REP. OF TURKEY

TED UNIVERSITY

GRADUATE SCHOOL

DEVELOPMENTAL FOCUSED CLINICAL CHILD AND ADOLESCENT PSYCHOLOGY

PSYCHOSOCIAL AND POLITICAL MECHANISMS OF AMBIGUOUS LOSS AMONG CHILDREN HAVING A PARENT WITH SCHIZOPHRENIA: A GROUNDED THEORY STUDY

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ANKARA, 2022

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A Thesis Submited To
The Graduate School
of
TED University

by

İlayda Arkan

In Partial Fulfillment of The Requirements
For
Master of Science
in
Developmental Focused Clinical Child and Adolescent Psychology

ANKARA, 2022

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ABSTRACT

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Master of Science, Developmental Focused Clinical Child and Adolescent Psychology

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August, 2022

The main purpose of the current study was to establish a theory investigating ambiguous loss experiences of offspring with parental schizophrenia through psychosocial and political lenses. The data were obtained via semi-structured interviews with 10 participants. A qualitative design was employed, and for the analysis of the qualitative data, the grounded theory approach was utilized. The results of the analysis presented that having a parent with schizophrenia was associated with several impediments to offspring lives under three different contexts that were (1) impediments in the home environment, (2) impediments in the relationships with extended family members, and (3) impediments in the socio-politic realm. These impediments were interdependent and reinforced by a vicious cycle of secrecy around the disease, the lack of support resources, and stigmatization. Hence, offspring were isolating themselves and

searching for meanings to comprehend their experiences regarding parental schizophrenia. Afterward, this path combines with the parentification and ambiguous loss under the effects of the psychological absence of the affected parent and longing for normality. As a result, multi-factorial losses with unresolved grief and parentification emerged as the outcomes of parental schizophrenia. The findings of the current study emphasized the necessity of psychological and sociopolitical arrangements for the target population in line with the importance of increasing awareness regarding community mental health resources in Turkey.

Keywords: Parental Schizophrenia, Ambiguous Loss, Socio-Politic Context, Parentification, Grounded Theory

ÖZET

EBEVEYNİ ŞIZOFRENİ TANISI ALMIŞ ÇOCUKLARDA MUĞLAK KAYIP DENEYİMİNİ AÇIKLAYAN PSİKOSOSYAL VE POLİTİK MEKANİZMALARIN İNCELENMESİ: BIR TEMELLENDİRİLMİŞ KURAM ÇALIŞMASI

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Master of Science, Gelişim Odaklı Klinik Çocuk ve Ergen Psikolojisi

Tez Yöneticisi: Yağmur Ar-Karcı

Ağustos, 2022

Bu çalışmanın temel amacı, ebeveyni şizofreni tanısı almış çocukların muğlak kayıp deneyimlerini psiko-sosyal ve politik bileşenler temelinde inceleyen bir teori oluşturmaktır. Veriler, 10 katılımcı ile gerçekleştirilen yarı yapılandırılmış görüşmelerden elde edilmiştir. Elde edilen verilerin analizi için gömülü teori yaklaşımı kullanılmıştır. Analiz sonuçları, şizofreni tanısı almış bir ebeveyne sahip olmanın, çocukların üç temel bağlamda çeşitli engellerle karşılaşmalarına neden olduğunu ortaya koymuştur: Bu engeller (1) ev ortamındaki engeller, (2) geniş aile üyeleriyle ilişkilerde ortaya çıkan engeller ve (3) sosyo-politik engeller olarak kavramsallaştırılmıştır. Söz konusu bariyerlerin birbirleriyle ilişkili olmasının yanı sıra, gizlilik, destek kaynaklarının eksikliği ve damgalamanın oluşturduğu kısır döngü ile de pekiştiği ortaya koyulmuştur. Bu nedenle, ebeveyni şizofreni tanısı almış olan çocukların kendilerini izole ettiği ve ebeveyn şizofrenisiyle ilgili deneyimlerini anlamlandırma süreçlerinde tek başına kaldıkları bulunmuştur. Ebeveynin psikolojik yokluğu ve normale duyulan özlemin ise ebeveynleşme ve muğlak kaybı beraberinde getirdiği sonucuna ulaşılmıştır. Sonuç olarak, ebeveynleşme ve ebeveyn şizofrenisinin neden olduğu

çözümlenmemiş yas, ortaya çok faktörlü kayıplar çıkarmıştır. Bu çalışmanın bulguları, Türkiye'de toplum ruh sağlığı hizmetleri konusunda farkındalığın artırılmasının önemini ve buna paralel olarak hedef kitleye yönelik psikolojik ve sosyo-politik düzenlemelerin gerekliliğini vurgulamıştır.

Anahtar Kelimeler: Ebeveyn Şizofrenisi, Muğlak Kayıp, Sosyo-Politik Bağlam, Ebeveynleşme, Temellendirilmiş Kuram

To My Beloved Aunt…

ACKNOWLEDGMENTS

I would like to express my deepest gratitude to my thesis supervisor, Assist. Prof. Yağmur Ar-Karcı, for her genuine understanding, patience, support, and guidance. I am profoundly grateful for your priceless contributions both to my personal and academic development. You always believed in me and encouraged me to keep going. You were always there; you did not give up on me even when I gave up on myself. You are my lifetime inspiration. Thank you for touching my life and thank you for all the things you taught me.

My sincere thanks also go to Dr. Beyza Ünal. This study would not be possible without your guidance and support. I cannot thank you enough for your precious contributions. You were with me at each stage starting from my master's proposal to the end. Thank you for our meetings which I enjoyed and learned so much and thank you for your warm smile which meant a lot to me. I am also grateful to all participants of this study for opening themselves, and for their precious contributions. It was a pleasure to know you all, thank you very much.

My special friends, Duygu Üresin, Ayşenur Dirican, Özge Akkoç and Ebru Sertkaya. Having you ladies by my side with endless warmth and support at any time and in any situation was invaluable to me. Thank you for sharing the tears and laughter! Cheers to many years of friendship and many more to come!

I also want to thank my lovely aunt Melek Yavuz, I cannot describe how much you mean to me. I wish I could be able to share all of this with you. But at least I could see the smile on your face when I said I devoted my thesis to you. Thank you for all the moments you carried me in your arms and played games with me. My dearest mother Sultan Arkan and father Haluk Arkan and my lovely brother Mehmet Arda Arkan. I feel very fortunate to be a member of this family. Without you, without your love, support, and understanding, I could not do any of this. Thank you, mom, and dad! Thank you for always doing everything to be there for me!

Lastly, my deepest thanks is for my beloved partner, Cihan Çobanoğlu. I know, you do not like, "me thanking you too much". However, this time I want to thank you profusely… You, and your love have changed my life. You have given me hope, believed in me, and made me feel stronger even over long distances (hope it will end soon). You are my safe harbor. Thank you very much for everything. I love you!

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CHAPTER 1

INTRODUCTION

1.1 Overview

Schizophrenia is a chronic mental illness not only affects the individual but also one's family system. While the impacts of schizophrenia on family have been studied quite a lot, studies especially targeting the psychosocial experiences of children with parental schizophrenia are quite limited. This thesis mainly aspired to examine the operations of psychological and social structures impacting ambiguous loss experiences of Turkish offspring with regard to having and growing up with a parent having schizophrenia. Principally, (1) adolescent and adult offspring and (2) their unaffected parents (i.e., parents without a diagnosis of schizophrenia) were included in the present study to broaden the source of information with respect to the conceptualization and operation of parental schizophrenia in the family system.

In the first chapter, the structure and symptoms of schizophrenia were briefly mentioned. After that, the outcomes of parental schizophrenia in the context of psycho-social development of offspring and family functioning were discussed in relation to existing literature findings. Finally, the chapter was concluded through explaining the rationale, aim, and research question of the present thesis.

1.2 What is Schizophrenia?

Schizophrenia is a chronic, neurological-based mental disease compromising the cognitive, emotional, behavioral, and social functioning of an individual (World Health Organization [WHO], 2022). Even though the etiology has still not been completely figured out, existing studies have suggested an interaction of heredity, brain chemistry, and environmental conditions (Mayo Clinic, 2020). Consistent with the heterogeneous origins of the disease, symptomatology also demonstrates itself diversely. The diversity of the symptoms is mainly categorized under two headings, namely positive and negative symptoms according to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric

Association [APA], 2013). To roughly explain, positive symptoms cover features that are not normally present but have emerged due to the distortion of reality. Hence, delusions, hallucinations, and disorganized and catatonic behaviors are categorized under positive symptoms (APA, 2020). By contrast, negative symptoms cover the features that are expected to be present but have been withdrawn due to the progressive nature of the disease. Thus, difficulties with the fundamental principles of daily living, lack of motivation, indifference regarding social interactions, and impairments in communication reveal themselves as the main features of negative symptoms (Galderisi et al., 2018). Although schizophrenia is a very rare mental disorder with a lifespan prevalence around 0.7% (Gejman et al., 2010; Moreno-Küstner et al., 2018; van der Werf et al., 2014), the chronic and demobilizing nature of the disease shape one's entire life experiences.

Schizophrenia is not a curable yet treatable mental disorder. Thus, the sustainment of regular treatment matters in increasing the functionality of the individuals to a certain extent. However, setbacks in the treatment are common due to the side effects of the antipsychotic medications and low insight pertaining to the nature of the disease (Emsley et al., 2013). Discontinuity in the psychiatric and psychosocial treatment eventuate the unstable prognosis of schizophrenia. Affected individuals deviate from the normative sense of functioning in several domains of life. Unfortunately, such deviations not only surround the affected patients but also their family members. Thereof, changes in the conventional functioning of the nuclear families become inevitable resulting in negative impacts on the well-being of all family members (Weisman, 2005).

1.3 Impacts of Parental Schizophrenia

Several studies have yielded that the parenting styles of the patients diagnosed with schizophrenia are compromised profoundly due to the unstable and atypical nature of the disease. The psychosocial development of the children are hampered due to the dysfunctional parenting attitudes observed in families with parental schizophrenia (Cummings et al., 2005; Sathiyaseelan, 2018). In general, schizophrenia manifests itself through visible and unusual symptoms (e.g. hallucinations, delusions, and disorganized behavior/speech). Offspring eventually witness the strange nature of the psychotic attacks that are also visible to the outsiders in their social environment.

Hence, psycho-social conditions that offspring have been facing through such unusual visibility is a subject that needs to be addressed. However, the existing research usually focuses on the genetic transmission of the disease and the neurocognitive skills of the affected offspring (Erlenmeyer-Kimling, 2000; Gejman et al., 2010; Goldstein et al., 2010; Gur et al., 2007; Ozan et al., 2010; Tsuang, 2000). Similarly, previous studies regarding the familial impacts of schizophrenia have been limited to the perceived stress and caregiver burden of the affected family members (Awad & Voruganti, 2008; Bulger et al., 1993; Chan, 2011; Kusumawardani et al., 2019; Levene et al., 1996; Szmukler, 1996; Tamizi et al., 2020; Tristiana et al., 2018). Nevertheless, only a few studies have systematically investigated the operations of psychological, social, and political structures in explaining the psychosocial experiences of children growing up with parental schizophrenia. In the following section, the findings of the available studies reporting on the psychological and social barriers experienced by offspring with parental schizophrenia were explained.

