excluded by the social environment:

"They are generally understanding, but I think they are also a bit hesitant. Young people, especially children and their families, those who are Barış's age or a little younger, don't seem to want to meet much. I mean, it is as if there is some exclusion for him. If not too much."

Participant 1 explained that after seeing her child's behaviors during the attack period, she thought that family members distanced themselves and their children:

"At some time, of course, especially during the attacks, I guess they are scared too. For example, one of my brothers distanced himself from me when Görkem hit the windows."

The sub-theme also covers idea that the participants sometimes felt that they were not understood by their social environment, that they did not receive the support they expected from their social networks, or that they were exposed to discourses about the stigma associated with schizophrenia. For example, Participant 9 stated that she felt that she was not understood by her social environment and that she did not receive the social support she expected:

"You expect help from your first-degree relatives as support, but I expected it, but I didn't get it. They didn't support me; they didn't support me, and they became a burden. They come home, for example, a relative,

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I can't accept them because I can't right now, my child is important. And my first-degree relatives, my husband or me, used this word a lot: "When something happens, you immediately take hiding behind the children, a solution, a salvation". No, it is not. At first, I acted like this with a lot of things, so as not to offend them, but then I realized that there is no such thing. The health of my child is important."

Participant 5 emphasized that she felt that she was not understood and criticized by her social environment:

"I mean, this is what happens Ms. İrem, no one can understand you. I accept that they have very good intentions, they have always tried to help. Only those who are going through the same thing as us can understand us, they can't. Sometimes they criticize you, for example, if you do it like this, it will always be like this. I don't know, my son started working, for example, he can't take the shuttle service to and from work, we drop him off. One of my brothers says, "Oh, you want it to be like this all the time, just let him go." It seems like we, arbitrarily, drop him off and pick him up in the morning. They don't understand the subtleties, whereas it is necessary to go step by step, it is not possible to withdraw suddenly."

4.4. Coping

One of the research questions of the current study is how parents cope with the burdens they experience and as one of these burdens, the ambiguous loss. The findings show that the participants coped with the difficulties they experienced with the help of (4.4.a) Cognitive Coping, (4.4.b.) Behavioral Coping, (4.4.c.) Coping

through Social Support and (4.4.d) Coping through Psychiatric/Psychological support. The findings of these sub-themes are presented below.

Figure 4.4. Coping Code Map
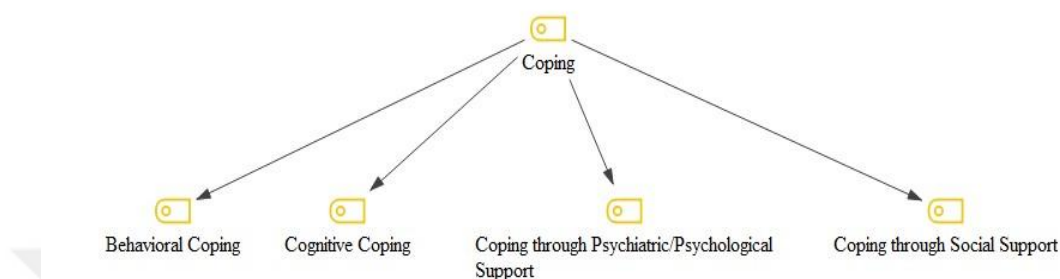
4.4.a. Cognitive Coping

Cognitive coping sub-theme includes the mental strategies that people develop to cope with stressful situations. In the data obtained from the participants, it was noteworthy that there was a transition from denial to acceptance of the disease over time. Most participants also stated that being informed about schizophrenia was a helpful factor for them. Participant 4 said the following about this situation:

> *"I never thought about it, and I was a bit scared, this is a serious problem, but I never thought about what it was. When the doctor told me, I didn't accept it. I said no, it can't be, my child was misdiagnosed. I mean, it could be another psychiatric illness but not this one. Then I learned that each schizophrenia patient is unique, and each one experiences the process in a different way. Then I was relieved, I mean I was relieved when I started to learn a little more."*

Participant 6 stated that he interpreted schizophrenia as a test due to his religious beliefs, so he tried to overcome this difficulty by trying to be informed about the disease:

"But in the meantime, as we learned how to overcome the disease through treatment, we found some consolation and turned in that direction. I mean, we learned that we need to overcome this difficulty together, to help each other, to overcome it together. And as I said, since we are people of faith, maybe this is a test for us in the world. Therefore, we need to pass this test successfully. In that respect, we don't really have any complaints."

Participant 8 emphasized a realistic view of the disease, stating that he had no other choice but to accept it and therefore adopted a solution-oriented way of thinking:

"When it happens to you, you learn more about some things. Then we found that association through a friend of ours.... I mean, of course, no father, no parent would want their child to be in this situation, but there is also the reality. This is the reality. I mean, living face to face with this reality, living in the same place, etc. becomes an inevitable situation. We had to accept the fact that there is no cure for what happened to the deceased, as they say among the people. What can we do based on this reality; I am personally at that point now."

One of the cognitive coping strategies is to adopt an avoidant mindset to minimize the impact of the current situation. Participant 9 stated that she thought that she needed to get away from her negative emotions in order for her children and herself to feel better, and she expressed this as follows:

"Being positive, as much as possible, how sad you are, you're a mother, you're so full, you're so full all of a sudden, but not in front of them. I try not to reflect it, when they come in, it's as if the atmosphere is very happy and everything is fine. They are also looking, they are aware of it, but even if you don't reflect it, I don't reflect it to them (to her children), it feels like my mother is happy. They are happy too, and when they are happy, I am happy too. I help them all together. This is a good thing. You will adapt yourself to that environment. You know how an actor goes on stage and is happy with success because he thinks he did well? This continues throughout his professional life. I've become like that now. I go on stage once and I get here as soon as I can."

Participant 4 also stated that she thought it was functional for herself and her child to keep a distance from her emotions: *"When I say that it has changed in a positive way, I mean that I have learned not to be sad. If I say that this is how my daughter is and cry for three days, I cannot be productive for my daughter."*

One of the cognitive coping strategies expressed by the participants is the strategy of looking at events with hope and optimism. Hope is associated with the belief that one will have positive experiences in the future. Some of the participants stated that this hopeful perspective was one of their personal characteristics, while others stated that they were hopeful by interpreting the good progress of their child's treatment positively. For example, participant 9 stated that the progress of her child created hope for her: *"...my son's well-being gave me hope. As my son's recovery period progressed, he said that these things are not important for me. I am happy, so I am not sad."*. Participant 5 emphasized that he preferred to be hopeful as a personal perspective:

"I always believe that there is hope. For example, during the days we lived during these events, my husband was saying let's get in the car and all three of us commit suicide. I remember I was very angry, I said you don't have that right. Every day something new may come out, a new medicine may come out. I said there is always hope, there is hope as long as we take our last breath. I thought his suggestion was ridiculous. I mean, I said you have no right to do anything about his life on his behalf."

In summary, within cognitive coping strategies, participants talked about the stages of transition from denial to acceptance, the emotional relief they felt as they learned more about the schizophrenia, and the benefits of having a positive or hopeful outlook towards events. In addition, some participants stated that they cognitively adopted more avoidant coping strategies; they thought it was necessary to distance themselves from their emotions.

<u>4.4.b. Behavioral Coping</u>

Behavioral coping sub-theme involves the processes by which a person tries to cope with a stressful situation or event through actions. Unlike cognitive coping, behavioral coping strategies consist of trying to cope with the situation through some activities. Participants gave various examples of behavioral coping strategies; these examples consisted of processes in which they were behaviorally active. Participants' motivation to get information about the nature of schizophrenia is associated with cognitive coping strategy. On the other hand, the active efforts of the participants to be informed about the illness, attending trainings organized in associations, and

reading books about schizophrenia were evaluated within behavioral coping strategies. Participant 10 stated that working life helped her to cope as follows. *"I can say that working life saved me. You forget everything when you go there. It is a very nice school, very nice environment. The children they have are perfect and so are the parents. It has a different satisfaction.".* Participant 9 stated that activities such as walking, solving puzzles, and singing songs were good for her and that this well-being was reflected on her child:

> *"For myself, I take a walk in the open air. Even humming a song. All songs, folk songs, art music, it doesn't matter. I read books, I do crossword puzzles. Or I like to go out and walk alone, look at shop windows, these kinds of things make me happy. And when I am happy, it means that I have taken a few steps forward for my son today. If this is reflected in my home, in my children."*

Similarly, participant 4 also mentioned that having a hobby and a social life is beneficial for her and her children:

> *"Now I have a life too, I have to stay social, I have to build my life outside of the disease. I have hobbies, I have new hobbies, I have new friends, I can take both together. I have seen that I can take it healthier, and I am more productive. The children are happy about it too. "*

Participant 1 stated that going to and from the association and activities such as knitting gave her a sense of relief:

> *"Now, my dear, coming and going to this association relaxes me. here, I cook, I make tea. you know, I want to be of some use to someone, and these are sick children. when I am free, I knit, I give gifts to friends and*

relatives. I mean, I don't read much. there is no time, house cleaning,

children.... sometimes I go for a walk. I mean, I educate myself, I have to

be grateful."

4.4.c. Coping through Social Support

The person facing a challenging situation may seek support from family members, friends or an institution/organization. Therefore, social support from the environment forms the basis of this coping strategy. Many of the participants stated that the social support they received through the associations was good for them. They evaluated this social support from different perspectives. For example, Participant 1 emphasized that having similar experiences facilitated understanding:

"...next, she saw that there was a bazaar under Armada, the Association

for Solidarity of Schizophrenia Families, and she immediately bought a

card. She forced me and Ali to go there. It was very good for Ali, the

association was good for me too because even if you don't know them,

there are people you have something in common with. He started to draw

pictures. It's like that, you know, the one who falls off the roof

understands the plight of the one who falls off the roof."

Participant 5 stated that they were able to find different solutions to their problems thanks to the association:

"Because they understand us the most and we can understand each other.

A problem that one of us cannot solve, the other may have solved it in a

different way. Then you get ideas from them. In your search for different

ways, there is another hope, and you can try it. I mean, this applies to so many things. "

Participant 7 mentioned the positive impact of listening to the experiences of different families*: "I benefited a lot from this place, when I listened to the stories of the families here, I was grateful most of the time."* Participant 10, unlike the other participants, stated that the support she received from her husband was good for her as follows:

"I got married again after my separation. He became a good friend to me and my son, and a good father. Since he was older than me, he was more insightful. He probably helped me get through this process. We built summer houses on plots of land; we went and came and so on. We built a life for ourselves."

4.4.d. Coping with Psychiatric/Psychological Support

Coping with psychiatric or psychological support appears to be another coping strategy used by participants to cope with the challenges of caregiving. Six of the participants stated that they have been taking psychiatric medication regularly or as needed since the onset of their child's illness. One participant stated that she was undergoing psychotherapy along with psychiatric medication. This participant 4 stated that the awareness she gained in the therapy was beneficial for her and summarized this situation as follows: *"Then when I started to receive therapy, I learned that when everyone stays healthy and lives in more humane conditions, depression decreases, productivity increases, and our communication with each other becomes better..."*

4.5. Explanation of the Relationships between the Main Themes

In this section, the relationship between the main themes will be briefly explained. The Figure 4.5. below shows the relationship between the main themes.