1.3.1 Child Outcomes of Parental Schizophrenia

Apart from having a genetic predisposition to mental health difficulties (Seeman, 2010), offspring who have a parent with schizophrenia are exposed to lower standards of living in familial and social contexts (Ellersgaard et al., 2020). These living conditions are shaped through different level barriers ranging from the chronic nature of the disease to the lack of policies that are unavailable for the target population (Östman, 2008; Rosenfield, 1997; Stromwall & Robinson, 1998; Webster, 1992). Accordingly, affected children experience not only parental neglect but also the neglect of society and states in general (Blakeman et al., 2019; Gantriis et al., 2019).

The emotional needs of the offspring are not fulfilled on a stable basis in families with parental schizophrenia (Corrigan & Miller, 2004). They suffer from difficulties in the comprehension of the parental disease and are given age-inappropriate responsibilities (Fudge & Mason, 2004). Although limited in number, available qualitative studies have provided valuable insights about the psychosocial experiences of children raised in a family with parental schizophrenia (Blakeman et al., 2019; Chan & Chau, 2010; Duncan & Browning, 2009; Kadish, 2015; Kahl & Jungbauer, 2014; Nieto-Rucian & Furness, 2019). For instance, children with parental schizophrenia reported to not have affectionate relationships with their parents. They

particularly felt alone during the identity formation stage. This is why they alone strive to form a stable and consistent identity through the subjective interpretation of the personal and familial history (Blakeman et al., 2019; Kadish, 2015; Nieto-Rucian & Furness, 2019). Besides, lack of financial resources resulted in economic difficulties for the affected families, which, in turn, endangers offspring's psychosocial development. Particularly, the affected parents' low levels of education and being unemployed create socio-economical barriers compromising the already limited resources of the families (Ranning et al., 2018; Simoila et al., 2019). In turn, children with parental schizophrenia prematurely dropped out of school, and started working in a paid job to cover family expenses (Vafaei & Seidy; 2003).

Despite the presence of several obstacles in the emotional and socio-economic domains, children do not attempt to search for formal or informal support networks. They internalize and adopt a helpless position due to the fear and shame regarding their parents' mental disorder (Trondsen, 2012). The reason for not seeking support by offspring might be attributed to the previously faced stigmatizations that have been targeting the affected parent and themselves. Particularly, the visibility of the positive symptoms (e.g., hallucinations and delusions) and unconventional social behaviors increased the risk of stigmatization for patients with schizophrenia. Affected children also becomes the target of discriminatory acts and try to protect themselves through isolation and withdrawal (Loganathan & Murthy, 2008). False beliefs and illiteracy regarding the origins and nature of schizophrenia reinforce the discriminatory attitudes of the outsiders (Audu et al., 2013; Wolff et al., 1996). Being rejected by the society, these children are shy away from social connections (Gladstone, 2010; Haug-Fjone et al., 2009; Mordoch & Hall, 2008). Consequently, they experience decreased self-esteem, increased guilt, and shame, isolation, and difficulties in emotional expressions (Blakeman et al., 2019; Empfield, 2000; Chan & Chau, 2010; Munivenkatappa & Raguram, 2014; Nieto-Rucian & Furness, 2019; Phelan et al., 1998).

To conclude, children with parental schizophrenia are not only at risk in their family environment due to chronic and unpredictable nature of the disease. Instead, macro-level stigmatization also jeopardizes the offspring's physical and emotional well-being in their social environment (Gater et al., 2014; Shiraishi & Reilly, 2019).

1.3.2 Familial Outcomes of Parental Schizophrenia

According to Systems Theory (Kerr & Bowen, 1988), families are composed of interdependent social units and one's behavior in the family system eventually has an effect on the functioning of the other (Pfeiffer & In-Albon, 2022). Basically, "A single family member may exhibit symptoms, receive a diagnosis, and undergo treatment, but because of the interdependence that exists within a family system, each and every family member is affected in some specific way" (Kinsella et al., 1996, p. 24). Accordingly, schizophrenia is a chronic neurological disorder affecting not only the individuals themselves but also their family members. Affected families are going through various psychological and social changes that are interconnected with each other. However, previous studies have mostly focused on the perceived burden of the caregivers failing to capture the psychosocial positioning other family members (Chan, 2011; Kusumawardami et al., 2019; Tamizi et al., 2020).

Although limited in number, existing studies have yielded that families with parental schizophrenia have lower levels of cohesion and harmony. The spousal conflicts particularly centered around issues of providing care for the offspring (Gantriis et al., 2019; Yin et al., 2013). Atypical presentations of the symptoms also resulted in instability in the home environment (The Schizophrenia Society of Canada [SSC], 2021). Likewise, parenting attitudes are affected drastically which, in turn, debilitates the capability of managing close relationships within the family system (Seeman, 2010; Yamamoto & Keogh, 2018).

Not surprisingly, families having a member with schizophrenia tend to brush off emotional issues without processing. Like the rest of the society, they avoid talking about issues surrounding parental schizophrenia (Häefner, 2014). Such maladaptive ways of communication precipitate the use of dysfunctional coping strategies within the family system (Caqueo-Urízar et al., 2017). In fact, Bowen touches upon that cut-off tendency in families with chronic illnesses through underlining the presence of overwhelming anxiety (Skowron & Friedlander, 1998). Similarly, roles are shifting, and boundaries become blurred in those families starting from the onset of schizophrenia. Children are usually assuming adult-like responsibilities to compensate for the absence of the affected parent. As these families do not have access to support resources, offspring tend to assume progressively more and more responsibilities

through parentification (Alkan et al., 2016; Mordoch & Hall, 2002). Role reversals mainly stem from the lack of supervision and neglect (Sathiyaseelan et al., 2019; Stanley et al., 2003). Since schizophrenia impairs the behavioral and social skills of the affected individuals, duties regarding parenting and caregiving become unmanageable. Therefore, offspring starts to complete adult-like duties in the family system by taking the position of a parent (Strand et al., 2020; Van Parys et al., 2015). Shifted roles inside the family system create an environment full of inconsistency. Hence, target families not only face an excessive number of difficulties related to the management of the disease but also suffer from several familial and relational losses in the presence of parental schizophrenia.

1.3.2.1 Ambiguous Loss and Grief

Family members suffer from extraordinary caregiving loads in the presence of severe mental disorders (Birchwood & Smith, 1987; Cook et al., 1994; Pariante & Carpiniello; 1996). The unending responsibilities are accompanied by sorrow and grief when a parent has been diagnosed with a chronic mental problem (Eakes, 1995; Davis & Schultz, 1998; Rose et al., 2002; Ryan, 1993). Family members long for the old normal and grieve for losing the person they have known (Davis & Schultz, 1998; Miller, 1996; Parker, 1993). The term anticipatory grief has been first coined by Rando to define the grief reactions that emerge earlier than the physical death of a person (2000). The presence of debilitating symptoms together with the cognitive, psychological, and physical deterioration of the affected patient might evoke intense grief reactions in such families (Holley & Mast, 2009). A gradual decrease in the affection and proximity with the loved one also triggers sadness influencing the lives of others intensely (Rando, 2000; Sanders & Corley 2003).

Expanding on Rondo's anticipatory grief work, the ambiguous loss (AL) concept has been invented by Boss (2000) to express features of indecipherable losses experienced specifically in dementia. Since several studies have revealed the fact that dementia has common grounds with schizophrenia due to its neurological basis, AL is a construct also applicable to the loved one's and relatives of schizophrenia as well (Cai et al., 2018; Kochunov et al., 2021; Mathys, 2018). AL includes uncertain losses without a clear beginning or an end (Boss, 2000). Despite the physical presence of a loved one, the psychological absence of the diagnosed individuals leads to excessive

ambiguity and confusion for others increasing the suffering (Brady & McCain, 2004; Doka, 2010; Kaasa, 2013) and ongoing sorrow (Sanders & Corley; 2003). Hence, cognition and coping processes are hindered by ambiguity in the sense of what is going on and the ambivalence of feelings. Berger and Luckmann (1966) defined the functioning of meanings as they are established and sustained via social interactions including rituals, symbols, and other components while being influencers of the actions or inactions of individuals. However, those who experience AL usually are unnoticed by their social connections due to the conventional sense of loss and the presence of a loved one (Boss, 2006). Since there is not an actual death of a loved one, the possibility of grieving becomes overlooked and leads to the enhancement in the perceived and experienced difficulties of the ones who suffer from ambivalence and ambiguity. Therefore, seeking meaning becomes paralyzed even if making sense is enormously needed to cope and keep going. In fact, Boss (2000) pointed out the importance of communication among family members to enhance resilience to cope with those uncertainties and ambivalence regarding finding meaning as:

> Few people, professionals, or family members can tolerate for long being in a situation that is out of their control. The stress is too much. As the ambiguity persists, conflicts increase, not just among family members, but also between the family and clinicians. Indeed, even health care workers are not always sure how to respond to families struggling to cope with an ambiguous loss. This is where communication is so important; even telling a family "I don't know what will happen" in response to their questions about the future is more welcome than silence. If families are to care for their chronically ill loved ones when there are few answers, they need help sorting through the emotions that accompany caregiving work in the context of ambiguity. (p. 50)

Despite the relevance of the concept, only a few studies have so far focused on the dynamics and mechanisms of ambiguous loss in families with parental schizophrenia (Greenberg et al., 1993; Kristoffersen & Mustard, 2000; McLoughlin, 2010). However, families with parental schizophrenia might be particularly at risk for intense grief reactions throughout the course of the disease because such families are devoid of communication, interaction, and support resources (Brady & McCain, 2004; Caqueo-Urízar et al., 2017; Herbert et al., 2013) while trying to handle different level barriers within the family system.

1.4 The Scope and Aim of the Study

Parental psychopathology might have debilitating impacts on the psychosocial development of children (Sathiyaseelan, 2018). Affected families might be exposed to several impediments apart from the disease itself especially in developing countries due to lack of available services and ill-defined policies (Bernheim et al., 1982; Bland & Foster, 2012; Corrigan et al., 2014; Groom et al., 2003). However, clinical psychology literature usually fails to capture the impacts of sociopolitical structures on the subjective experiences of families with chronic mental illnesses. Instead, abundance of studies has focused on either the perceived burden of the caregivers or expressed emotions of families having a member diagnosed with schizophrenia (Awad & Voruganti, 2018; Jagannathan et al., 2014; Martín-Carrasco et al., 2016; Hazel et al., 2004). Hence, there is a major need to understand how offspring perceive and experience parental schizophrenia under the influence of existing sociopolitical and cultural structures in Turkey. We have particularly chosen children as the focus of this thesis because the existing studies usually sampled spouses and parents in the context of schizophrenia. Besides, ambiguous loss experiences were defined as our outcome variable due to the scarcity of research about the psychosocial and political origins of grief in families with parental schizophrenia. Specifically, the Grounded Theory [GT] approach has been utilized form an exploratory theory of parental schizophrenia in the context of ambiguous loss to delineate psychosocial and political mechanisms of offspring's ongoing grief in Turkey. Hence, the following research question was developed:

"How do psychosocial and political structures operate in explaining ambiguous loss experiences of children with parental schizophrenia in Turkey?"