As can be seen in the figure, there are interrelationships between the themes of family burdens. For example, an increase in challenges related to caregiving, which falls under the main theme of objective burdens, may increase emotional distress, which falls under the main theme of subjective burdens. On the other hand, the opposite relationship may also be possible; an increase in emotional burden may lead to a more intense perception of objective burden. To summarize, objective burdens, subjective burdens, family, and social burdens are closely related to each other and affect each other reciprocally.
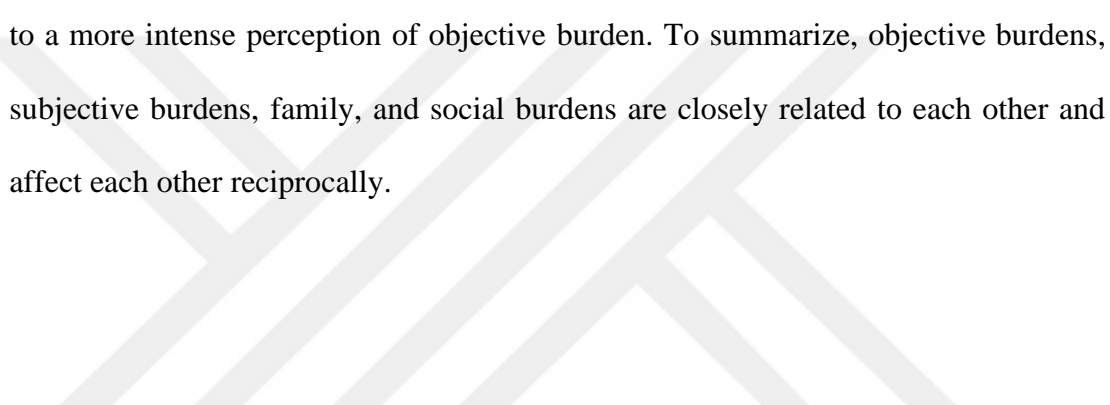
Figure 4.5. Explanation of the Relationships between the Main Themes
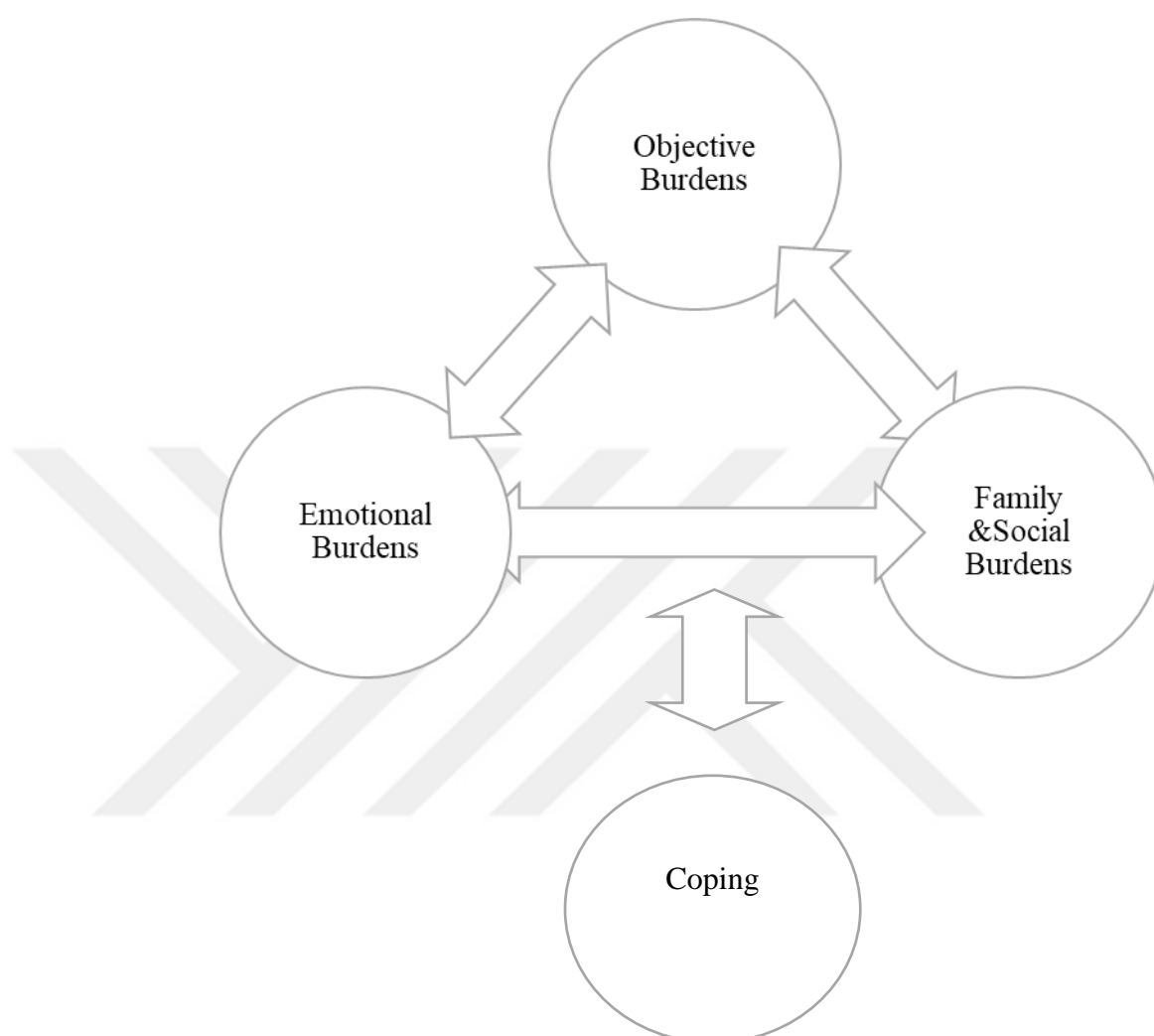
A similar relationship was also emphasized by Williams- Wengerd & Solheim (2021), saying that parent and adult child relationship are interdependent. The cyclical relationship between these three burdens has the potential to determine the way of coping; on the other hand, the coping strategy chosen to cope with difficulties may affect the existence of burdens or their perception by the individual. For example, a participant who thought that she did not receive support from her social environment stated that she thought that not showing her emotions worked as a coping strategy. On the other hand, a mother participant who stated that she was

behaviorally active and talked about her hobbies stated that she spent more time for herself. She stated that the more behaviorally active she was, the better she felt, and the better she felt, the more behaviorally active she preferred to be. Therefore, the relationship between the burdens of caregiving and coping appears to be bidirectional. In the next section, the findings obtained from this chapter will be discussed together with the findings of the related literature.

CHAPTER V

DISCUSSION

In this section, the results of the qualitative analysis of the data obtained from ten participants will be discussed. Before discussing the findings obtained from the interviews, it would be useful to briefly review the sociodemographic characteristics of the participants because some sociodemographic characteristics seem to be closely related to caregiver burden (Awad & Voruganti, 2008). In line with the literature, the majority of the participants were mothers who care for their children (Wiens & Daniluk, 2017; White & Unruh, 2013). Williams-Wengerd & Solheim (2021) attributed the fact that the majority of the participants in the studies were mothers to the gender-based assigned parental role of mothers. It is thought that a similar situation is also valid in the Turkish sample, and in most circumstances, mothers are the primary caregivers of their children with schizophrenia (Karanci, 1995). Systematic reviews of studies with parents caring for their children with persistent mental illness reported that the age of caregivers ranged from 40 to 84 years, while the age of diagnosed children ranged from 18 to 55 years (Wengerd & Solheim, 2021). Similar to the literature, the age range of the participants of the current study was between 52 and 80 years, while the age range of children diagnosed with schizophrenia was between 29 and 59 years. Thus, it can be seen that the participants are in a progressively older age range and thus may be in a particularly vulnerable group with their own needs for care. Another important demographic variable when it comes to caregiver burden is socioeconomic status. Socioeconomic status is a factor that affects people's access to economic resources, mental health and other

health services, and some social networks (Wengerd & Solheim, 2021). When the literature is examined, it is seen that there is a gap regarding the socioeconomic status of caregivers. In the current study, participants were asked to rate their socioeconomic status on a scale of 1 to 10. The average socioeconomic status of the participants was 5.7. Considering that half of the participants stated their socioeconomic status as 5 and below 5 and the other half of the participants evaluated their socioeconomic status as above 5, it can be considered that there is a homogeneous group of participants in terms of socioeconomic status. On the other hand, 4 of the participants stated that their children with a diagnosis of schizophrenia were working as civil service employees. The literature states that only 10% of people diagnosed with schizophrenia are employed (Marwaha et al., 2007) or more than half of people diagnosed with schizophrenia have never worked in a sustainable job (McGurk et al., 2003). The data obtained from the participants in the current study, on the other hand, presents a more favorable picture compared to the picture in the literature.

The findings obtained from interviews are largely in line with previous studies in the literature. However, the qualitative analysis method provided a more detailed and in-depth understanding of the nature of the participants' experiences. In the next section, the main themes and sub-themes presented in the results section will be discussed with reference to the literature.

5.1. Objective Burdens

The first theme obtained from the interviews with the participants is the objective burden experienced by parents caring for their adult child with schizophrenia. Objective burden includes the changes and difficulties experienced by

the caregiver in his/her financial situation, work, home, social life, and personal activities due to the caregiving situation (Magliano et al., 2005). Teschinsky (2000) classified the objective burden as the tangible effects on the family and defined the challenging behaviors of the ill person, role mixtures within the family and the financial burden of the illness as an objective burden. The participants in the current study also mentioned the objective burdens they experienced. Among these burdens, the sub-themes that the participants shared were financial loss, disruption of personal life priorities, challenges in caregiving and challenges with healthcare system, which will be discussed in detail in the following sections. Considering that caregiving burdens are interrelated, an increase in objective burden has the potential to increase other burdens. Under the main theme of objective burdens, there are four sub-themes: *financial loss, disruption of personal life priorities, challenges in caregiving* and *challenges with the health system.*

The first sub-theme *financial loss* focused on the financial losses experienced by the participants during the process of caring for their children. Participants emphasized that they experienced financial loss due to various reasons. The most common situation was the difficulties experienced due to the cost of the treatment process. Participants mentioned that they changed cities from time to time in order to receive the appropriate treatment for their children, and that they consulted different psychologists and psychiatrists to get different opinions about the treatment and the course of their children, which placed financial strain on them. In parallel with the current finding, a recent systematic review of 38 articles revealed that the care and treatment costs of people diagnosed with schizophrenia are covered by their families and that long-term medication creates a financial loss for families (Issac et al., 2022). The common opinion in the literature is that families caring for a child with

schizophrenia face a financial burden due to the costs of the treatment process (Karanci, 1995; Rössler et. al., 2005).

Some participants stated that they quit their current jobs after their children were diagnosed in order to provide better care for them. This situation negatively affects both the financial difficulties experienced by the participants and their career plans for the future. Ozlu et al. (2015) also pointed out in a study conducted in Türkiye that financial burden is characterized by families caring for a child diagnosed with schizophrenia and that families quit their jobs or look for part-time jobs to take care of their children.