CHAPTER 2

METHOD

2.1 Methodological Background

In the last 20 years, qualitative research methodologies have gained importance in understanding multilayered constructs in psychology literature. Even though quantitative research methodologies offer strong, generalizable, and credible findings via robust statistical analysis, qualitative methods are especially preferred when the focus of the research is to obtain in-depth and idiosyncratic data associated with the subjective experience of the individuals (Joffe, 2012). Qualitative methods differentiate themselves from other methodologies by offering space to researchers for rendering expository theories and constructs through inspection of the narratives of the target population (Bryman, 1988). As suggested by Cromby, when sentiments cannot be declared in words or reached via self-reports, qualitative methods are of great help in revealing embodied aspects of psychosocial experiences (2012). The aim of the current thesis was to reach out to a thick and detailed description of ambiguous loss experiences of offspring with parental schizophrenia in Turkey. Schizophrenia is a chronic disorder affecting not only the individuals themselves but also their family members' experiences of living via social, cultural, psychological, and even political routes (Brady & McCain, 2004; Sathiyaseelan et al., 2019). Considering the multi-dimensional impacts of parental schizophrenia on offspring, we have decided to establish a theoretical framework based on the narratives of first-hand individuals in order to make sense of the visible and invisible aspects of the basic psychosocial and cultural operations centering on this experience.

There are several reasons for choosing grounded theory over other qualitative methods within the scope of this research. The grounded theory provides available expanse and guide to the researcher to discover and develop an explanatory theory of social operations at which they take place (Glaser & Strauss, 1967; Mills et al., 2006).

To be specific, grounded theory methodology evaluates motivations, surroundings, features, outcomes, likeliness, and covariance of social mechanisms to map out the conceptual associations among embedded themes (Strauss & Corbin, 1998). This valuation is accomplished via the inductive investigation of qualitative data that might have been obtained from diverse sources like bibliographic materials, field observations, focus groups, and usually semi-structured interviews (Bowen, 2009). There are several strategies to utilize grounded theory and one of them is the constructivist approach. The constructivist approach presumes that while studying social mechanisms, there is an absence of objective reality, instead, the reality is established on account of social associations, including the one established with the researcher (Charmaz, 2008). To expand, the way of collecting and evaluating the data is shaped by the researcher's understanding and interpretation of the issue that is on the table (Charmaz, 2000, p. 524; Mills et al., 2006). As stated above, we aimed to construct a new explanatory framework mapping out the dynamic relations among psychological, social, cultural, and political issues around ambiguous loss experiences of children in the context of parental schizophrenia, instead of solely portraying the phenomenology of this experience. This was one of the main methodological reasons for our choice of the grounded theory approach within the scope of this thesis. Besides, chronic disorders like schizophrenia are now started to be viewed from a multilayered perspective examining the interaction among biological, psychological, social, cultural, and political dimensions (Caqueo-Urízar et al., 2017; Tamizi et al., 2020). Thus, grounded theory allowed us to examine the impacts of social and cultural structures of Turkish society on offspring's experiences of living with parental schizophrenia in the context of ambiguous loss.

2.2 Participants and Sampling Method

In grounded theory, the goal of the research is to develop a new explanatory theory based on a conceptual model describing the target phenomenon. Therefore, the researcher is expected to reach out to a heterogeneous sample who have diverse experiences regarding the topic under investigation (Timonen et al., 2018). Accordingly, the sample of the present study was reached through the theoretical sampling method, which enables the researcher to shape and re-decide the characteristics of the subsequent participants based on the analysis of formerly

obtained data in an attempt to establish a comprehensive theory. Thus, the researcher searched for participants up to the point that theoretical saturation had been attained, which means that the established theory is grounded in the data (Glaser & Strauss, 1967).

The inclusion criteria were primarily specified for the offspring as follows: a) being older than at least 13 years old, b) having a parent diagnosed with schizophrenia spectrum disorders, and c) being aware of parental psychopathology (i.e., at least having been informed about the name of the disease before participation). As the data collection and analysis took place, unaffected parents (i.e., parents who did not have a diagnosis of schizophrenia) were also reached out, consistent with the principles of theoretical sampling. In other words, healthy parents of adolescent and adult children were also recruited to elaborate operations of familial and political factors in the context of ambiguous loss. The sample size was determined based on the preconditions of grounded theory studies (e.g., scope, data quality, theoretical saturation). At its core, the sample size of the studies conducted with grounded theory varied between 10 and 60 participants (Starks & Brown Trinidad, 2007). In that sense, the number of participants in the current study was determined to be in line with the conventional grounded theory studies documented in the literature.

The sample consisted of eight offspring and two unaffected parents. Offspring's ages ranged between 13 and 40, while unaffected parents' ages varied between 59 and 43. Of the offspring group, three participants graduated from high school, one graduated from university, three were university students, and one participant whose age was 13 was a student at secondary school. Besides, three children were born after their parents had been diagnosed. Others were at the ages of 1, 2, 13, 18, and 32 when the diagnosis had been given. On the other hand, the unaffected parents consisted of one high school graduate and one primary school graduate (see Tables 1 and 2 for the details). Out of 8 participants in the offspring group, only one had lost her affected parent, while others' affected parents were still alive. Among those whose affected parents are alive, five still live with their affected parents, while two do not. Of the ones who live separately from their affected parents, one of them shares the same building on different floors with her parents and keeps in touch with them daily, while

one of them meets with her parents once a year for a month due to the long distance between cities they live in.

Table 1

Descriptive Information about the Participants

Name	Age	Education	Age at the Diagnosis of Affected Parent
Sevinç	30	High school	18
Tülay	30	University	2
Yelda	23	Currently university student	Before birth
Mine	23	Currently university student	Before birth
Yılmaz	21	Currently university student	13
Mukaddes	40	High school	32
Tarık	13	Student at university	Before birth
Faruk	18	High school	1

Note. Premorbid features of schizophrenia of Mukkaddes were present since her childhood

Table 2

Descriptive Information about the Unaffected Parents

Name	Age	Education	Years of Marriage
Kamuran	59	Primary school	43
Ziynet	43	High school	19

2.3 Procedure

Prior to data collection, the approval of Human Research Ethics Committee of TED University was obtained for the present study (see APPENDIX A). The participants were reached through word of mouth in collaboration with researchers' colleagues and social circle. Besides, an announcement was also shared through social media platforms to reach out possible participants. With those who were interested in participation, the researcher scheduled an initial appointment either via telephone or video call, or face-to-face. These appointments lasted around 15-20 minutes in an

attempt to clarify whether the participants fulfilled the inclusion criteria while also offering detailed information related to the purposes and data collection procedures of the study. During those interviews, date, and places of the interviews were arranged jointly by the researcher and participants. Most of the meetings were conducted online through video communication platforms due to the different residing locations of the participants. For online meetings, informed consent was obtained via "Qualtrics" software right before the beginning of each interview. Similarly, written informed consent was taken for face-to-face interviews (see APPENDIX B) for adult offspring group. For the one minor offspring, the unaffected parent filled out the parental consent form (see APPENDIX C), then the minor also filled out the minors' version (see APPENDIX D). Similarly, written informed consent was also obtained from unaffected parents' (see APPENDIX E). Interviews lasted around 49-120 minutes, with a mean of 83 minutes.

Having provided detailed information regarding the study procedures and confidentiality, semi-structural interviews started up with warm up questions to enhance the rapport and then continued with questions aimed to reveal impacts and dynamics of having a parent or a spouse with schizophrenia (see Appendix F for offspring's set of questions; see Appendix G for minor's set of questions; see Appendix H for unaffected parents' set of questions). The flow of the meetings was shaped depending on the participants' own narratives related to the target topic while they were also comforted by the researcher to express their experiences without feeling restricted by any preliminary framework. Questions directed to the unaffected parents focused on not only their own experiences regarding having a spouse with schizophrenia but also the experiences of their children who had been the active parts of this process. Consequently, subjects including but not limited to psychosocial dynamics of parental schizophrenia, familial roles, and conflicts, support resources, attitudes of both nuclear and external family members, and policy-related challenges were discussed. As proposed by grounded theory, the set of questions was checked and modified after each data analytic process has been completed in order to enrich the understanding of emergent themes (Glaser & Strauss, 1967). Whole conversations were recorded and transcribed verbatim by the researcher prior to data analysis and

identity disclosing information was distorted during transcription and reporting of the results.

2.4 Data Analysis

At the data analytic phase of the study, each conversation was subjected to open coding word by word in an attempt to stay close to subsequent data (Charmaz, 2008). Afterward, created codes were evaluated and divided into expressive categories. This way of processing data, referred as focused coding, enabled the researcher to comprehend the theory that is grounded and embedded in the obtained data. Consideration of similarities and discrepancies within and across participants were checked through axial coding following an iterative process. Besides, memos were written regarding the emergent categories to gain a greater sense of their expression that would become the core conceptual parts of the theory. Through extensive axial coding and use of memos, conceptualizations of the themes and associations among concepts became crystallized. This process was repeated at the end of each interview resulting in an interactive phase between obtaining and evaluating the data. These repetitions allowed the researcher to figure out novel features and issues to focus on in the following interviews. Throughout each stage of the analysis, qualitative data analysis software, MaxQDA was used (Verbi Software, 2005).

2.5 Trustworthiness of the research

The trustworthiness criterion of qualitative research comprises subjectivity, reflexivity, the sufficiency of the data, and its clarification. Since the qualitative approach pursues a constructivist epistemology, it acknowledges the subjective viewpoint of both the participant and researcher, the inherently subjective nature of the data, and operations of analysis rather than seeking an "objective" reality (Morrow, 2005). Hence, subjectivity is not controlled or restricted but is used as a resource to enrich and increase the quality of the research. To determine the trustworthiness of a qualitative study, Smith (1996) proposed some criteria to pay attention to which are internal coherence, presentation of evidence, independent audit, triangulation, and member validation. Besides, keeping memos throughout the whole process further contributes to trustworthiness as it provides an opportunity for an audit trail for investigators. That is, researchers can keep track of their own opinions, beliefs, and

responses about the phenomenon under investigation through memo writing (Cutchliffe, 2003).

Based on these recommendations, cohesion and constancy principles of the grounded theory were systematically applied throughout the analysis and clarification phases of the data. Having completed the coding of each interview individually, I arranged meetings with a psychiatrist and two clinical psychologists who were experienced in qualitative analysis. While one of the clinical psychologists was professionally interested in the impacts of parental psychopathology, the other one was a disability activist who had profound knowledge about the operations of social structures in chronic diseases. I updated drafts of the theory based on their suggestions until the point that the theory was constructed. Additionally, in the reporting phase of the findings, I presented the mechanisms of the established theory via quotations from the interviews to clarify the conceptual essence of the obtained narratives.