The socioeconomic status of the family is seen as one of the most crucial factors affecting the extent of financial loss and its impact on the family. Zafar et al. (2013) reported that caregivers with low and medium socioeconomic status are more prone to experience financial burden. Five of the participants in the present sample chose 5 and below 5 on the socioeconomic level scale, ranging from 1 to 10. When the discourses of these participants about financial loss are examined, it is seen that they emphasized the economic difficulties they experienced and cut costs in other domains of their lives in order to provide appropriate care for their children. When the literature is examined, it is seen that poverty negatively affects the health of the child with schizophrenia and the burden experienced by families; therefore, it negatively affects the caregiving capacity of the caregiver (Caqueo-Urízar et al., 2016). When the findings from the literature and the findings of the current study are evaluated together, it is seen that financial burden is an important part of the overall burden experienced by the family. This is because financial burden also affects other aspects of caregivers' lives. For example, participants stated that they had to quit their careers when they could have advanced in their careers, had to sell their current

homes, or reduced their personal shopping. Lee & Cagle (2021) reported that objective factors such as caregiver's loss of job, limited insurance coverage, budget constraints, loss of saving, care related expenses create emotional distress in caregivers and affect their subjective interpretation of the illness. Similarly, in the findings of the current study, it is thought that the experience of financial burden may be a factor that may have affected the emotional burden felt by the participants.

The second sub- theme is *disruption of the life priorities*. Participants stated that they had to sacrifice and compromise other parts of their lives because they had the responsibility of caring for their children. This finding is consistent with the general findings in the literature. In the review study conducted by Issac et al. (2022), one of the challenges faced by caregivers in the reviewed articles is the inability to fulfill or postpone personal priorities due to caregiving responsibilities. In the current study, family members stated that their dreams of a future social life were not fulfilled due to caregiving responsibilities, that they could not go to the places they wanted to go to in order to care for their children, and that they had to quit their careers when they could have advanced in their careers. In addition, the participants emphasized that they prioritized their children and devoted themselves to their children when making decisions about their social lives. Ozlu et al. (2015) stated that the duration of caregiving is also an obstacle for caregivers to fulfill their own life responsibilities. In the current study, many of the participants stated that their children could not establish a life independent of them and that they had been providing care for more than 20 years. Most of the participants stated that this situation affected them psychologically negatively and that they felt that their expectations regarding their individual lives were not fulfilled. When the literature is examined, it is seen that disrupted daily life activities, routines and behaviors are

associated with high levels of caregiver burden (Martorell et al., 2011; Ochoa et al., 2008).

In parallel with the literature (Awad & Voruganti, 2008; Gülseren et al., 2010), the majority of caregivers in the current study were mothers. Participant mothers stated that they were both responsible for domestic responsibilities (cooking, cleaning, shopping, etc.) and caring for their children. This should be considered as a factor that makes it difficult for these participants to allocate time for their own life priorities (Isaac et al., 2022).

The disruption of caregivers' personal priorities is also an issue that can be examined from the perspective of ambiguous loss. Because in this sub-theme, parents underlined that they lost their personal priorities as a result of caregiving responsibility. Things such as the activities they gave up, the activities they dreamed of but could not do because of the caregiving responsibility, and the focus of their lives being on their children are indicators that the caregiver has lost their personal priorities. They have not only experienced the loss of their current social roles and routines, but also the expectation of losing their future (McAuliffe et al., 2013; Stein et al., 2013). Worden (2009) also stated that there are secondary losses following a primary loss; the primary loss in mental illness is the ambiguous loss of the child, which is felt due to the decline in the cognitive and emotional processing skills of the affected person (Wittmann & Keshavan, 2007). Disruption of personal life priorities can be interpreted as a secondary ambiguous loss caused by the ambiguous loss of the child with schizophrenia on the caregiver mother/father.

Not having information about the future of the illness increases the ambiguity experienced by the caregiver (Abrams, 2001) and prevents them from setting their plans and priorities for the future. In line with these findings, the fact that the

participants could not achieve the experiences they had imagined about the future is consistent with the literature and seems to be associated with the theory of ambiguous loss. Each postponed plan or dream can create a new sense of loss (McAleer, 2003). Thus, both the loss of unfulfilled expectations for the past and the possibility of realization of future expectations may be jeopardized with the current ambiguity. In addition, caregivers' inability to focus on their individual lives can create high expressed emotion. This can be a complicating factor for both the course of the child's illness and the parent-child relationship. At this point, it is very important for caregivers to create opportunities to allocate time for their own life priorities and to feel entitled to take steps for their own lives (Young et al., 2004). In order to achieve this, first, the health system and government support policies should be designed to reduce the objective burden on families. Secondly, the ability of families to create space for their personal lives should be supported by professionals working in the field through psychoeducation or family intervention programs.

The third sub-theme under the heading of objective burdens is *challenges in caregiving.* Information obtained from the participants revealed that the participants' children's older age, changes in daily skills periodically, and the caregiver's lack of sufficient knowledge about schizophrenia were factors that made caregiving challenging. The emotional, cognitive and behavioral changes experienced by a child diagnosed with schizophrenia cause a decline in daily functioning (Feldman & Crandal, 2007). For this reason, the participants stated that they helped their children to continue with their daily activities. Boss (1999) defined psychological ambiguous loss as a situation in which a person is physically present but not psychologically present. In parallel with this definition, although the families did not use the word "loss" when talking about the difficulties of caregiving, they mentioned difficulties

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that can be understood within the framework of the theory of ambiguous loss. After schizophrenia, their children's difficulty in doing the activities required by their age (for example, needing a caregiver to perform self-care) and the change in some skills and behaviors during episodes were described as challenging for families. The common feature of these challenging situations is that the child is physically present but is unable to fulfill the requirements of his/her age, or that he/she periodically changes psychologically and cognitively. Boss & Couden (2002) stated that the skill changes experienced during the illness process are as confusing as the illness itself. This objective burden, which includes the difficulties of caregiving, also affects the subjective burden experienced by families and their coping. Boss & Couden (2002) likened this situation to a roller coaster experience in which families alternate between hope and despair about their children's abilities and future.

Lack of sufficient knowledge about schizophrenia was also seen by the participants as one of the factors making caregiving difficult. Systematic review studies have also revealed that one of the needs of caregivers of individuals with schizophrenia is information and education about schizophrenia; moreover, prior knowledge about the disease has been reported as a factor that reduces confusion (Issac et al., 2022). Boss (1999) reported that people feel paralyzed and unable to take action when they lack clarity about a situation. In parallel with this situation, the participants stated that when they did not have enough information about schizophrenia, they were affected negatively with the stigma and were afraid or thought that the illness would be temporary; after they were informed about the illness, they accepted the disease and started to investigate how they should provide care. Therefore, having information about the disease is considered to be one of the

factors that reduces the difficulty experienced by individuals during caregiving and facilitate coping.

The last sub-theme *challenges with the health system* focused on the difficulties experienced by the participants in hospitalizing their child due to restrictions in hospital beds, communicating with health professionals, obtaining a report for exempting their child from military service or establishing a disability status, and the lack of an institutions in Turkey that supports them and their children with schizophrenia. Lack of adequate support from health professionals and institutions in the country is characterized by increased caregiver burden (Magliano et al., 2000, 2002; Chien et al., 2004). Systematic review studies have reported that the problems caused by the health system create frustration and helplessness in caregivers (Issac et al., 2022). The qualitative study conducted by Attepe Özden and Tuncay (2018) in Türkiye, with families caring for a child with schizophrenia also mentions similar findings; families mentioned the inadequacy of the health services they received and that there was no institution to take care of their children after their death. Difficulty in accessing health services and long waiting times to access treatment is a factor that increases the burden of schizophrenia for patients and their caregivers (Kamil & Velligan, 2019). At the same time, the information given to the family by healthcare professionals and the way this information is given is also seen as a situation that affects caregiver burden (Caqueo-Urízar et al., 2016). Issac et al. (2022) also stated that caregivers need to be able to communicate and cooperate effectively with healthcare professionals. However, Gülseren et al. (2010) stated that the treatment of schizophrenia in Türkiye is mostly aimed at reducing the symptoms of the patients and that the necessary support cannot be provided to the caregivers of the patient due to the lack of workforce of healthcare professionals. The findings of

the current study seem to be in parallel with the finding that the difficulties related to the health system mentioned in the literature increases caregiver burden. In addition, within the scope of this sub-theme, some of the participants mentioned that they dreamed of an institution for their children and themselves where they could socialize, receive support, receive different trainings, and be close to healthcare professionals; they stated that they could work voluntarily in such an institution. The findings of the current study, as supported by numerous studies in the literature (Awad & Voruganti, 2008; Kamil & Velligan, 2019; Attepe Özden & Tuncay, 2018; Issac et al., 2022; Di Sarno & Louzã, 2023), reveal that strengthening the resources of the health system and interventions organized for caregivers may prove to be one of the most effective ways to reduce caregiver burden. Policymakers in Türkiye need to take steps to ensure that families with schizophrenia and their children have easy access to health services and to build institutions to provide psychological support.

5.2. Subjective Burdens

The subjective (emotional) burden of caregiving is related to the emotional reactions of the caregiver to the difficulties experienced. Subjective burden was defined by Awad & Voruganti (2008) as the extent to which the problems associated with objective burden disturb the family, and by Magliano et al. (2005) as the psychological reactions of family members to the difficulties they experience, such as feelings of loss, anxiety, depression, and shame. In the current study, utilizing these definitions, we focused on the ambiguous loss and grief parts of subjective burden expressed by the participants. Young et al. (2004) criticized professionals working in the field of mental illness for focusing on concrete and objective matters while missing subjective, emotional, and symbolic expressions. Considering this

criticism, it is important to examine the subjective burdens that emerged in the current study in detail. It is believed that understanding the subjective burdens expressed by the participants by trying to understand them without pathologizing them will help build strategies to alleviate their burdens (Young et al., 2004). From this perspective, *unfulfilled expectations from the child*, *difficulty in understanding illness and confusion*, and *emotional distress* will be discussed within the main theme of subjective burden, as they are the most prominent sub-themes of the ambiguous loss and grief process.

The first sub-theme is *unfulfilled expectations from the child*. Within the scope of this sub-theme, the participants talked about their expectations for their children such as marriage, work, education, taking a role in family life, being socially active, and establishing a life independent from the family; they underlined that these expectations were not fulfilled or only partially fulfilled after schizophrenia. Parents may have expectations that their children will lead an independent life as they grow older, that caregiving will end, and that the relationship with their children will become more reciprocal (Williams-Wengerd & Solheim, 2020). Kagitcibasi (1982) stated that parents living in less developed countries, especially those with low socioeconomic status, attach more importance to the concept called "old age security" and that this concept reveals parents' expectations of their adult children both financially and psychologically. This finding seems to be supported by the current study. Some of the participants pointed out that they had expectations that their relationship with their children would become more reciprocal over time, but on the contrary, caregiving would be lifelong for them.

Parents may have certain dreams about their children's lives as they grow up, in terms of education, work, social life, and family formation (Williams-Wengerd &

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Solheim, 2020). Failure to meet these expectations is called "loss" as it is closely related to situations such as loss of the child's former or idealized state, loss of ambiguity and expectations about the future, and disappointment (Richardson et al., 2012). However, this loss is experienced with a relational change rather than a physical loss because the child diagnosed with schizophrenia is still physically alive. Therefore, this kind of loss involves ambiguity and is called ambiguous loss. The child about whom the parents have developed expectations and dreams is still alive; however, most of these expectations have not been fulfilled and there is no certainty that they will be fulfilled in the future. All these factors are confusing for families (Boss & Couden, 2002). To summarize, the first challenge arises from the continued physical presence of the person about whom the dreams are made; the second challenge arises from the ambiguous course of an illness such as schizophrenia. The fluctuating nature of the illness means that the person's abilities change periodically; it is often impossible for families to predict the next step (Young et al., 2004). Parents grieve for the hopes and dreams lost after such an ambiguous loss, but the ambiguity of the situation also complicates the grieving process (Williams-Wengerd & Solheim, 2020; Boss, 1999). The grief reactions of the participants in this study will be examined under the *emotional distress* paragraph.