As mentioned above, I have written memos throughout the data collection and analysis phase to make sense of my understanding of the participants' interactions. Writing memos was particularly beneficial in the conceptualization and bridging of the themes allowing me to become aware of my expectations, assumptions, and experiences as a person who has a close family member with schizophrenia. Another advantage of writing memos was bracketing which aims to create a see-through stance for the researchers to their background including their orientations, expectations, beliefs, and prejudices (Fischer, 2009, Gearing, 2004). Among six types of bracketing tools (Gearing, 2004), reflexive bracketing was preferred for the present study. Apart from self-based bracketing, I acknowledged that external systems' assumptions deeply rooted in culture, society, and politics cannot be entirely bracketed out but can be blended into the conceptualization to make sense of the target phenomenon. In the following section, I summarized my personal and professional stance on data collection, analysis, and reporting of the results.

2.6 Reflexivity

The present study was inspired and motivated by my personal experiences with my maternal aunt, who was diagnosed with schizophrenia in her early 20s. As her eldest niece, I was the only child who witnessed our family's struggles, difficulties, and conflicts brought by the disease. I remember constantly feeling sad and frightened as so many unanswered questions were on my 7-year-old mind. The curiosity I have had never ended because of the active attacks she was experiencing on a stable base. As a child, it was difficult for me to understand what was going on while not feeling scared or sorrowful. Besides, I felt guilty because I was afraid of her even though she was so sensitive towards me in those days. I also remember feeling resented about the familial losses that were not fair. This disorder also affected my social interactions profoundly. For instance, I was not comfortable when my aunt visited us at our house no matter how much I loved her because I was worried about the possibility of my peers asking questions such as "Is your aunt crazy?" In short, the discomfort was the dominant feeling for my family members and me. Although it became easier to cope and live with a family member having schizophrenia, I am still longing for my aunt and trying to compensate for her losses brought by the disease. However, I realized that anything I perceived as a loss and unfair in the name of my aunt was not something she needed back in those days and present due to her disease. Even this enlightenment has helped me a lot regarding my feelings of guilt and sadness, but it took years and years to realize because of my inner conflicts and lack of awareness regarding the disease. My bachelor's education in psychology provided me the professional and social support and helped me increase my understanding of those around me. Subsequently, my own therapy process and graduate education in clinical psychology also allowed me to discover more about my inner world. Hence, impediments that surrounded my family and me were transformed into something more bearable in my perception. Taking the bad with the good, I wanted to explore what it's like to have a parent primarily with schizophrenia in a more profound manner as parents are important figures for children because schizophrenia brings many impacts even on to those lives who are part of affected persons' extended family. To sum up, my narrative of having and growing up with a family member who has schizophrenia and my education in psychology impacted the present study entirely. Besides, my personal history also helped me reach

the current study's participants. The ones who were reluctant to participate changed their attitudes positively after I disclosed my similarity with them. They shared their comfort and relief during and after the interviews, so I also felt an alliance with them reciprocally.

Moreover, some participants' reports have had some catchy points. In other words, familiarities with my own narrative led to tender moments during and after the interviews. Conversely, discrepancies also showed up themselves, eliciting some strong emotions that were hard to face for me. Throughout the analysis of obtained data, rendering a comprehensive theory that includes psychological and social dynamics of schizophrenia out of stigmatizing or pathologizing the experience of the target population was difficult while being the insider of the experience, too. Hence, watching for appropriate language to utilize while accounting for what the study tells by not victimizing was one of the core challenges of the current research.

Dr. Yağmur Ar-Karcı, my thesis supervisor, inspected the current study throughout all the micro and macro stages of the current research as a senior expert in psycho-social factors which impact people with chronic diseases and their family members and the ambiguous loss among those families. As a result, she not only supported me in processing the current study theoretically and practically but also helped me on regulating my own opinions and feelings in line with my personal growth and awareness. Likewise, Dr. Beyza Ünal, part of the research team of the current study, is an activist in the disability field. Hence, she led us to catch the political realm of the present study. Additionally, she contributed to and supported the current research regarding the flow of the chosen methodology, in data collection, analysis, and establishment of a theory.

Overall, the present study has enlarged my perspective on clinical psychology research and practice and motivated me also to make an effort in my personal life. From now on, my aim is to spread awareness by conveying that 'lives of offspring with parental schizophrenia are not doomed to failure as long as they have been provided sufficient formal and informal resources.

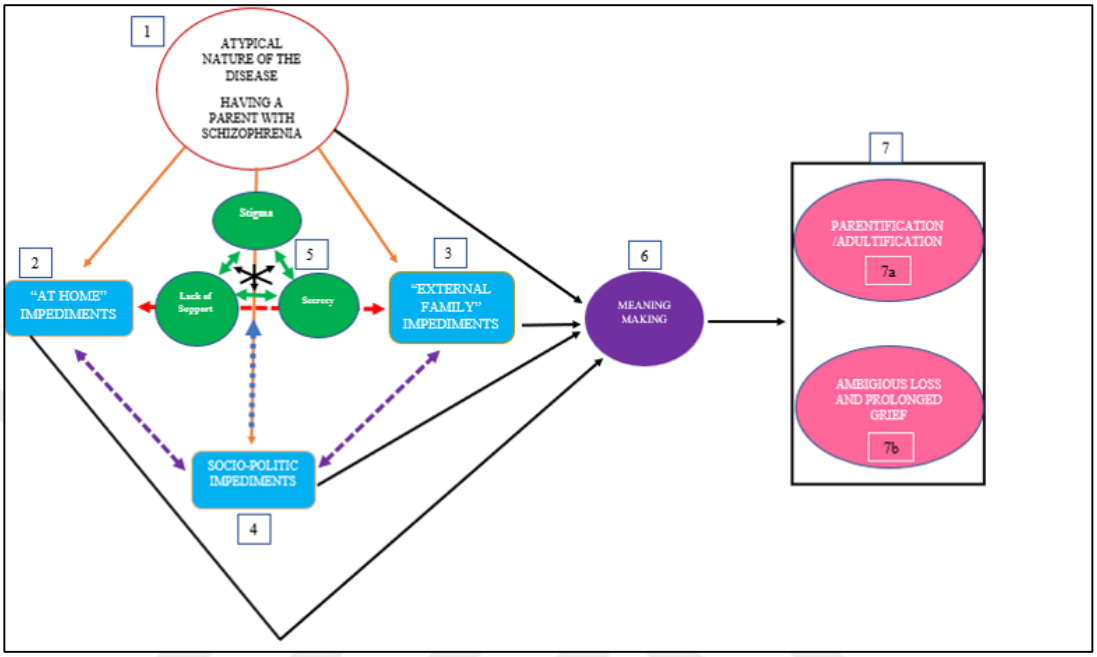
CHAPTER 3

RESULTS

As it was presented in Figure 1, having a parent with schizophrenia by itself brought different level impediments to the offspring's lives due to atypical nature and prognosis of the disease (Category #1). These impediments revealed themselves at home environment (Category #2), via interactions with external family members (Category #3) and through the functioning of the socio-politic system in Turkey (Category #4). Several barriers were interactively associated and getting shaped by each other in a cyclical manner resulting in a vicious cycle among secrecy around the disease, stigmatization/discrimination and compromised support resources (Category #5). All these multilayered barriers eventually shaped the offspring's making meaning process to come up with the answers to the "what happened" and "why did it happen" questions (Category #6). Besides, making meaning process was directly influenced by the atypical nature of the disease as well. Since the symptoms of schizophrenia have unusual manifestations that are difficult to understand for the ones with limited knowledge, the hard-to-comprehend nature of the disease itself hindered the meaning making process. In turn, sustainment of such patterns leads to the increased tendency among target offspring to adultification and parentification, along with the experience of ambiguous loss and chronic grief (Category #7). Emergent categories were explained together with the participants' accounts in the following chapter. The fact that having and growing up with parental schizophrenia affected personal experiences diversely. Hence, these diversities were also reflected across the obtained findings, as well.

Figure 1

The Experience of Having a Parent with Schizophrenia



3.1 Category #1: Having a Parent with Schizophrenia and Atypical Nature of the Disease

This category covered the psycho-social experiences of having a parent with schizophrenia along with the uncertainties and confusion brought by the disease itself. The origin of the target pattern was the nature of the schizophrenia which was accounted more or less by the symptoms, prognosis, and treatment process. In line with the unpredictable and atypical nature of the symptoms, feelings of fear and worry continuously surrounded the affected offspring, particularly during active psychotic episodes. Interviewed children described the terror and confusion they felt upon the paranoid delusions that their parents had experienced. As the affected parent became persecuted, s/he started to demonstrate violent behaviors towards others for self-protection.

As the paranoid symptoms reached to the peak with violent behaviors, children felt helpless and confused while trying to find ways to prevent imminent danger. To exemplify, Faruk (18), who had a father with schizophrenia described:

> O zamanki korkuyla yani zaten hayal meyal hatırlıyorum yani bıçağı masaya koyması ve kapıyı kapatıp gitmesi. Bir taraftan annem ağlıyor falan. Hastalığının kötüleştiği

zamanlarda halamla kavga ediyor, eve çıkıyor bıçak almaya geliyor alt kata inip halamı öldürecek. Ben durduruyorum konuşuyorum, diyorum öldürürsen hapse gireceksin falan. biraz daha duygusuna basmaya çalıştım bize kim bakacak falan dedim biraz düşündü bıçağı elinden aldım, odasına kapattım. Ondan sonra da çarşıya gitti zaten kurtardık yani.

I vaguely remember because of the fear of those times, how he put the knife on the table and shut the door and left. On the one hand, my mother was crying and stuff. […] When his disease worsened, he fought with my aunt, coming home to take a knife, and went downstairs to kill my aunt. I stopped him, I said, if you kill her, you will go to jail or something. I tried to end his feelings a little more, I said who will take care of us, then he thought for a while, I took the knife from his hand and locked him in his room.

Similarly, Tarık (13), who also had a father with schizophrenia and one brother, expressed that:

Tarık: Yani kavga ettikleri zamanlar abim yani hep şey diyordu ee barışacaklar inşallah vs bir şeyler diyordu ama
Araştırmacı: Tarık, doğru mu anladım, sen annen ve baban tartışırken işte anne babalar tartışır bu da onlardan biri gibi düşünüyordun
Tarık: Evet evet öyle düşündüm çünkü hep oluyordu
Araştırmacı: Bu zorlukların bir hastalıktan kaynaklandığını düşünmedin
Tarık: Evet
Araştırmacı: Peki hastalıktan kaynaklandığını bilmek nasıl geldi sonrasında sana?
Tarık: Hastalığından kaynaklı olması tuhaf yani, ama zaten şey, çok da tuhaf gelmedi bir yandan da çünkü zaten normal bir tartışmaya göre çok fazla sinirleniyordu. Çok fazla bağırıyordu, yani kendini fazla kaybediyordu ondan dolayı zaten anlaşılıyordu yani
Araştırmacı: Bu tartışmalar sırasında sen nasıl hissederdin?
Tarık: Korkardım
Araştırmacı: Bu korku nasıl bir korkuydu? Kendine yönelik mi?
Tarık: Yok anneme yönelik birazcık
Araştırmacı: Anneme zarar gelirse gibi bir korku mu?
Tarık: Evet evet

Tarık: I mean, when they were fighting, my brother was always saying something like, 'they will reconcile', etc. He was saying somethings but…
Researcher: Tarık, have I understood correctly? When your parents were arguing, you were thinking like all parents argue and this is also one of them, right?
Tarık: Yes, yes, I thought so since it was always happening.
Researcher: You didn't think these difficulties were caused by a disease
Tarık: Yes.
Researcher: So how did it make you feel to know later that it was caused by a disease?
Tarık: It's weird that it is due to his disease, but it also didn't seem too weird as well because he was already getting very angry compared to a normal discussion. He was yelling a lot, he was losing himself a lot, so it was already understood.
Researcher: How would you feel during these discussions?
Tarık: I was afraid
Researcher: What kind of fear it was? Self-directed or?
Tarık: No, a little for my mother
Researcher: A fear like if my mother gets hurt
Tarık: Yes, yes

As schizophrenia leads to changes in the normative functioning of families, children in those families were usually exposed to a constant limbo of ambiguity. Affected children were exposed to "weird" behaviors of their parents at an early age. The unusual symptoms (e.g., hallucinations and delusions) coupled with fear of harm resulted in staying alert all the time. Communication decreased among family members as well due to the lack of knowledge with regard to symptoms and treatment procedures. As the information regarding symptoms and prognosis was limited, the fear and confusion experienced by the offspring escalated. For example, Yelda (23) described the confusing and fear-inducing symptoms of his father as follows:

> Şüpheci, işte siz benim düşmanlarımsınız, işte ben allahın elçisiyim içinizden birini kurban etmek zorundayım. İbrahim mi bi peygamber kesmiş mi kurban mı etmiş bir şey olmuş ya bu tarz cümleler. İşte hepiniz kafirsiniz, müslüman piçlerine hiçbir şey öğretemem, hani geçmişte öğretmendi ya. Sonra baş örtülü olan insanlara karşı büyük bir nefret işte kendini böyle mesih isa gibi bir şey olarak gördüğü önemsediği için bizi de önemserdi ama yeri geldiğinde bize zarar vermekten de çekinmezdi yani. Bir yandan hiçbirimizin zarar görmüşlüğü yok yani öyle büyük bir zarar ama eğer engel olunmasaydı belki de olurdu.
>
> Suspicious, like 'you are my enemies', 'I am the messenger of Allah, I have to sacrifice one of you'. I think either prophet Abraham or someone slaughtered and sacrificed, or something happened, these kinds of thoughts. He said 'you are all infidels, I cannot teach anything to Muslim bastards', as he was a teacher in the past. Then he has a great hatred for people with hijabs and thinks like that. He cared about us since he sees himself as a messiah, but he didn't hesitate to hurt us as well. On the one hand, none of us have been that much harmed but maybe it would have happened if it had not been prevented.

Similarly, Mine (23), expressed her observations via referring to a persistent fear she experienced upon to active attacks of her father:

> Çok absürt düşünceleri oluyordu zaten. Gizli insanların onu izlediğini düşünüyordu. Ajanların olduğunu falan düşünüyordu. Kendi kendine mutfakta konuşuyordu. İşte buzdolabının ses çıkardığını falan söylüyordu. […] Bunu hatırlıyorum, sonra kendine söyleniyordu sürekli işte annemi öldüreceğinden falan da bahsediyordu kendi kendine ben de odadan dinliyordum. İşte seni öldürücem, intikamımı alıcam senden gibi. Birkaç kere annemi uykusunda boğmaya çalışmış, hani gece uyumaya bile korkuyordum-korkuyorduk. Ya biz uyurken bir şey olursa (sesi titriyor). Sabah uyandığımızda annemi ölü bulursak senaryoları çok dönüyordu kafamızda. O tarz korkularımız vardı yani en kötüsü bu sanırım.
>
> He was already having very absurd thoughts. He was thinking strangers are watching him and there were secret agents or something. He was talking by himself in the kitchen. He was saying that the refrigerator was making a noise or something. […] I remember these, and then he was saying to himself that he was going to kill my mother and I was listening to him from my room. He kept saying 'I am going to kill you; I will take my revenge'. He tried to suffocate my mother in her sleep several times, I was afraid to even sleep at night - we were all afraid. We had a lot of scenarios in our minds as what

> if something happens while we were sleeping and if we wake up in the morning and find my mother dead. We had those kinds of fears, so I guess that's the worst.

It is also worth to mention while some offspring were born into the isease of their parents, others abruptly witnessed to the onset and prognosis. Thereof, how, and when they were exposed to parental schizophrenia also influenced their search for meaning differentially. In families where parents had been diagnosed prior to the birth of the child, offspring tended not to question the situation as the parent's symptoms were already part of their family routines. For instance, Mine (23), the youngest of her family out of seven children and has a father with schizophrenia, explained the normalization process she had experienced as follows:

> Yani ilk nasıl öğrendiğimi hatırlamıyorum çünkü ben doğduğumdan beri zaten hastaydı. Hep ailem söylüyordu, baban böyle böyle hasta vs diye. Küçüklüğümden beri aslında hep biliyordum. Ama tam olarak ne zaman öğrendiğimi hatırlamıyorum. Yani nesi var gibi bir şey sorduğumu direk olarak hatırlamıyorum ama onlar direk baban hasta diyorlardı.
>
> So, I do not exactly remember how I first found out because he was already sick when I was born. My family always said that 'your father is sick like this and that,' etc. I've always known since I was little. But I do not remember exactly the time when I found out. I do not remember myself asking what's wrong directly, but they were just saying that 'your father is sick' directly.

By contrast, children who had faced the onset of the disease perceived the situation as a life-changing event and usually longing for the past memories with their parents prior to the diagnosis. To illustrate, Yılmaz (23), who was the fourth and last born of his family conveyed that*:* "Life before was going well until my age was around 13 to 14. Then this disease has found my mother, and she lost her charm" *(Önceden, benim 13-14 yaşıma kadar hayat güzel gidiyordu ondan sonra annemin başına bu hastalık geldi, annemde bir tat tuz kalmadı yani).*

Resistance of symptoms also brought about a unique confusion to the affected offspring. Children were not informed by either professionals or other family members about the nature and prognosis of the disease. This might be why our child participants attributed to the lack of insight to the affected parents' personality traits. Hence, the parent with schizophrenia were perceived as the cause of the difficulties that families had endured. Some children even blamed the patients as they believed their parents intentionally refused the treatment. For example, Tülay (30), expressed that: "My

father doesn't accept his disease, he is not saying 'I am sick or I should be getting treatment'. So he kinda says 'accept me like this'. We tend to accept him in that way but it doesn't work" (*Babam da yani kendini kabul etmiyor. Ben böyleyim, ben hastayım ya da ben tedavi göreyim yani bu da yok. Yani diyor ki beni bu şekilde kabul et diyor. O şekilde kabul etmeye yöneliyoruz ama olmuyor*). Similarly, Mukaddes (30), who had a father with schizophrenia conveyed that:

> Kendini görememesi. Adam resmen kendine bi dünya kuruyor yaşıyor ve asla ikna edemiyorsun. […] Onun söylediklerine ben ikna oluyorum ama o ikna olmuyor yani. O çok zor bir şey. Bi şeyleri anlatamamak yaşadıklarının tamamen hayal ürünü olduğunu söylemek anlatamamak çok zor bir şey. O kadar zor ki biz bunun mücadelesini babama karşı veriyorduk artık dediğim gibi bu son dönemde onu da bıraktık…
>
> His inability to see himself. The man is literally living in a world of phantasy that he has established, and you cannot convince him ever. […] I am convinced about what he says, but he is not. It's a very difficult thing. It's very difficult to not being able to explain things and say to him that 'what you experience is completely imaginary'. We were trying to keep fighting for my father, but it is that much difficult as I said we gave up on him lately.

Such misperceptions eventually influenced the treatment process as well which was already bounded with ambiguities due to chronicity of the disease. As the families depleted their own psychosocial resources, patients were left alone both by the system and close family members leading to greater impediments that surrounded the affected family. For instance, Ziynet (40), who had a husband with schizophrenia and two children, expressed that:

> Böyle salıyorsun biliyor musun artık umursamıyorsun. Almış almamış iğne vurulmuş vurulmamış artık yani yoruluyorsun belli bir şeyde. Ben onu kestim çünkü kocaman adamsın senin bu ilaçları ömür boyu kullanman lazım çünkü neden sen bu ilaçları kullanmazsa kendini iyi hissetmediğini kendinde bir değişiklik olduğunu kendin de fark ediyorsun. Ben her zaman senin peşinde koşamam her zaman senin yanında olamam onun için bu ilaçlarını içmek zorundasın diye söylüyordum. Ondan sonra bu bırakmış ben birkaç kere fark ettim ondan sonra sordum içiyor musun ilaçlarını diye içiyorum dedi.
>
> You let it go, you know, you don't care about him anymore. You feel exhausted, whether he takes his medication or needle shot… I am done with it because you are a big man, you have to use these drugs for life because if you do not use them, you realize that there is a change in yourself, and you do not feel well. I was saying that I cannot always look after you, I cannot always be there for you, that's why you have to take these drugs. After that, he quitted, I noticed it few times, then I asked him are you taking your meds, he said 'yes, I am'.

As it can be inferred from the quotations above, the attributions about the lower insight regarding the symptoms impacted on not only families' coping strategies but also the treatment process. In fact, lack of knowledge regarding schizophrenia seems to depleted the familial resources creating feelings of helplessness. Being the only adult caregiver, healthy parents reported exhaustion as they simultaneously dealt with other family issues including children. These interactions inside the home not surprisingly were observed by offspring affecting their identity developmental and mental well-being. As it can be seen in Figure 1, having a parent with schizophrenia influenced the normative family functioning and brought about impediments at three levels which were also affecting each other to certain degrees. These were impediments experienced at home, impediments with the extended family members and socio-politic impediments, categorically.

3.2 Category #2: Impediments at Home

Due to unpredictable and chronic nature of the disease itself, parental schizophrenia not only impacted on children but the family functioning as a whole. The never-ending ambiguities in the family environment affected family members' interactions with the inner and outer world. Accordingly, this category covered the impediments and challenges experienced by the offspring at home as a result of living with parental schizophrenia. The psychological absence of the affected parent was one of the dominant discourses which seem to be closely related with neglect and negative parenting attitudes. The parenting styles of the healthy parents were eventually compromised because of being the only adult caregiver at home. Healthy parents felt exhausted and angry as they had been left alone both by their own relatives and by the system. They usually directed their hostility either to children or their spouses at home. As a result, affected children felt left alone and postponed their own needs in order not to overburden their already exhausted parents. For instance, Mine (23) described her observations about her parents' spousal relationship and how those dynamics impacted on her as follows:

> Ya aslında babam çok iyi bir insan, baktığınız zaman gerçekten kalbi temiz biri cidden. İşte kimseye zarar vermeyecek birisi ama hastalığından dolayı bir sürü hata yaptı. Annemle babam 10 yıldır aynı odada uyumuyorlar bile, annem pek hazzetmiyor kendisinden ama boşanmadı da […] Sadece aynı evde yaşıyorlar. Ya annem de çok iyi birisi değil ama, çok sinirli. Eskiden öyle değildi de babamdan etkilendi büyük ihtimal hani sürekli olaylar vs olunca. Baya asabi birisi o da, yani her şeye sinirleniyor kızıyor

şey yapıyor. Annemle ergenken 15-16 yaşlarımda çok kavga ediyordum. Evden falan gitmiştim. Hatta annem kendisi evden kovmuştu diyeyim. O zamanlar çok kavgalar ediyorduk, tartışıyorduk falan. Yani ben de etkileniyordum tabii ki evde olan şeylerden dolayı. […] Annem baskıcı, çok sinirli. Bu sinirliliğinin çok normal olduğunu düşünmüyorum. O yüzden ben hasta olabileceğini düşünüyorum ama kabul etmiyor, hiç hastaneye gitmek gibi bir teklifi dahi olmadı. Hasta olabilme ihtimalini düşünmüyor hiç.