Some participants made comparisons between their children before schizophrenia and after/now and emphasized that they used to dream of a different life for their children, for example, they thought that their children, whom they saw as successful and promising in education, would have very good professions in the future, but this did not happen. These statements are consistent with Boss & Couden's (2002) description of the fact that it is a contradictory and difficult situation for families when the diagnosed child physically exists but psychologically

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does not fulfill the expectations from before. At the same time, the effect of the change experienced by the child after the illness on the parents was explained by Miller (1996) and Osborne & Coyle (2002) as the parents' belief that their children had lost their real selves. Some participants emphasized the low expectations they had for their children; for example, they stated that they only expected their children to be able to do their daily tasks. It is noteworthy that some of the participants who emphasized this point were caregiver fathers. Unlike mother participants, father participants preferred to comment less on their expectations for their children, which indicates that the reasons for this difference in perspective needs to be investigated further. Considering the family culture in Turkey, the fact that the mother-child relationship is closer and based on sharing than the father-child relationship may be considered effective in this regard (Ataca et al., 2005). It is thought that one of the reasons for the difference in the perspectives of the participants who stated that their expectations from their children were low may stem from the parents' perceptions of their children's pre-illness selves (Osborne & Coyle, 2002). Parents' perceptions of their children before the illness, for example, always seeing their child as a difficult child or different from others, may be a factor that may affect the disappointment or sense of loss they experience when their expectations are not met after the illness. For example, Participant 7 stated that her child was very bright and successful before the illness and that she felt very sad that these expectations were not met after the illness. On the other hand, Participant 1 stated that her child had a difficult childhood before the illness, and when asked about her expectations, she stated that she had low expectations for her child. Thus, the pre illness capabilities of the child may shape the perceptions of the caregivers.

Although the participants' expectations for their children are in different areas and to different extents, the common point of unmet expectations is that they create a sense of "loss". However, the physical presence of the child diagnosed with schizophrenia, the lack of certainty about the course of the illness and whether their child will be able to increase their independence increase the ambiguity experienced by families (McAuliffe et al., 2013; Nyström & Svensson, 2004). The variable nature of the illness makes it difficult for families to understand what they have lost (Williams-Wengerd & Solheim, 2020).

The second sub- theme is *difficulty in understanding illness and confusion*. The concept of meaning defines events, people, objects, thoughts, that is, connecting fragmented information and establishing a relationship between them. Yalom (1980) said that people need to make sense of the situations they encounter because only through making sense can they acquire a framework that can explain the world and the events in the world. Schizophrenia is a mental illness in which symptoms may change periodically or from person to person; diagnosis, prognosis and treatment of the disease are difficult (Landon et al., 2016; Wiens & Daniluk, 2017). Therefore, the illness itself is characterized by complexity and ambiguity; it is very difficult to make sense of its symptoms and predict its future. With the exception of two mother participants (who mentioned that their spouses also had schizophrenia), all participants in the study experienced schizophrenia for the first time with their children. Therefore, the nature of the symptom's characteristic of schizophrenia such as hallucinations, delusions, speech impairment, catatonic behaviors and withdrawal create a difficult situation for families to make sense of. Participants reported that their children sometimes talked to friends who did not exist, laughed, or developed delusional beliefs about the people around them; in such cases, they felt confused,

frightened, and helpless. The study by Darmi et al. (2017) revealed a similar finding, stating that the symptoms of a serious mental illness cause parents to feel alienated from their children. In addition, studies show that parents may experience confusion about who their children are after the illness and therefore grieve the relationship they had with their children before the illness (Darmi et al., 2017; Johansson et al., 2010; Wiens & Daniluk, 2009, 2017).

While the symptoms characterized by the illness are difficult for the caregiver to make sense of, the ambiguous nature of schizophrenia also seems to make it difficult for families to meet the need for meaning (Wiens & Daniluk, 2017). Boss & Couden (2002) stated that when families cannot get precise information about their loved one's condition, they feel as if life is frozen, they postpone making decisions, roles in the family become unclear, and relationships become confusing. In addition, some participants stated that their children were adults and therefore they were confused about which responsibilities they could and could not take on. A person with schizophrenia may appear normal on the outside, so outsiders may overlook the inner world and psychological difficulties of the people with the illness (Boss & Couden, 2002). On the other hand, the condition of the child may sometimes be the same as before the illness, while at other times there may be differences in behavior and appearance due to increased symptoms (Boss & Couden, 2002). Therefore, caregivers may feel confused about their child's current situation. The rules, roles, and behaviors in the parent-child relationship change from day to day, so it becomes difficult to make sense of it (Boss& Couden, 2002). This state of confusion creates ambiguity in families about how to treat their children (Johansson et al., 2012; Kılıç & Saruc, 2015). At this point, the participants in the current study stated that they had more difficulties during the period when they did not have enough information

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about the illness, but they felt more comfortable as they gained information about the fluctuating nature of the illness and its symptoms. Some participants even expressed their motivation to understand the world of hallucinations seen by their children after learning about the illness. Therefore, it is thought that informing caregivers about schizophrenia by professionals working in the field will help to reduce the ambiguity they experience and make it easier to cope.

The last sub-theme under the main theme of subjective burdens is *emotional distress*. When losses occur in a loved one's personality, behavior and affect, the symptoms that caregivers show are often similar to melancholy or complicated grief, with depression and anxiety at the forefront (Boss, 2009). However, a death has not occurred; the loved one is still alive. Boss (2009, p. 140) described this as "part is gone, part remains." The ambiguous loss of their own life priorities and their children, the loss of social relationships, and the difficulties related to prognosis and treatment create emotional difficulties for the caregiver. Studies show that caregivers grieve the ambiguous loss they experience (Young et al., 2004; Richardson et al., 2012). In the findings of the current study, while some participants used expressions that directly defined the grief process, some participants talked about their emotional distress in the face of the difficulties they experienced. There may be different reasons why the participants did not call this process as a grief process. It is thought that the confusion caused by the continued physical presence of the child and the inability to recognize what happened as a loss may prevent the participants from placing their emotional reactions within the scope of grief (Boss, 1999). Another point is that the participants may not be able to place the experience in a context and make sense of it due to the fact that the grief process is not socially visible (Doka 1989; Young et al., 2004).

The most common emotional distress reactions among the participants were sadness, guilt, helplessness, fear, loneliness and anxiety. However, it should not be overlooked that these emotions may also be part of the grief process. Lafond (2000) pointed out that when the experience of parents is not framed as grief, it can be seen only as feelings such as anger, frustration, exhaustion, and this can lead to ignoring or pathologizing the feelings of the parents.   For this reason, the theme in this study was named emotional distress in order to have a more inclusive name, but it should not be forgotten that the emotions within the sub-theme include emotions that can also be found in the grief process. In parallel with this, Corcoran et al. (2015) also stated that parents who care for their child with mental illness experience emotional distress and grief during the caregiving process. As a result, the emotional processes expressed by the participants are consistent with the finding that families experience grief after a permanent mental illness as mentioned in the literature (Boss, 2009; Young et al., 2004, Osborne & Coyle, 2002; Williams- Wengerd & Solheim, 2021, Richardson et al., 2012).

Although most of the participants emphasized that they had accepted the illness, they stated that they were still emotionally distressed. Some of the participants expressed that they were emotionally distressed about their children's unfulfilled dreams, some about the lack of social support, and some about the future. The fact that the participants felt emotionally distressed and gave grief reactions even though years had passed since their children were diagnosed seems to be consistent with the finding that the grief process is frozen in a loss characterized by ambiguity (Boss, 1999). In the case of an ambiguous loss, it is unclear when the end of the illness will come, whether it will get better or not, there are no social rituals that make the loss visible, so the grief cannot be resolved and the bereaved remain in a

stressful traumatic situation (Boss, 2009). In summary, while the continued physical presence of the loved one makes it difficult to characterize the experience as a loss (Osborne & Coyle, 2002), the fluctuating nature of the illness and the lack of rituals that make the loss socially visible (Boss, 2009) cause people to react with emotional distress; if this is a grief process, grief becomes unresolvable. The findings of this study also show that families face emotional distress and some of them react with grief reactions. It becomes difficult for the person who is faced with loss to make sense of what happened and to mobilize again (Boss, 2009) because the person is deprived of the support, he/she will receive during the grieving process, and the ambiguous loss is invisible to the society (Doka, 1989).

Qualitative research with caregivers emphasizes that the grieving process does not diminish over time, that symptoms are often persistent and intensify as they are remembered with ambiguous losses (Richardson et al., 2012). In the present study, many of the participants reported being emotionally affected when talking about the past, and some participants cried. All of the participants stated that they had accepted the illness since they first learned about it, but that they still had emotional difficulties. This is consistent with Olshansky's (1962) concept of chronic sadness, which is used to describe the long-term sadness experienced by caregivers of the ill person. The lack of a predictable end to a illness, such as schizophrenia, can bring about a cyclical sadness. At the same time, feelings of loss, fear, frustration, anxiety, etc. can be triggered by internal and external stimuli; therefore, the feeling of disappointment and loss at the beginning of the illness can last for years (Olshansky, 1962). Richardson et al. (2012), in a qualitative study conducted with parents of children with mental illness, reported that grief reactions included self-blame thoughts, hopelessness, avoidance, anger, frustration, sadness, crying, numbness,

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anxiety, shock and denial. This finding is also consistent with the finding of the current study. However, in addition to these grief reactions, the participants of the current study also emphasized the feeling of loneliness. Considering that the participants lost their social ties and lived a more socially isolated life than in the past, this finding seems to be consistent with the concept of disenfranchised grief. Doka (1989) stated that in disenfranchised grief, the social support received decreases as the loss is socially invisible and this prolongs the grief process.

How the emotional distress experienced by parents is perceived by their children diagnosed with schizophrenia and how it affects the parent-child relationship is also an important issue. A study conducted with people diagnosed with schizophrenia showed that patients experience conflicts with their families and feel guilt and sadness because they think they are a burden on their families (Karanci et al., 2019). When analyzed through the concept of expressed emotion, this confirms that the emotional reactions of parents to their children may be a factor that may negatively affect the prognosis of the illness. Therefore, increasing functional coping strategies to reduce parents' emotional distress is also supported in the current study.

It would also be useful to discuss a situation observed during the interviews. Although the questions asked during the interviews were directly aimed at understanding the participants' own feelings and thoughts, some participants tended to answer the questions by describing their children's behaviors. Osborne & Coyle (2002) also stated that they observed such a pattern in their interviews and explained this situation with the tendency of parents to suppress their own emotions as stated by Miller (1996). Considering that the participants mentioned that they had lost their own life priorities, it can be inferred that they focused on their children's needs, emotions and behaviors, while they had difficulty focusing on their own emotions.

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5.3. Family and Social Burden

Participants mentioned that many changes occurred in their lives after their children were diagnosed with schizophrenia. One dimension of these changes is the change in the family and social environment and the difficulties related to this change. The social support received from the immediate environment or family members during caregiving for a person with schizophrenia is associated with increased coping strategies of the caregiver and better functioning of the patient (Rao et al., 2020). Therefore, difficulties experienced in the family and other social areas seem to increase the burden of the caregiver. There are two sub-themes under the theme of family and social burdens. These sub-themes are *challenges with the family* and *challenges with social network*.