In fact, my father is a very good person, when you look at him, you see that he has a pure soul, really. He cannot hurt anyone, but because of his illness, he made a lot of mistakes. My mom and dad haven't even slept in the same room for 10 years, my mom doesn't like him much, but she didn't get divorced either […] They just live in the same home. But my mother is not a very nice person either, she is very angry. She wasn't like in the past but probably she was influenced by my father since constant issues have happened etc. She became very irritable, gets angry and mad towards everything. I used to fight a lot with my mother when I was a teenager around the ages of 15-16. I had left the house, I mean, my mother kicked me out of the house. We were fighting a lot back then; we were arguing and stuff. I mean, I was also affected, of course, from what happens at home. […] My mother is oppressive, very angry. I don't think that her anger is normal. That's why I think she might have a disease, but she doesn't accept it, she never even offered to get help from the hospital. She never thinks about her possibility of having a psychological problem.

Similar to Mine, Tülay expressed her unseen and unheard needs resulting from her mother's low tolerance and psychological absence of her father:

Çünkü zaten annem de onu tam anlamıyla yüklenemediği için hem anne hem baba olmayı. […] Biz o yolda tek başımıza yürüdük. Ben hiçbir zaman annemin ya da babamın veli toplantısına geldiğini hatırlamıyorum ya da bir herhangi bir gösterime işte tiyatroma vs. Böyle şeyleri hiç önemsemezlerdi, duymazlardı yani bilmiyorum. Söylerdik, önemsemezdiler öyle. […] Hala öyle, yani biliyoruz arkada bir anne baba var evet mesela, tabii bir şey olduğunda ilk gittiğimiz kişi oluyor, ama hep kendi kendimize kalkmaya devam ediyoruz yani küçükken nasılsa o şekilde. […] Annem bir yandan da sinirli, nereye kadar kaldırabilir ki, biz anlayamıyorduk o dönem mesela annemin sinirini. Mesela evde sürekli bir şeyleri, işte sinirden çatal kaşık fırlatır mutfakta bir şeyler fırlatır, anlamlandıramıyorduk ki yani öyle olunca da ne yapacaksın? Baban ayrı annen ayrı başına bi iş gelince de tek başına. […] Tam anlamıyla çocuk olamadık, tam anlamıyla bir anne baba sohbeti bir o sıcaklığı o ilişkiyi tam anlamıyla yaşayamadık.

Because my mother couldn't handle being both a mother and a father at the same time […] We walked alone on that road. I never remember that my mother or father came to a parents meeting, or to any performance, to my theater, etc. They wouldn't care about such things, they were not aware, I don't know. We used to say so, they did not care. […] Still, it is, yes, we know that we have a mother and a father behind us and when something happens, we first ask for their opinions, but we always get up on our own as how it was used to be since we were little. […] Besides, my mother is angry, how far she can stand, we couldn't understand her anger at those times. She was throwing things constantly out of her anger at home, like fork, spoon in the kitchen, we couldn't make

> sense of, how would you behave as a child when something like this happens. Your father is on one side, your mother is on the other side and if something happens to you, you are on your own. […] We couldn't be a child literally, we couldn't experience that relationship, that warmth, that parental relationship with a mother and father.

These quotes were prototypical examples of the unaffected parents' emotional and psychological state due to being the only adult caregiver. Healthy parents expressed their anger against external family members for not offering emotional and instrumental help. They also complained about lack of health regulations in Turkey aiming to enhance internal and external resources of the affected families. They felt rejected not only by their close environment but also by the state's institutions. This exhausting process eventually hampered their parenting skills as they did not have adequate physical and emotional resources to fulfill their children's needs. In this context, Yılmaz pointed out the absence of parental figures during his childhood especially after his mother's diagnosis as follows:

> Evet, babam zaten kendi halindeydi hep. Annem de hastalıktan sonra konuşmayı şeyi çok azalttı. Babamla benim ilişkime baktığımız zaman yani babamla oturup uzun uzun sohbet edemiyoruz. […] O süreçten sonra daha çok sokaklara atıldım. Sokaklarda geziyordum, farklı insanlarla takılıyordum ondan dolayı biraz annem hasta olmasaydı, biraz daha mutlu olabilirdim. Çünkü bir aile, yani insanın hayatında büyük etkisi var ailenle yaşadıklarının, ailenin senin yanında durması ya da arkanda durması. Onların varlığını hissetmen çok güzel bir şey yani.

> Yes, my father was always calm and distant. My mother also stopped talking and stuff after her illness. If we look at my relationship with my father, that is, we cannot sit down and have a long conversation with my father. […] After that phase, I went out to the streets more. I was wandering around the streets, hanging out with different people, so I might have been a bit happier If my mother had not been sick. Because, what you experience with your family has great impact on an individual's life whether your family stands beside you or stands behind you. It's something beautiful that you feel their presence.

While assuming profound responsibilities regarding the care of the affected spouses, healthy parents simultaneously tried to compensate for the psychological absence of their partners. They admitted taking wrong decisions about their children as they were not comfortable about the parenting tasks of their spouse particularly due to gender roles. To exemplify, Ziynet (40) described her decision to register her first-born child to a state dormitory during middle school years to compensate for the lack of a paternal figure:

Bir baba çocuklarını küçüklükten alır, götürür ellerinden, bir traş oldurur vs. Ama anne yapıyor öyle şeyleri. Ergenliğe ulaşıyorlar mesela, bunu anne mi anlatır baba mı anlatır, özel bölge temizliğini, rüyalar onlar bunlar. Ben bunları mesela kendim anlatmak zorunda kaldım. Yurda gönderdim öğrensin diye, diyorum şimdi de sen kardeşine anlat. Faruk biraz harcandı, cahilliğime geldi. Şu an Tarık'ı veremiyorum mesela.

A father mentors his children starting from their childhood, assists and leads them, takes them to have their first shave etc. However, the mother has to do these kinds of stuff. For example, they reach to puberty, do you think a mother should talk about cleaning their private areas, or about dreams or should a father do these? I had to tell these to them by myself. I sent him (referring to her older son) to a dorm so he could learn about those things, so I say to him, now you have learnt, and you can teach your young brother. Faruk was a bit wasted, came to my nescience. Now, for example I cannot register Tarık to a dorm.

Almost all interviewed children reported to witness domestic violence as a result of the persecutive delusions of the affected parent. Indisputably, insufficient delivery of in-patient and out-patient treatments had an impact on such outcome. Controlling and managing the paranoid symptoms became much more challenging for the families due to low-quality psychiatric and community mental health delivered to those families. Not receiving adequate professional and social help, families were coping with violent symptoms by their own which further impede the meaning making process of the affected children. Children were not able to comprehend the unstable behaviors of their parents and also avoided asking questions about the situation. One of the unaffected parents, Kamuran (59) explained her victimization of physical abuse as follows and provided clues about the impacts on her children:

Kamuran: Dışarıda olduğu zamanlarda daha çok tepkisi vardı bana. Mesela, o polisken eve gelince kavga çıkarıp beni dövünce, çocuklar ağlıyorlardı, saklanıyolardı. Çocuklar korkuyordu, mesela tencereyi getirdim masanın üstüne, alıyordu halının üstüne atıyordu, kapıya atıyordu kapıyı kırıyordu, pencereyi kırıyodu. […] Niye böyle yapıyosun sen niye böylesin diyordum, o beni dövüyordu ferahlıyordu. Ondan sonra öfkesi geçtiği zaman da ben seni seviyorum da sana kıyamam da şöyle yapamam da diye şey yapıyodu.
Araştırmacı: Peki Kamuran Hanım, çocuklar o dönemde size soruyorlar mıydı, babalarıyla ilgili ne oluyor, neden oluyor gibi?
Kamuran: Ya sormaları nasıl mesela, ee bir evin içinde yaşayıp da şey yaptıkları anladıkları için bazı zaman derlerdi, ben üzülüp de beni dövdüğü zaman. Genelde sormazlardı, bazı zaman da derlerdi hani bizim babamız böyle bize şey yapmıyor, baba mı sanki gibi birbirlerine derlerdi duyardım.

Kamuran: He had become much more reactive towards me when he was outside.For example, when he came home while he was a policeman, he started a fight and beat me,

children were crying and hiding. Children were afraid, for example, I brought the pot on the table, he was picking it up, throwing it on the carpet, throwing it to the door, breaking the door, breaking the window. […] I was asking 'why are you doing this, why you behave like this?', he was beating me then he was relaxing. After that, when his anger subsided, he would do something like "I love you, I can't hurt you, I can't do anything to you".
Researcher: Well, Miss Kamuran, were children asking questions about what is going on with their father or why is it happening?
Kamuran: So, how they were asking, for example, as we live in the same house and when they were seeing and realizing, when he made me sad and beat me. Generally, they were not asking but sometimes I was hearing that they were saying to each other 'our father is like that, he does not do a thing for us, he is not a father'.

To underline the seriousness of the violence that the offspring had witnessed, it would be beneficial giving place to the account of Yelda (23) expressing how the violent nature of the symptoms affected them as a family:

Mesela, Bir gece babam bir bıçak eline alıyor ve büyük ablamı kurban edicem allaha diyip bu şekilde bir kriz geçiriyor. Ben de bunu görüyorum, ben bağıramıyorum, o an bağırmaya çalışıyorum en sonunda zaten bağırdım ve annem uyandı. Sonrasında da hani orada kardeşim, zaten bizim evimiz o zaman sobalıydı onlar diğer odada biz çocuklar diğer odada uyurduk. Bunu gördüm, bunu gördükten sonra zaten jandarma falan da geldi. […] Babamın öyle kötü olduğu zamanlarda bizim hemen evimizin karşısında okul vardı biz okula kaçardık bir şey olduğunda kurtulmak için o an evden çıkmak için. Çünkü annem derdi çabuk siz hemen çıkın çıkın derdi biz koşa koşa yalınayak üstümüzde ne varsa koşar giderdik yani. O an işte teyzem gelirdi hemen evden gidip eşyalarımızı alır bizi götürürdü işte üç gün kalırdık sonra eve dönerdik.

For example, one night my father took a knife and had a crisis shouting that 'in the name of God he will sacrifice my elder sister'. I saw this, I could not scream, I was trying to shout at that moment, finally I shouted, and my mother woke up. Afterwards, at our house, we were using a stove at that time, so they were (referring to her parents) sleeping in the other room, we, as children, were sleeping in the other room. I saw this, after seeing this, the constabulary came anyway. […] When my father was that much bad, we used to run to a school which was right in front of our house, when something happened, we got out of the house. Because my mother used to say that 'you should get out quickly', so we were running barefoot with whatever we had on us. At these moments, my aunt (referring to her mother's sister) was coming and taking our belongings from home and took us to her place which we would stay for three days and then returned to home.

Unfortunately, the sense of certainty and predictability which we all seek to some extent in our lives was on the exact opposite side of the continuum for the target sample. The only certainty and predictability for them was the idea that 'anything can happen anytime at home'. Being pre-occupied with the possible consequences of unusual behaviors of their parents, their school success had also been put to the

background. Coupled with the psychological burden imposed by the chaotic home environment, their academic needs had not been attended sufficiently by their parents. For example, Mine, the youngest of her siblings, conveyed their academic difficulties as follows:

> Benim ablalarım, hiçbiri okumadı mesela. Okuyamadılar ve çalışmak zorunda kaldılar erken yaşta. Babamın bizi, borçlardan dolayı, daha doğrusu yaptığı borçlardan dolayı çalışmak zorunda kaldılar hep. […] Okula gidip geliyordum, ama aklım hep evde oluyordu mesela. Acaba babam anneme zarar verir mi gibisinden, çünkü belli olmuyordu hani öyle bir şey olabilir gibisinden hep korkarak yaşıyorduk. […] Tabii psikolojik olarak da çok etkiliyor, sürekli hep kavgaların içinde büyüyorsun. Okula odaklanamıyorsun. Başka şeylere odaklanıyorsun. Yani aklın sürekli evde, bir şey olacak mı bugün gibi. Ve sıkça bizim eve polis ve ambulans gelme süreci oldu. […] Küçükken de pek ilgilenmiyorlardı zaten okuldur şeydir, hani hangi liseye gittiğimi bile bilmiyordular. Bilmezler de. Veli toplantıları falan olduğu zaman katılmıyordu ikisi de.

> For example, none of my elder sisters completed their education. They couldn't complete their education and they had to work starting from early ages. Because of my father's debts, they always had to work […] I was going to school, but my mind was always busy with the home. What if my father would hurt my mother because it was unexpected,, and we were living in fear of something might happen at any time. […] Of course, it also affects you psychologically too, you grow up observing never-ending fights. You cannot focus on school. You focus on other things. So, your mind is always at home, what if something happens. And police and ambulance were frequently coming to our house. […] When I was little, my parents were not very interested with school my school life anyway, they didn't even know which high school I was going. They still don't know. When there were parent meetings or something they did not attend.

Since the home environment was full of uncertainties, children who had a parent with schizophrenia had to change their priorities. Management of the family problems arousing from the parent's symptoms overshadowed their academic concerns. As an unaffected parent, Ziynet (40) reflected on the impediments that her children experienced in their academic lives as:

> Öğretmenlerinin sadece dedikleri sizin çocuklarınızın kapasitesi var ama yapmıyorlar işte yapmamalarının en büyük sebebi de ev ortamı. Çünkü Faruk diyor ki, anne diyor okuldan gelirken diyorum işte eve gidicem şöyle çalışıcam, kendimi motive ediyorum eve gelince her şey bitiyor diyor. Çünkü ev ortamı öyle bir ortam değil. Kavga, gürültü, bölünüyor. […] Sorumluluk zaten bütünlemesine Faruk'un üzerine yüklendi şu an, çalışıyor neden çalışıyor çünkü borç harç var şu an. 18 yaşında, yaşıtları üniversiteye hazırlanıyor ama bizimki çalışıyor, belki borçlarını bitiririm de daha iyi olurlar diye. Erken yaşta Faruk büyüdü, erken yaşta bir sürü sorumluluk üstlendi. Normal bir hayatları yok işte.

> Their teachers always says that ‘your children have the capacity, but they don't use their potential because of the home environment’. Faruk says that (referring to her older son) ‘mother when I am coming back from school, I am saying to myself that I will work todat and I motivate myself but when I come home everything is over’, he says. Because home environment is not such an environment. Quarrels, noises which distrupted him. […] The whole responsibility is already on Faruk now, he is working because we have debts and fees now that’s why he is working. He is 18, his peers are studying for university, but he is working by thinking that ‘if I pay their debts they might be better’. Faruk grew prematurely and took many responsibilities at an early age. So, they don’t have a normal life.

Impediments experienced by the affected offspring at home were all interrelated. Yet, they did not happen in a vacuum, instead they were influenced, and reinforced by external factors. One external barrier having a reciprocal relationship with the at-home-impediments was the difficulties imposed by the external family members. In the following category, impediments experienced via interactions with extended family members which also had a role on the nuclear family challenges were discussed.

3.3 Category #3: Impediments Brought by the Extended Family Members

This category covered the attitudes of close relatives towards target families that reinforced the actual and perceived impediments at nuclear and extended family contexts. Since parental schizophrenia led to changes in normative functioning of the family, affected families needed profound assistance and support on several domains of life. However, the instrumental and emotional needs of the target family were not realized by their extended family members. Hence, this category referred to the additional burden imposed upon offspring and healthy parents due to rejecting and isolating attitudes of external family members. Extended family members tended to blame the unaffected parent as the reason for the current psychiatric state of the affected parent. The blaming and hostile attitudes of the external family members increased the tension and distress experienced by both offspring and healthy parents. Affected families totally became alienated from their social environment which, in turn, maintained and strengthened the already existing barriers at home. For example, Faruk (18) expressed the guilt-inducing attitudes of his grandmother as follows:

> **Faruk:** Babaannemler yani tabii böyle eee şey nasıl anlatsam, niye böyle oldu vs babaannem biraz annemi de zorladı. Seninle evlendikten sonra oldu gibi şeyler de dediler, suçladılar, kavga ettiler […] Hazzetmiyorlar işte oğullarını kötüleştirdi diye.
> **Araştırmacı:** Bu senin açından nasıl bir suçlama?

> **Faruk:** Gerçekçi değil, kadın ne yapacak da adama öyle kafayı yedirttirecek. Herhangi bir şey yapması lazım, adamın sabah akşam kafasında davul çalması lazım ki adam kafayı yesin, herhangi bir kusuru yok bu anlamda.
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> **Faruk:** My grandmother, I don't know how explain, pressurized my mother like 'why it happened like this', etc. She said things like 'he became like this after he had married with you', she accused her (referring his mother), they fought […] They don't like my mother because they believe she made their son worse.
> **Researcher:** What kind of accusation is this from your point of view?
> **Faruk:** It's not realistic. What can a woman do to make a man go crazy like that. She has to do something such as playing drums on his head from morning to evening so that a man can goes crazy, she has no fault in this sense.

Besides, unusual nature of the positive symptoms was usually attributed to the religious causes (e.g., being under the influence of a spell) by the extend family members. Relatives' spiritual inferences increased the affected families' anger and resentment since they felt invalidated and unheard. As a result, they became more isolated while dealing with disease related difficulties. For example, Kamuran (59) explained how she felt upon the religious explanations of extended family members as follows:

> Bana Orhan'ın bir şeyi yok, işte senin ailen muska yaptı dediler. Hep muska yapıldı dediler. Hala bile sebep olarak muska diyorlar, muska yaptılar muskadan oluyor diyorlar. İşte bu var ya insanoğlunun yanlış saplantıları, cahillikleri, kabullenmedikleri. İşte hanımıyla çocuğu çekiyor. Her şeyde tek başına kalıyorsun.
>
> They said that 'Orhan is well, your family put a spell on him'. They always said that spells were put on him. They still say so as a reason, they say that they put spells on him, and it happens because of spells. That's it, human beings' wrong obsessions, ignorance, and things that they do not accept. So, wives and children suffer. You are alone in everything.

Similarly, Mukaddes (40) conveyed that "They never thought there might be something wrong medically, it was always about putting spell on. My aunt has a similar psychiatric condition too. My aunt is already staying in a clinic right now. […] But according to them, there was nothing wrong with any of them, they were all very strong, healthy, they are just like that because of the spells that were put on them" (*Hiç düşünmediler tıbbi bir şey olabilir diye, hep büyü yapılmıştı. Halam da benim böyleydi. Halam zaten şu anda klinikte yatıyor. […] Ama onlara göre hiçbirinde hiçbir şey yoktu, hepsi çok sağlamdı, sağlıklıydı, büyü yapıldığı için böylelerdi*). These attributed reasons which are kind of supernatural not only influence the relationships

of target family members with the close relatives but also close relatives' stance towards target families, too. Since they do not perceive there was something wrong medical wise, they insisted on seeking for traditional healing methods via clergies. As a result, they did not take responsibility for the medical needs of the affected parent. Faruk (18), commented on his grandparents' actions regarding religious treatment as: "Those thoughts seem a bit nonsense to me. […] I mean, what the hodjas are doing, they are reading verses from the Qur'an, or something. We might do that too, it is easy, they do it and also get paid. I think it's useless" (*Bana o taraflar biraz saçma geliyor. […] Yani hocalar falan ne yapıyorlar ki, kurandan ayet falan okuyorlar. Onu biz de yaparız o kolay, onu yapıyor bir de üstüne para alıyor. Yani bir faydası yok*). In addition to that, problems at home were considered as normal relational problems that any couple could experience, once again dismissing the medical side of the problem. Instead of offering instrumental solutions, they either suggested divorce or repairing the relational problems. Such an attitude increased the feelings of loneliness and hopelessness for both unaffected parents and their offspring, as they felt their experiences were not validated by close relatives. For instance, Tarık (13) reflected his experience as:

> **Araştırmacı:** Akrabalarının sence tutumları nasıl bu duruma yönelik?
> **Tarık:** Bilmiyorum, bazıları boşan diyor anneme. Bazıları da aranızı iyi yapın diyor yani (sesi titriyor). Herkesin dediği farklı yani birbiriyle çelişiyor herkesin dediği.
> **Araştırmacı:** Aslında bu boşanın ya da aranızı iyi tutun gibi telkinler haricinde, ne yapabiliriz sanıyorum ki konuşulmuyor?
> **Tarık:** Yok hayır kimse onu soruşturmuyor
> **Araştırmacı:** Bu nasıl geliyor sana?
> **Tarık:** Bu mantıksız geliyor çünkü yani babam (ağlamaklı) isteyerek yaptığı bir şey değil sonuçta. O yüzden mantıksız geliyor.
> **Araştırmacı:** Şey gibi mi değerlendiriyorlar, bu onun tercih ettiği bir şey gibi?
> **Tarık:** Evet evet.

> **Tarık:** I don't know, some say 'divorce' to my mother. Others say, 'take it easy' (his voice trembles). Everyone is suggesting different solutions and they contradict with each other.
> **Researcher:** Actually, apart from these suggestions such as getting divorced or keeping your distance, do they offer other solutions?
> **Tarık:** No, no one tries to understand him (referring to his father).
> **Researcher:** How does that sound to you?
> **Tarık:** That seems illogical because it's not something that my father (with tears) does intentionally. That's why it doesn't make sense.
> **Researcher:** Do they treat it like, like, something that he chooses?
> **Tarık:** Yes, yes.