The first sub-theme is *challenges with the family*. Many of the participants stated that they experienced difficulties in the family with their child's illness. These difficulties consisted of the difficulty of family members to accept the illness and therefore not receiving the expected social support, confusion of roles within the family and related conflicts, and thoughts that the other child in the family was neglected. Studies also show that conflicts occur within marriage (Kılıc & Saruc, 2015; White & Unruh, 2013). In the current study, especially the mother participants stated that their spouses had difficulty in accepting the disease, and therefore they experienced problems within the family and in their marriages. Three of these mothers stated that they and their spouses separated after their children were diagnosed with schizophrenia. As mentioned in the previous section, caring for a child with schizophrenia is both emotionally exhausting and objectively challenging; therefore, problems between spouses seem to be quite common. Spouses' differences

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in accepting the illness may be explained by differences in their level of tolerance for ambiguity (Boss, 2009) or differences in coping with the stressful event experienced.

Other studies focusing on children in the family have stated that the relationship between other siblings in the family and the sibling diagnosed with a serious mental illness becomes distant, which causes tension within the family and negatively affects the relationship between parents and other siblings (White & Unruh, 2013; Fernandes et al., 2021). Avcıoğlu et al. (2019) stated that most of the burden studies in the literature focus on mothers and fathers, and the effects of having a sibling diagnosed with schizophrenia on the other sibling are not sufficiently emphasized. In this direction, their study stated that in order to increase the well-being of siblings, the social support they receive should be increased, problem-oriented solution strategies should be increased, and families should be supported to provide the necessary care and attention to siblings. Furthermore, Teschinsky (2000) stated that in families with an individual diagnosed with schizophrenia, older siblings may have responsibilities such as helping at home and earning money from an early age, while the younger sibling may not receive enough attention from parents. Similarly, some participants stated that there was not a close bond between siblings and some participants stated that they thought that they could not pay enough attention to their other children because the responsibility of caregiving took too much time and that they felt guilty from time to time because of this. Therefore, the findings of the current study seem to be consistent with the literature.

Some participants stated that they and their child had been exposed to family problems before their children were diagnosed with the illness. The participants stated that they thought that childhood traumatic experiences such as physical

violence in the family, witnessing a sibling exposed to sexual abuse, and family conflicts due to financial difficulties played a role in the emergence of the illness. When the literature is examined, there is a widespread opinion that childhood traumatic experiences (such as sexual abuse, psychological abuse, physical violence, neglect) increase the likelihood of developing psychosis and schizophrenia in adulthood (Varese et al., 2012; Bebbington et al., 2004; Janssen et al., 2004). However, the occurrence of schizophrenia is generally explained by the interaction of genetic and environmental factors. Therefore, although childhood traumas are one of the factors affecting the occurrence of schizophrenia, further studies are needed to explain this relationship. The fact that the participants see these traumatic experiences as the cause of the emergence of the illness seems to be quite consistent with the literature. Research in this field shows that childhood traumas are one of the causal beliefs of both caregivers and people diagnosed with schizophrenia (Marutani et al., 2022; Holzinger et al., 2003). Although the research questions of this study did not focus on early traumatic experiences, the fact that the participants emphasized this issue in the interviews shows that traumatic past experiences have an important place in the inner world of both diagnosed children and parents. In this sense, it seems important to study issues such as the effect of early experiences on the development of schizophrenia, the perspective of parents towards these traumatic experiences, and the function of developing causal beliefs.

The second and last sub-theme under the family and social burden main theme is *challenges with social network*. When the literature is examined, it is seen that caregivers' socialization decreases due to responsibilities related to caregiving and they have a more socially isolated life (Landon et al., 2016; Gülseren et al., 2010). A similar finding was found in this study. However, the participants mentioned that in

some cases they themselves preferred not to be socially active. For example, they stated that they were afraid of being judged because of their children's different appearance or that they avoided inviting guests to their homes because their homes were not organized. One participant even stated that she did not prefer to share her difficulties with her environment, saying "*Why should I? Why should I publicize it*?". There are different perspectives that can explain why families prefer a socially isolated life. First of all, Magliano et al. (2005) mentioned a similar finding and stated that people with schizophrenia in their family have difficulty in inviting guests to their home and mentioned a relationship between decreased social network and increased burden. Magliano et al. (2005) explained this finding with the stigmatization of schizophrenia in society, the low functionality of the person with schizophrenia, or the caregiver's inability to find energy to be socially active due to the heavy responsibilities of caregiving. He also stated that social networks in families with schizophrenia may not have been strong before the illness and that caregivers may have fewer social resources due to their older age. It is thought that the reasons for the social isolation of the participants in the current study may be similar. In particular, discrimination due to stigma is an important source in explaining the difficulties experienced by individuals in the social field in the findings of this study, as it is widely discussed in the literature. It has been stated that self-stigmatization and social stigmatization of people with schizophrenia in their families cause them to have difficulties with their social networks and have a socially isolated life (Issac et al., 2022). The second perspective comes from the perspective of disenfranchised grief. The failure to understand someone else's grief experience and what it means for that person is expressed as society's failure to empathize with the grieving person (Neimeyer & Jordan, 2002). Similarly, the participants expressed

concerns that they would not be understood by their social environment. The fact that society does not recognize an ambiguous loss such as schizophrenia and the related grief process may lead the person to disenfranchise himself/herself from the grief process. Self-disenfranchisement is defined as not understanding one's own grieving process, suppressing one's feelings about the grieving process, and not feeling entitled to grieve (Cesur Soysal, 2021). Under the influence of cultural and environmental messages, a person may deprive himself/herself of the grief process (Kauffman, 2002) and thus possible sources of social support (Cesur Soysal, 2021). Considering the findings of this study, it is possible that preventing one's own grief and becoming socially isolated may cause the loss experienced by the person to be ignored more by the social environment. In such a situation, a vicious cycle occurs, and as the person isolates himself/herself, he/she cannot receive social support, and as he/she cannot receive social support, he/she becomes more isolated. However, since the participants of the study were reached through solidarity associations, the participants also stated that they were able to receive social support through the association. At this point, social support received through associations appears to be an important coping mechanism and will be discussed in detail under the coping heading.

5.4. Coping

Caring for a child with schizophrenia is challenging in many ways. Caregivers have difficulty in realizing their own life priorities, financial losses are experienced, dreams of the child's future and independence may not be realized, the caregiver experiences difficulties in family and social life; all these difficulties can become

even more complex and confusing with the ambiguous course of schizophrenia. Ozlu et al. (2015) stated that one of the reasons why some family members can cope with intense stress while others have difficulty in coping is the effect of uncertainty of the future. According to Lazarus and Folkman's (1984) model of coping with stress, people's evaluations of a stressful event, such as the participants' inferences about loss in this study, shape their cognitive and behavioral coping styles. Gülseren et al. (2016) stated that psychological distress experienced by caregivers complicates the process of coping with illness. In the current study, the participants' perceptions, feelings and thoughts about the ambiguous loss they experienced differed; therefore, mentioning different coping styles is consistent with the literature.

When the literature is examined, it is seen that there are different coping strategies in coping with stressful events. For example, Ozlu et al. (2015) stated that problem-oriented coping methods should be supported instead of emotional coping methods in coping with family burden and uncertainty of the future. Similarly, a review study examining the studies conducted with caregivers of individuals with schizophrenia stated that the most common coping strategies used by families were problem-focused and emotional coping (Issac et al., 2022). However, the coping strategies emphasized by the participants in the current study were cognitive, behavioral, social support and psychiatric/psychological support. Among these coping strategies, behavioral and cognitive coping strategies were the most common among the participants. In this sense, it is thought that the fact that the coping findings obtained from this study differ from the most emphasized coping styles in the literature may be due to the fact that the current study focuses on the ambiguous loss experienced by the parents. Because the concept of ambiguous loss requires a mental comprehension and a cognitive coping process rather than a problem-oriented

perspective. In addition, the other reason for the difference in the findings may be due to the subjective position of the researcher in naming the themes. According to the researcher's position, it is important to reflect the uniqueness of the participants in a subject, such as loss and grief where uniqueness and emotions are at the forefront, and to try to understand this ambiguous situation without pathologizing it. Therefore, for example, cognitive coping naming, which focuses on how the problem is made sense of, was preferred rather than problem-focused coping naming for loss.

Other studies in the literature indicate that coping styles differ between mothers and fathers. For example, Ryan (1993) stated that mothers try to cope with their feelings of interruption and loss by accepting their children, avoiding conflict, adopting a hopeful outlook towards the future and participating in support groups. This finding seems to be generally consistent with the finding of this study. Wintersteen and Rasmussen (1997) stated that fathers tried to cope with their feelings of loss by turning to work and hobbies. However, both father participants in the current study mentioned the social support they received from the association and the psychoeducational activities conducted in the associations as coping strategies.

According to the information obtained from the participants in the interviews, the coping strategies used by the participants to cope with the burdens they experienced, and the ambiguous loss situation were determined as *cognitive coping, behavioral coping, coping through social support* and *coping through psychiatric/psychological support* which will be discussed next.

The first sub-theme is *cognitive coping*. Humans filter the challenges they face through a cognitive filter. When faced with an ambiguous loss, much of the coping can take place at the cognitive level. Boss (1999, p. 127) put it this way: "It is a combination of optimism and realistic thinking that enables people to move forward

despite ambiguous losses". Cognitive coping strategies describe the intellectual process that people use to cope with a negative event or emotion (Garnefski et al., 2001). Therefore, the participants' ways of thinking, not their actions, were analyzed under the heading of cognitive coping. Cognitive processes such as rumination, putting events into perspective, self-blame, positive reappraisal can be given as examples of cognitive coping (Littleton et al., 2007). Issac et al. (2022) stated that caregivers of patients with schizophrenia benefit from coping strategies such as cognitive restructuring, religious coping and cognitive reappraisal. In the current study, coping strategies such as the process of transition from denial to acceptance, developing a solution-oriented perspective on the problems experienced, motivation to learn about schizophrenia and relaxation as they become informed, religious coping, developing positive thoughts, and suppressing emotions were evaluated within cognitive coping. The findings of the current study confirm that the participants showed symptoms related to the grief process after the ambiguous loss they experienced. The grief process involves cognitive processing of the loss and making sense of what has been experienced. In this direction, when the grief literature is examined, in line with Kübler-Ross (2005)'s stages of grief, the participants first denied the existence of the illness by having difficulty coping with the stressful situation they experienced, and then they accepted the situation they experienced over time and started to use more solution-oriented coping in this direction. Similarly, Boss (1999) stated that he found it more functional to accept an ambiguous loss with hopeful optimism rather than unconscious denial. However, it should not be forgotten that factors such as the ambiguous nature of schizophrenia and the ups and downs of symptoms bring along a frozen grief; therefore,

participants who stated that they accepted the illness also stated that they experienced flashbacks from time to time.

Ozlu et al. (2015) reported that people's religious beliefs can reduce the stress and self-blame caused by the illness; one of the fathers in the current study stated that he saw this illness as a test given by God and that he tried to pass it in the best way possible. Huang et al. (2008), in their study with caregivers of individuals with schizophrenia, stated that one of the coping strategies used by caregivers was cognitive coping. He stated that cognitive coping strategies include problem-solving-oriented coping strategies by thinking positively after acceptance of the illness and motivation to learn about schizophrenia in order to provide the best care to the patient. In parallel with the findings of Huang et al. (2008), the participants in the present study stated that they developed the motivation to learn about schizophrenia after accepting the illness and that the information they received from the associations was useful for them. Some participants underlined that they especially benefited from the family meetings organized in the association and led by psychologists. Participants also stated that after this experience with their children, they became more sensitive towards disadvantaged individuals in the society and developed positive perspectives.

Coping with positive thinking is considered as a positive cognitive coping strategy as it increases the likelihood of people to go for solution-oriented results and reduces the perceived burden (Huang et al., 2008) and it seems very important to be supported by professionals working in the field. On the other hand, it is thought that cognitive coping with suppression of emotions and denial may become dysfunctional when it is at extremes. While more avoidant cognitive processes such as denial and suppression of emotions may sometimes help the caregiver to maintain optimism, in

some cases they may cause the patient's problem to be ignored (Boss, 1999), or as one participant in this study stated, they may cause the grieving person to disconnect from their own emotions. For this reason, it seems very important for professionals working in the field to understand the extent to which parents use denial and suppression of emotions and to intervene if this situation has become dysfunctional. At this point, the theory of ambiguous loss offers the idea of approaching ambiguity with flexibility rather than denial in order to cope with an ambiguous loss, which includes the idea that the loss experienced should not be denied and at the same time working for a positive outcome and maintaining hope (Boss, 1999). In other words, the person experiencing ambiguous loss should learn to live with two opposing ideas and gain cognitive flexibility. In parallel with this finding, some participants of the study stated that they adopted a hopeful perspective towards the future, which can be considered as a functional perspective according to the perspective of the theory of ambiguous loss. In general, the steps that professionals working in the field can follow to strengthen families' functional cognitive coping strategies instead of dysfunctional denial mechanisms can be listed as follows: providing families with as much information as possible about the type of loss they are experiencing (psychoeducation about ambiguous loss), working on improving tolerance to ambiguity, presenting the idea that acceptance of the illness and a sense of hope can be experienced at the same time (Boss, 1999).

The second sub-theme and most common coping strategy of the participants was determined as *behavioral coping*. In behavioral coping, the participants talked about activities such as walking, working life, taking care of their favorite hobbies, etc., in which they kept themselves actively active, and stated that these pursuits were good for them. In addition, the participants mentioned active efforts to obtain

information about schizophrenia, attending meetings in the association or doing research. This behavior was also included in behavioral coping. Previous studies have also reported similar findings (Huang et al., 2008; Howard, 1998). Boss (1999) also stated that connecting with something stable in the life of an individual struggling with ambiguous loss can be an effective way to cope with the stress of ambiguous loss. Similarly, a recent systematic review study also mentioned that one of the ways caregivers' copes is behavioral coping and that caregivers keep themselves behaviorally busy and away from ruminative thoughts, thus feeling less emotionally burdened (Issac et al., 2022). Therefore, hobbies and behavioral activities that become routine can be considered to be quite functional for parents to cope. In addition, some participants stated that doing their favorite activities was good for them and that their children diagnosed with schizophrenia were happy with this situation. This situation can be explained by the concept of expressed emotion. Parents' excessive emotional reactions and critical attitudes towards their children have been explained by the concept of high expressed emotion in the family (Ajithakumari & Hemavathy, 2022). Highly expressed emotion from caregivers can negatively affect the prognosis of the ill child and increase the risk of relapse. Doing activities that are good for them behaviorally seems to enable parents to open a space for themselves in their lives, thus positively affecting their psychological well-being. The psychological well-being of the parent is likely to reduce situations characterized by high expressed emotion; thus, the child with schizophrenia is likely to be positively affected by this situation. For this reason, it seems quite necessary for caregiver parents to turn to activities that can give space for their own life priorities and to have access to time, energy and financial power to be able to turn to these activities.

The third sub-theme is *coping through social support*. Many previous studies have revealed that social support is a factor that alleviates caregiver burden (Stein et al., 2013; Issac et al., 2022; Magliano et al., 2005; Attepe Özden & Tuncay, 2018). Another recent study revealed that caregivers who receive support from relatives and family members cope better with the difficulties and burdens related to caregiving. In addition, it has been reported that social support enables both the caregiver to show lower levels of psychopathology and the diagnosed person to be more functional (Rao et al., 2020). Similarly, the participants of the current study stated that the support they received from the people around them or the Schizophrenia Solidarity Associations they were members of was good for them. Some participants stated that the reason why the association was good for them was to be together with people who were in the same situation with them, so that they did not feel alone. Young et al. (2004) also mentioned a similar finding and stated that caregivers can socialize more easily with people who have the same traumas with them. In addition, some participants stated that they shared some of the problems they encountered during the caregiving process with their friends in the association and were able to find a common solution. All but two of the participants mentioned the support they received from the association rather than friends or family in terms of social support. If this situation is analyzed from the perspective of disenfranchised grief, it seems likely that people receive social support from the members of the association with whom they share common life experiences in an environment where they think that their loss and grief are more visible and accepted. Young et al. (2004) stated that connecting with other people would facilitate healing for someone struggling with and grieving ambiguous loss. Similarly, the participants also stated that it was good for them when they shared with people, they felt comfortable with. Therefore, it

seems very important for professionals working in the field to encourage caregivers to connect socially, to direct them to social resources within and outside the family, and to address this issue if there is a difficulty in this regard (Young et al., 2004).

The last sub- theme is *coping through psychiatric/ psychological support*. When the literature was examined, it was observed that there is a very limited literature on coping by using psychiatric and psychological help by parents caring for a child with schizophrenia. While there is a large literature on the symptoms of caregivers such as depression and anxiety, there is very limited information on whether they use medication or receive psychotherapy support.

Six of the participants in the current study mentioned that they have been receiving psychiatric medication at regular intervals or when needed since their children were diagnosed. All of the participants who stated that they received medication added that they received this treatment for depression or anxiety. These findings are consistent with the literature, which emphasizes that caregivers of relatives with schizophrenia struggle with depression, anxiety and low quality of life (Awad & Voruganti, 2008). On the other hand, Mikkola et al. (2021) in a study conducted with family members who assumed the responsibility of caregiver, stated that intensive caregivers used more antidepressant-type psychiatric drugs than the general population. However, higher antidepressant use was associated with age and gender; being a female caregiver and being over 70 years of age were associated with higher antidepressant use. In the present study, the participants who reported receiving psychiatric medication were female, but there was no significant finding related to age. One of these participants stated that she received psychotherapy and that this process was beneficial for her. Although there is no finding in the literature on the individual psychotherapy processes of parents caring for their children,

considering that group psychotherapies and psychoeducational activities reduce the perceived burden and facilitate coping, it is thought that individual psychotherapy will also open a space for the person to name and make sense of the burdens experienced. The current study has shown that caregiving families may face ambiguous loss in many aspects. Therefore, although psychiatric medication may be useful or necessary in some cases, it seems important for professionals working in the field to utilize the perspectives of ambiguous loss and grief and to evaluate, for example, symptoms of depression from these perspectives (Lafond, 2000).

5.5. Clinical Implications

In parallel with the literature, the findings of the study showed that caregiving parents who care for their children with schizophrenia face diverse burdens. One of these caregiving burdens is the sense of loss experienced by the parents. Therefore, the findings were analyzed from the perspectives of ambiguous loss and disenfranchised grief as a newer concept. In this direction, the findings of the study showed that while struggling with an illness such as schizophrenia, they experienced ambiguous loss in many ways. Participants talked about the loss of expectations for themselves and their children, the objective burdens they experienced, the emotional processes that are part of the grieving process, and the changes in their family/social lives. The theory of ambiguous loss emphasizes that a person with a persistent mental illness continues to exist physically but is not the same psychologically and is not always available. In the ambiguous loss of an individual with schizophrenia, the boundaries of the relationship between parents and their children become unclear, the ambiguous nature of the illness makes it difficult to find meaning, the objective or social burdens associated with this loss increase, and furthermore, the grief may not

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be recognized by society. At this point, it is thought that evaluating the process experienced by parents caring for their children with schizophrenia from the perspective of ambiguous loss will open a wider space for their feelings in providing psychological support.

The theory of ambiguous loss emphasizes the normalization of parental grief (Boss, 1999). For example, many of the participants mentioned depressive or anxious symptoms. However, it is thought that if professionals working in the field go beyond these symptoms and try to make sense of the process experienced without emphasizing pathology with the process of ambiguous loss and the related grief process, it will enable families to put the process they experience into a new perspective and normalizing grief may have a comforting effect (Williams-Wengerd & Solheim, 2021). Boss (2009) emphasized that parents who experience ambiguous loss are in danger in terms of psychological well-being and mentioned a 6-item guideline that professionals working with these individuals can use. The items of this guideline are (1) finding meaning, (2) tempering mastery, (3) reconstructing identity, (4) normalizing ambivalence, (5) revising attachment and (6) discovering hope (Boss, 2009). In addition, Boss & Couden (2002) stated that families will be in a paradoxical situation while learning to tolerate ambiguity and that families should give up their expectations of achieving a perfect outcome regarding their loved ones' illnesses in order to master coping with ambiguity.

Other authors (Osborne & Coyle, 2002; Young et al., 2004, Jones, 2004) suggested that professionals working in the field should reframe the experience of families as loss and grief, make the loss and grief visible, help them to understand and make sense of their experiences, support families in working with the dilemma, review family relationships within the framework of this dilemma and use functional

coping strategies with their existing resources. In addition, burdens related to the caregiving process increase the likelihood of experiencing emotions such as anger, guilt and shame (Jones, 2004). Therefore, it is important for professionals working in the field to make space for these negative emotions in a non-judgmental therapeutic environment, to normalize these emotions and to be in an emotionally supportive position for families (Jones, 2004). In summary, it is thought that recognizing and naming the grief and loss experienced by families by professionals working in the field will serve as a therapeutic comforting function and will relieve families facing ambiguous loss (Young et al., 2004). All these suggestions mentioned in the literature seem likely to meet the potential needs of the participants in the current study. In this sense, it should be taken into consideration that psychoeducational studies, family intervention programs and family therapies regarding ambiguous loss and grief processes may be beneficial for both parents and the child diagnosed with schizophrenia. Because the well-being of caregivers in their individual psychology is also reflected in their relationships with their children. Considering family systems theory, all individuals in the family have the potential to influence each other (Bowen, 1966). Therefore, it is expected that a positive change in a child diagnosed with schizophrenia will positively affect the rest of the family. Conversely, the psychological relief of the parents will be reflected positively on their children.

Meta-analysis studies prove the effectiveness of family intervention programs (Pilling et al., 2002). It is thought that it would be very useful to address these studies from a newer perspective with the theory of ambiguous loss. In addition to the emotional support that professionals will provide to families, informing people about the nature of schizophrenia will also reduce the ambiguity to some extent, and it is clear that experts working in the clinical field have a critical role for people

experiencing ambiguous loss. However, Awad & Voruganti (2008) stated that although family intervention programs designed to reduce family burden are effective, the rate of inclusion in the treatment plan is low, and this is due to the lack of funding for such studies. Considering that a similar situation may be valid in the Turkish sample, it seems very important to support Schizophrenia Solidarity Associations, which are a very valuable resource for families, economically and in other ways in order to keep them open, to increase the visibility of these associations and to create public opinion. During the interviews, both the people in the management of the associations and the participants of the study stated that they had difficulties in keeping the associations open under the current economic conditions in Turkey. On the other hand, in order to carry out family intervention programs to be carried out outside the associations and for personalized treatment plans, it seems extremely important and necessary to reduce the burden on health professionals, to provide convenience to professionals working in the field and to support the budgets allocated for these studies by the state. Therefore, there is a need to improve mental health policies and to increase the number of institutions and organizations that will serve both patients and caregivers in mental health. The participants of the current study also underlined this issue. Participants stated that they need rehabilitation centers where they can be intertwined with healthcare professionals, where they can access accurate information, and where they can socialize. They added that such an institution would have a positive impact on both their children's health and their own well-being.

In sum, the present study suggests that the theory of ambiguous loss may play a role in framing the experience of families. It is thought that intervention programs to be carried out in the light of this theory can be very useful. The current study

supports the need for governmental support for future studies, the need to open institutions where families can also benefit, and the importance of reducing the burden on healthcare professionals for more efficient treatment planning.

5.6. Limitations and Directions for Future Research

The present study has some limitations although it provides important findings. The first limitation stems from the low generalizability of the study due to its use of qualitative design. Since qualitative studies aim to understand a topic in depth, the sample size is quite low compared to quantitative studies. In the current study, the sample size was 10 people because the research questions focused on a specific sample and required in-depth analysis. Future studies to be conducted with parents caring for children with schizophrenia may contribute to the literature by providing meaningful results by using mixed methods that include both a qualitative design that includes in-depth understanding and quantitative analysis that provides more generalizable results.

Another limitation stems from the unbalanced gender distribution of the participants. Since one of the inclusion criteria was to be the primary caregiver of the child diagnosed with schizophrenia, 8 of the participants were mothers, while only 2 were fathers. This situation shows that the duty of caregiving is generally attributed to mothers in line with both the existing literature and the culture. However, it is thought that a detailed examination of fathers' ambiguous loss and grief processes in future studies may provide meaningful findings. Most of the mother participants stated that their spouses had difficulty in accepting their children's illness, and some participants stated that their relationships with their spouses ended after their children were diagnosed. Therefore, studies focusing on how fathers make sense of the loss or

how ambiguous loss affects the relationship between spouses may be very valuable for the literature on ambiguous loss and schizophrenia.

Thirdly, the fact that the participants were reached through schizophrenia associations can be interpreted as a limitation. All of the participants who were members of the associations stated that they had been caring for their children for more than 20 years. Having been exposed to the burdens of caregiving for a long time may have led the participants to be accustomed to the process they were going through and therefore to talk about their feelings and thoughts about ambiguous loss in a more limited way. In addition, the participants have accessed accurate information about the illness through associations, but they stated that they had prejudiced information about schizophrenia before joining the association. In this sense, participants also stated that they benefited from the peer-to-peer support groups organized in the association. Therefore, there is a need for longitudinal studies focusing on the changes from the first time the parents experienced ambiguous loss to the following time. Such a study may provide important findings on how parents who care for their children with schizophrenia make sense of the loss over time, the concept of frozen grief, the burdens related to schizophrenia and the change in coping strategies over time. Another limitation of reaching the participants through associations is the possible positive effect of the social network provided by the associations. The social support provided by the associations to the participants is one of the most frequently mentioned factors that facilitate coping; in this sense, it is very valuable, and it is very important to support it. However, a study conducted with mothers/fathers who do not have access to associations or with parents whose child has recently been diagnosed with schizophrenia are likely to have limited social

support may reveal important findings in examining the concept of disenfranchised grief, which includes both ambiguous loss and social non-recognition of loss.

Finally, although the current study attempts to understand the ambiguous process of loss and grief experienced by families whose children have schizophrenia, none of the participants used the words "loss" and "grief". Although it is stated that some participants used expressions that directly describe the grief process, this interpretation was made by the researcher. A similar limitation was also emphasized by Osborne & Coyle (2002). In line with the framework provided by the theory of ambiguous loss, it should be taken into consideration that the continued physical presence of the child may keep families away from calling their experiences a loss. In addition, the influence of culture and religious beliefs may be an obstacle for parents to characterize the situation as a loss. Considering all these together, it seems important to investigate the factors affecting the ambiguous loss experienced by individuals and to develop measurement tools to determine the level of ambiguous loss experienced.

CHAPTER VI

CONCLUSION

The study revealed that caregiving parents face objective, subjective and family & social burdens. Discussing these burdens from the perspective of ambiguous loss theory is an innovative perspective. Although parents have expectations for their children to lead independent lives, these and other expectations become difficult to meet after their children are diagnosed with schizophrenia. The diagnosed adult child is physically present but cognitively and psychologically absent, so parents continue to care for their children even as they become adults. Moreover, this sense of loss becomes even more difficult and confusing to make sense of with the fluctuating course of the illness. This ambiguous loss seems to affect many aspects of parents' lives.

Participants reported that their personal priorities were interrupted, their expectations for their children were not realized, they faced various difficulties in their family and social lives, and they experienced emotional distress. Another aim of the study was to understand how parents coped with the ambiguous loss and objective difficulties they experienced. The findings show that parents coped through cognitive coping, behavioral coping, social support and psychiatric/psychological support. The ambiguity of the course of the illness, the ambiguity of the loss (a child with schizophrenia is physically present but not psychologically present), and the lack of social visibility of the grief following the ambiguous loss seem to be factors that make it difficult for parents to cope. For this reason, it is thought that it is very

important for the coping capacity of parents that professionals working in the field inform families about the illness, make the loss they experience visible by naming it and to provide support for them in dealing with this taxing process.

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APPENDIX

APPENDIX A

T.C.
TOBB EKONOMİ VE TEKNOLOJİ ÜNİVERSİTESİ
İnsan Araştırmaları Değerlendirme Kurulu

Sayı : E-27393295-100-28691   26.08.2022
Konu : 2022-46 numaralı başvuru

Sayın Prof. Dr. Ayşe Nuray KARANCI

İnsan Araştırmaları Değerlendirme Kurulu'na etik yönden değerlendirilmek üzere sunmuş olduğunuz 2022-46 kayıt numaralı "Şizofreni Tanısı Olan Yetişkinlerin Ebeveynlerinde Belirsiz Kayıp Süreçleri, Etkileri ve Başa Çıkma Yolları" başlığını taşıyan projeniz etik yönden uygun görülerek onaylanmasına karar verilmiştir.
Bilgilerinizi rica ederiz

Prof. Dr. Tayyibe Nur ÇAĞLAR
Kurul Başkanı

APPENDIX B

TOBB EKONOMİ VE TEKNOLOJİ ÜNİVERSİTESİ
İNSAN ARAŞTIRMALARI İÇİN AYDINLATILMIŞ ONAM FORMU

(Araştırmacıların Açıklaması)

"Şizofreni Tanısı Olan Yetişkinlerin Ebeveynlerinde Belirsiz Kayıp Süreçleri, Etkileri ve Başa Çıkma Yolları" başlıklı bir araştırma yapmaktayız. Sizin de bu araştırmaya katılmanızı öneriyoruz. Ancak hemen söyleyelim ki bu araştırmaya katılıp katılmamakta serbestsiniz. Çalışmaya katılım gönüllülük esasına dayalıdır. Kararınızdan önce araştırma hakkında sizi bilgilendirmek istiyoruz. Bu bilgileri okuyup anladıktan sonra araştırmaya katılmak isterseniz formu imzalayınız.

Bu araştırma TOBB ETÜ Sosyal Bilimler Enstitüsü Klinik Psikoloji Yüksek Lisans Programı tarafından gerçekleştirilecektir. Bu araştırmayı yapmak istememizin amacı, çocuğunuzun almış olduğu şizofreni tanısının sizin üzerinizdeki etkilerini ve bu etkilerle nasıl başa çıktığınızı araştırmaktır. Bu çalışmaya katılımınız araştırmanın başarısı için önemlidir.

Eğer araştırmaya katılmayı kabul ederseniz, demografik bilgi formunu doldurmanız ve yaklaşık 1 saatlik bir görüşme yapmamız gerekmektedir. Çalışmaya katılmayı kabul ettiğiniz takdirde, görüşme boyunca ses kaydı alınacaktır. Bu ses kayıtları yazılı hale dönüştürüldükten sonra yok edilecektir. Kişisel verilerinizin yayın dahil üçüncü kişilerle paylaşılması ya da alenileştirilmesi söz konusu olabileceği için isminiz rumuz kullanılarak anonimleştirilecektir. Kişisel bilgilerinizin gizliliği özenle sağlanacaktır.

Bu çalışmaya katılmanız için sizden herhangi bir ücret istenmeyecektir. Çalışmaya katıldığınız için size ek bir ödeme de yapılmayacaktır.

Bu çalışmaya katılmayı reddedebilirsiniz. Bu araştırmaya katılmak tamamen isteğe bağlıdır. Çalışmanın herhangi bir aşamasında onayınızı çekme hakkına da sahipsiniz.

(Katılımcının Beyanı)

Prof. Dr. A. Nuray Karancı ve İrem Kadiroğlu tarafından TOBB ETÜ Sosyal Bilimler Enstitüsü Klinik Psikoloji Yüksek Lisans Programı'nda bir araştırma yapılacağı belirtilerek bu araştırma ile ilgili yukarıdaki bilgiler bana aktarıldı. Bu bilgilerden sonra böyle bir araştırmaya "katılımcı" olarak davet edildim.

Eğer bu araştırmaya katılırsam araştırmacılar ile aramda kalması gereken bana ait bilgilerin gizliliğine bu araştırma sırasında da büyük özen ve saygı ile yaklaşılacağı, araştırma sonuçlarının eğitim ve bilimsel amaçlarla kullanımı sırasında kişisel bilgilerimin özenle korunacağı konusunda bana yeterli güven verildi.

Bu araştırmaya katılmak zorunda değilim ve katılmayabilirim. Araştırmaya katılmam konusunda zorlayıcı bir davranışla karşılaşmış değilim. Araştırmanın yürütülmesi sırasında herhangi bir sebep göstermeden çekilebilirim. Ancak araştırmacıları zor durumda bırakmamak için araştırmadan çekileceğimi önceden bildirmemin uygun olacağının bilincindeyim.

Araştırma için yapılacak harcamalarla ilgili herhangi bir maddi sorumluluk altına girmiyorum. Bana da bir ödeme yapılmayacaktır.

Araştırma uygulamasından kaynaklanan nedenlerle herhangi bir sorunun ortaya çıkması halinde, sorunun çözülmesi ile ilgili gerekli müdahalenin yapılacağı konusunda bana güvence verildi. Araştırma ile ilgili bir sorum olduğunda, İrem Kadiroğlu'yu … no'lu telefonundan arayabileceğimi biliyorum.

Bana yapılan tüm açıklamaları ayrıntılarıyla anlamış bulunmaktayım. Kendi başıma belli bir düşünme süresi sonunda adı geçen bu araştırma projesinde "katılımcı" olarak yer alma kararını aldım. Bu konuda yapılan daveti büyük bir memnuniyet ve gönüllülük içerisinde kabul ediyorum.

Karşılıklı imzalanan bu form kağıdının bir kopyası bana verilecektir.

Katılımcı
(Ad, soyad, adres, telefon ve imza)

Araştırmacılar
(Ad, soyad, adres, telefon ve imza)

APPENDIX C

Demografik Bilgi Formu

Şizofreni Tanısı Alan Bireyin: Annesi O   **Babası** O

1. Yaşınız: _____

2. Cinsiyetiniz:

O Kadın O Erkek

3. Eğitim Durumunuz:

O İlkokul   O Üniversite   O Diğer (Lütfen belirtiniz):

O Ortaokul   O Yüksek Lisans   _____

O Lise   O Doktora

4. Çalışıyor musunuz?

O Evet O Hayır

Çalışıyorsanız mesleğiniz nedir ? : _____

5. Medeni Durumunuz:

O Evli   O Bekar   O Boşanmış   O Dul

6. Hanenizde siz dahil kaç kişi yaşıyor? : _____

7. Kaç çocuğunuz var? _____

8. Hanenizde sizinle birlikte kaç çocuğunuz yaşıyor? : _____

9. Çocuklarınız dışında evde bakmakla yükümlü olduğunuz başka biri var mı?

O Evet O Hayır

10. Aşağıdaki merdivenin Türkiye'deki insanların durduğu yeri temsil ettiğini düşünün. Merdivenin tepesindekiler her şeyin en iyisine (en çok paraya, en iyi eğitime ve en saygın mesleklere) sahip olanlar. Merdivenin en altındakiler ise, en kötü koşullara sahip olanlar (en az paraya, en az eğitime ve en az sayılan mesleklere sahip olanlar ya da hiçbir işi olmayanlar). Bu merdivende daha yüksek bir konuma sahip olmanız en tepedeki insanlara daha yakın olduğunuz; daha aşağıda olmanız ise en alttaki insanlara daha yakın olduğunuzu gösterir.

Bu merdivende ailenizi nereye yerleştirirdiniz?...........................

11. Herhangi kronik bir rahatsızlığınız var mı?

O Evet O Hayır

Evet ise lütfen rahatsızlığınızı belirtiniz: _____

12. Herhangi bir psikiyatrik ilaç kullanıyor musunuz?

O Evet O Hayır

13. Daha önce psikiyatrik ya da psikolojik bir yardım aldınız mı?
O Evet O Hayır

Evet ise devam ediyor mu? _____
Evet ise temel sorununuz neydi? _____

Şizofreni tanısı almış çocuğa ait bilgiler:

1. Çocuğunuzun Yaşı: _____

2. Çocuğunuzun Cinsiyeti:

O Kadın O Erkek

3. Çocuğunuzun Eğitim Durumu:

O İlkokul

O Ortaokul

O Lise

O Üniversite

O Yüksek Lisans

O Doktora

O Diğer (Lütfen belirtiniz): _____

4. Çocuğunuz çalışıyor mu?

O Evet O Hayır

Çalışıyorsa mesleği nedir ? : _____

5. Çocuğunuzun Medeni Durumu:

O Evli   O Bekar   O Boşanmış   O Dul

6. Çocuğunuz şizofreni tanısını kaç yaşında aldı? _____

7. Çocuğunuz şizofreni tanısı aldıktan sonra kaç kez hastaneye yattı?
_____

8. Çocuğunuzla kaç senedir ilgileniyorsunuz? _____

9. Çocuğunuzla aynı evde mi kalıyorsunuz? O Evet O Hayır

APPENDIX D

ŞİZOFRENİ TANISI ALMIŞ KİŞİLERİN AİLELERİ İLE GERÇEKLEŞTİRİLECEK BELİRSİZ KAYIP ÇALIŞMASI İÇİN YARI YAPILANDIRILMIŞ GÖRÜŞME SORULARI

Tarih:

Başlangıç Saati:

Bitiş Saati:

Görüşmenin Gerçekleştirildiği Yer:

Görüşmeyi Yapan Kişi:

Görüşülen Katılımcı Numarası:

"Bugünkü görüşme için zaman ayırdığınız için ve vereceğiniz değerli bilgiler için şimdiden teşekkür ederim. Başlamadan önce üzerinde durmak istediğim bazı bilgiler var. Görüşmemiz yaklaşık bir saat sürecek. Size, çocuğunuzun şizofreni tanısı alması ile ilgili yaşam deneyimleriniz hakkında bir dizi soru soracağım. Vereceğiniz yanıtlar hem bilimsel bir araştırmaya katkı sağlayacak hem de ileride sizin gibi ebeveynlere daha yararlı destek programların hazırlanması için yol gösterici olacak.

İmzalamış olduğunuz gönüllü katılım formunda da ifade edildiği gibi bu çalışma gönüllülük esasına dayanmakta. Sizi rahatsız eden bir durum olduğunda ya da herhangi başka bir nedenle herhangi bir soruyu yanıtlamayabilir veya görüşmeyi yarıda bırakabilirsiniz. Böyle bir durumda bunu bana iletmeniz yeterli olacak. Ayrıca yapılacak araştırmada isminiz ve kimlik bilgileriniz kullanılmayacak, bunu da belirtmek isterim. Verdiğiniz bilgileri aslına uygun olarak analiz edebilmek için görüşmede ses kaydı almaya ihtiyacım var, ses kaydı almam sizin için uygun mu?"

"Görüşmeye başlamadan önce sormak söylemek istediğiniz bir şey var mı?"

Yanıt evet ise: Katılımcının soruları yanıtlanacak

Yanıt hayır ise: "Eğer görüşme sırasında herhangi bir sorunuz olursa rahatlıkla sorabilirsiniz."

"Şimdi izninizle ses kaydını başlatıyorum" *(katılımcının kabul etmesi durumunda)*

A. BAŞLANGIÇ SORULARI

1. **Çocuğunuzun hastalığı nasıl gelişti, kısaca anlatır mısınız?**

<u>Sondaj Soruları:</u>

-Çocuğunuz tam olarak ne tanısı aldı?

-Bu tanıyla ilgili daha önceden bilginiz var mıydı?

- Çocuğunuz bu tanıyı kaç yaşında aldı?

- Ne gibi belirtiler üzerine doktora başvurdunuz?

- Böyle bir tanı alacağından şüphelenmiş miydiniz?

B. ARAŞTIRMA SORULARI

Önbilgi/Bağlamsal bilgi: "Araştırmalar, şizofreni tanısı almış bireylerin dönemsel olarak değişen ruh hali ve becerilerinin ailelerde yoğun sıkıntılar yaşanmasına sebep olduğunu göstermektedir. Çocuklarının diğer çocuklardan farklı olması ve toplumdan destek görülememesi gibi faktörler sizler gibi ailelerin yaşadıkları zorlukları arttıran faktörler arasında sayılmaktadır."

<u>Geçiş Soruları:</u>

2. **Çocuğunuz hastalık tanısı almadan önce nasıl bir hayatınız vardı?**

3. **Çocuğunuz tanı almadan önce aile bireyleri arasındaki etkileşim nasıldı**?

<u>Anahtar Sorular:</u>

4.Çocuğunuzun aldığı tanıyı öğrendikten sonra ne gibi duygular yaşadınız?

<u>Sondaj Soruları:</u>

-Zaman içinde bu duygularda değişim oldu mu?

-Biraz daha anlatır mısınız?

5. Hayatınızın hangi yönleri değişti? (ve ne yönde değişti?)

6. Bu hastalık süreci çocuğunuzla olan ilişkinizi nasıl etkilendi?

7. Bu hastalık hayatınızda olmasaydı nasıl bir hayatınız olurdu?

<u>Sondaj Soruları:</u>

-Örnek verebilir misiniz?

-Bu beklentilerin karşılanmaması size nasıl hissettirdi?

8. **Çocuğunuzun yaşadığı bu hastalık yakın çevrenizle olan ilişkilerinizi nasıl etkiledi?**

<u>Sondaj Soruları:</u>

-Aile? Arkadaşlar? Akrabalar?

-Değişti ise nasıl değişti?

- Bu değişim size nasıl hissettirdi?

9. Çevrenizdeki bu kişiler ne yapsalardı daha iyi olurdu/ size daha iyi gelirdi?

10. Bu hastalık deneyimi ile hayatınızda olumlu bir yönde değiştiğini düşündüğünüz şeyler oldu mu?

Sondaj Soruları:

- Örnek verebilir misiniz?

"Buraya kadar verdiğiniz detaylı cevaplar için teşekkür ederim. Bu kısımdan sonra yaşadığınız zorluklarla nasıl baş ettiğiniz ve ne gibi beklentileriniz olduğu üzerine sorular sormak istiyorum."

11. Bu hastalık sürecinde sizi en çok zorlayan şeyler neler oldu?

Sondaj Soruları:

- Örnek verebilir misiniz?

12. Bu hastalık sürecinde sizi zorlayan şeylerle nasıl baş ettiniz/ediyorsunuz?

Sondaj Soruları:

- Örnek verebilir misiniz?

-Bu konu ile ilgili fiziksel veya psikolojik destek aldınız mı?

13. Hastalıkla baş etme sürecinde sıkıntılarınızı başkaları ile paylaştınız mı?

Sondaj Soruları:

-Kimlerle paylaştınız?

-Nasıl tepkiler aldınız?

14. Bu süreçte size neler yardımcı oldu? / Neler olsaydı daha iyi olurdu?

   C- KAPANIŞ:

"Benim sormak istediğim sorular bunlardı. Vermiş olduğunuz bilgiler için çok teşekkür ederim."

14. Benim sormadığım sizin aklınıza gelen söylemek istediğiniz herhangi bir şey var mı?

"Daha sonra iletmek istediğiniz veya sormak istediğiniz herhangi bir şey olursa vermiş olduğum iletişim bilgilerinden bana ulaşabilirsiniz."

15. Tüm bu sorular sonrasında kendinizi nasıl hissediyorsunuz?

"Tekrar teşekkür ederim. Hoşçakalın."

Görüşme sonunda, katılımcıya eğer ihtiyaç duyarsa araştırmacıya daha sonra ulaşabileceği iletişim bilgisi verilecektir.

APPENDIX E

GÖRÜŞME PROTOKOLÜ MATRİSİ (CASTILLO- MONTAYA, 2016)					
	Başlangıç Soruları	Bağlamsal Bilgi ve Geçiş Soruları	Çocukları şizofreni tanısı alan bireyler, bakım veren yüklerinden ve belirsiz kayıp süreçlerinden nasıl etkilenirler?	Çocukları şizofreni tanısı alan bireyler, bakım veren yükleriyle ve belirsiz kayıp süreçleriyle nasıl baş ederler?	Kapanış Soruları
1.Çocuğunuzun hastalığı nasıl gelişti, kısaca anlatır mısınız?	X				
2.Çocuğunuz hastalığa tanı almadan önce nasıl bir hayatınız vardı?		X			
3.Çocuğunuz tanı almadan önce aile bireyleri arasındaki etkileşim nasıldı?			X		
4.Çocuğunuzun aldığı tanıyı öğrendikten sonra nasıl duygular hissettiniz?			X		

5.Hayatınızın hangi yönleri değişti? (ve ne yönde değişti?)			X		
6.Bu hastalık sürecinden çocuğunuzla olan ilişkiniz nasıl etkilendi?			X		
7.Bu hastalık hayatınızda olmasaydı nasıl bir hayatınız olurdu?			X		
8.Çocuğunuzun yaşadığı bu hastalık yakın çevrenizle olan ilişkilerinizi nasıl etkiledi?			X		
9.Çevrenizdeki bu kişiler ne yapsalar daha iyi olurdu/ size daha iyi gelirdi?			X		
10.Bu hastalık deneyiminden sonra hayatınızda olumlu bir yönde değiştiğini düşün düğünüz şeyler oldu mu?			X		
11. Bu hastalık sürecinde sizi en çok zorlayan şeyler ne oldu?				X	
12. Bu hastalık sürecinde sizi zorlayan şeylerle nasıl baş ettiniz/ediyorsunuz ?				X	
13.Hastalıkla baş etme sürecinde				X	

sıkıntılarınızı başkaları ile paylaştınız mı?			177		
14. Bu süreçte size neler yardımcı oldu? / Neler olsaydı daha iyi olurdu?				X	
15. Benim sormadığım sizin aklınıza gelen söylemek istediğiniz herhangi bir şey var mı?					X
16.Tüm bu sorular sonrasında kendinizi nasıl hissediyorsunuz?					X