Additionally, close relatives also expected healthy parent to provide care for the older members of the extended family as a cultural tradition. This expectation resulted in feelings of anger and resentment for the unaffected partner since the difficulties they experienced due to disease were not appreciated. Besides, they felt left alone as no one from the extended family circle was taking care of them. To illustrate, Kamuran explained her additional burden due to taking care of her husband's mother as:

> Mesela şimdi annesi (eşinin) benimle, 7 kardeşler bu arada, onlar şey yapsa daha farklı olurdu. Bak bu adam bu halde, hasta. Bir de annesini üstüne bıraktılar ve gittiler. Tamamen bize bıraktılar. Zor hayat. Hiç destek görmedim, merdiven sildim çocuklarımı okuturken. Ev temizliklerine gittim. Şimdi babaanne bizimle, maaşı var ama 8 senedir bir kuruş dahi vermedi. E evimde oturuyorsun değil mi, halimizi de görüyorsun.

> For example, now his mother (referring to her husband's mother) is staying with me, they are 7 siblings by the way, the conditions might have been different if they had done something. They never thought that 'this man is sick'. And they left his mother They left her completely. Difficult life. I did not receive any support; I wiped the stairs while affording my children education expenses. I went to housekeeping. Now the grandma is with us, she has a salary, but she hasn't given even a penny for 8 years. Well, you're staying at my house, right, you see our situation.

3.4 Category #4: Socio-Political Impediments

This category referred to the barriers resulting from the operations of social and political structures in Turkey. That is, impediments encountered by the affected offspring also demonstrated themselves on the socio-politic base. This process started with the affected parent's inability to work due to exacerbation of symptoms and subsequent economic barriers. Families reported not to be adequately informed about the prognosis and treatment protocols. They were unaware of the community mental health services offered to patients with schizophrenia. They tried to use their own personal resources to manage the treatment related needs of the affected family members. Unfortunately, affected parents' professional lives were also compromised due to the lack of regulations about job accommodations and discriminating attitudes at workplaces. Consequently, the low-quality health care and lack of arrangements in institutions resulted in patients to quit their job. As the work life of affected the parents could not be sustained, economic barriers emerged. These economic barriers became eventuated especially when the affected parent was the father. Yet, the impacts of quitting work was evaluated less problematic in the context of maternal schizophrenia since the mothers had not worked prior to their diagnosis consistent with the societal

gender roles in Turkish family context. Economic barriers surrounding the nuclear families further accentuated as a result of the poor conditions of the disability retirement. The salaries offered to the individuals with any type of "disability" fell short of meeting the regular expenses of such families as they were already at a more disadvantageous position due to management of a chronic disease. Since affected parents had retired due to a sort of disability, their options became restricted due to stigmatization of mental illness. All these economic barriers led affected offspring to experience economic deprivation starting from their childhood. For example, Tülay described his father's retirement process who had been working as a policeman and its' negative outcomes for the other family members as follows:

> Zaten devlet emekli etti hani baktı tedaviye olumlu bir yanıt vermedi ve de ilaçlarını kullanmayı reddedince. […] Annem hani diyor ki baya uğraştılar başındakiler işte müdürü vs. çok yardımcı olmaya çalıştılar ama olmadı diyor. […] İşte bütün yük de sorumluluk da kadına kaldı haliyle bu şekilde. Annem şey diyordu babanın maaşı düşük, çok yüksek para vermiyorlar. İşte ne yapalım azla yetinicez yapacak bir şey yok. […] Baktı geçim olmuyor tek bir maaş, altı çocuk. Paraya ihtiyaç var, altı çocuk var. Bir emekli maaşıyla, o şekilde bizi bugünlere getirdi […] Abim mesela benim baba oldu bildiğiniz. Abim yani eve baktı, evin bütün geçimini üstüne aldı. Para pulu yönetme, evin erzaklarını alma. Küçük yaşta çalıştı, emlakçılık işte bilgisayarcılık yani onu yüklendi tamamen üstüne. Mesela ablalarım da hani çalıştı etti.
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> The state retired my father upon seeing he did not respond to the treatment and he refused to use his drugs. […] My mother says that they tried a lot. She says they tried to help a lot, but it didn't work. […] So whole burden and responsibility rested upon the woman (referring her mother). My mother was saying, your father's salary is low, they don't pay very high, we have to learn to live with less, there's nothing to do. […] She said that with a single salary and six children, there is no way of making a living. Money is needed, there are six children. She raised us with a single pension […] My brother, for example, became a father, you know. My brother, that is, looked after the house, he took the whole responsibility of the house on his own. Managing money, buying the supplies of the house. He worked at a young age, in real estate, computer businesses so he assumed all responsibility completely on himself. For example, my older sisters also worked, too.

Similarly, Kamuran explained the difficulties she experienced as a mother with spousal schizophrenia as:

> Evet tek maaşla yapmaya çalışıyorum, benim zaten hayatım hiç olmadı. Lastik etek giydim 10 liralık, o zamanda 5 liralık ayakkabı giydim. Bir mont aldıysam 3 sene giydim. Onlara da giydirdim yani alamadığım zaman olduğunda, onlara da şöyle derdim yani derlerdi ki bize almıyosun bize geçen senekileri eskileri giydiriyorsun derlerdi. Ben de derdim ki hep, bak hiç alamayanlar var elimde olsa esirger miyim, ben size alıcam diyordum. Alamadığım da oluyordu. […] Hepsi birbirinin eskisini giyerek büyüdüler. Mesela şu an üniversiteye giden çocuğum dedi ki bana, lise 1 e giderken ben ayakkabım

yırtılıyordu ayağıma su girene kadar size demedim, ki o ayakkabılarla okul birincisi olduğu gün ödülünü almış hep bunu söylüyor. Bunu hala unutamıyorum, Diğeri de sen 8. sınıfta dedin ki işte sen iyi bir lise kazan bisiklet alıcam dedin almadın, sen bana bisiklet bile alamadın diye şimdi diyor.

Yes, I'm trying to make a living with a single salary, I've never had a life anyway. I wore a rubber skirt for 10 liras, at that time, I wore shoes for 5 liras. If I bought a coat, I wore it for 3 years. I also made children dressed like me, when I couldn't afford buying, I would say to them, they would say that 'you don't buy new ones for us, you are making us wear the old ones from last year'. And I always used to say, 'look, there are those who can't get it at all', I was saying 'if I could, I would have bought it for you'. There were also times that I couldn't really buy. […] They all grown up by wearing each other's old clothes. For example, my child who is going to university now, said to me that 'when I was in the first year of high school, my shoes were torn but I did not say until I got water on my feet', she worn those shoes on the day she got awarded as the first ranking student, she always reminds this. I still cannot forget that. And the other one also says to me that, 'you said I will buy a bike to you if you have been accepted from a good high school, but you did not buy, you couldn't even buy a bike to me' he says now.

In addition to low retirement salaries, affected families also dealt with the fraud. Some of the extended family members took advantage of the compromised decision-making skills of the affected parents. Those behaviors decreased families' beliefs in others further alienating them from their social environment. Besides, poor state regulations regarding disability reports further accentuated the economic barriers faced by the affected families. For instance, Yelda explained her relatives' attitudes towards her father who was a teacher, also her considerations position among extended family members as:

Ve akrabalar, yani annem de dediğim gibi çok aslında böyle güçlü bir kadındı çünkü kimseye çocuklarının parasını rızkını yedirtmemeye çalıştı. Her defasında onlar faydalanmaya çalıştılar babamın bu sürecinden, ama annem buna izin vermedi. Böyle olunca da ailede sevilmedik istenmedik çünkü o borç istiyor bu istiyor o babamı kandırmaya çalışıyor çünkü babamı da kandırmak çok kolaydır açıkçası ama bir yerden sonra, annem, zaten babamın %86 işte zihinsel engelli raporu vardı, babama kendisini yasal vasi olarak atadı.

And our relatives, as I said, my mother, she was such a strong woman, because she tried not to let anyone to take her children's share. Each time they tried to take advantage of my father's condition, but my mother did not allow it. This is why we were not loved in the family, we were not wanted because somebody wants a loan, somebody wants to deceive my father, because frankly speaking, it is very easy to deceive my father. But after a while, my mother, my father already had a mental disability report at 86%, appointed herself as official custodian to my father.

Likewise, Mine narrated her family's economic difficulties resulting from the poor state regulations as:

> **Mine:** Çok borç altına sokuyordu bizi sürekli hani istemediği-aslında kendisi de istemiyordu da… İstemediği böyle boşu boşuna olan harcamalar yapıyordu, kredi çekmeler, araba almalar vs. O tarz şeyler yani hep duyuyordum, anlatıyorlardı. Kendim de şahit oluyordum
> **Araştırmacı:** Babanızın bir raporu söz konusu ve bu borç süreçlerinde rapor herhangi bir kolaylaştırıcılık sağladı mı?
> **Mine:** Raporun çok koruyuculuğunu görmedik açıkçası. Bu hastalığı bilip yararlanmak isteyen oldu bence. Çünkü bir dönem araba almıştı babam, ama büyük bir ihtimal birisi onu kandırıp da o arabayı sattı. Baya pahalı bir araba almıştı ama o paraya değecek bir şeyi yoktu o arabanın. Kandırıldı zaten. Öyle şeyleri olmuştur. Kandırılmaya baya meyilli birisi. […] Krediler vs. olduğu zaman babamın bankası kartından kesiyor. Tabii baya borçları azalttığımız için şu anda, aslında onun kredi çekememesi gerekiyor. Annemin imzası olmadan hiçbir şey yapamıyor aslında. Ama nasıl çekti ne şekilde çekti, banka nasıl kredi verdi bilmiyorum. Annemler dava açacağız dediler. Çünkü aklı başında bir insan olmadığı için imza atarak bir şeyleri alamaz.

> **Mine:** He used to put us under debt all the time, in fact he was not doing intentional – in fact he didn't want this either… He was making such useless expenditures
> that he didn't want, taking loans, buying cars, etc. I was always hearing such things, they were telling. I was also witnessing to these.
> **Researcher:** So, there is a report of your father's condition and did the report provide any protection in these debt processes?
> **Mine:** Actually, we did not see the protective role of the report. I think there were some people who were aware about my father's disease and wanted to take advantage of him. Because my father bought a car for a while, but most likely someone deceived him and sold that car. He bought a pretty expensive car, but that car wasn't worth that much money. He has already been deceived. Such things have happened. He's very prone to being scammed. […] Credits etc. When happens, my father's bank debits it from his card. Of course, since we have reduced a lot of our debts right now, he should not be able to get a loan. He can't actually do anything without my mom's signature. But I don't know how he took it, how he got it (referring the money), how the bank gave a loan. My mother said she will sue the bank. Because he is not a sane person, he cannot get something by signing.

Socio-political barriers not only demonstrated themselves at the economic level but also through the operations of public health services, as well. In the present study, the lack of scientific debriefing about the prognosis and treatment of schizophrenia with the target family emerged as an important issue that related with all impediments underlined so far. Unaffected parents did not question the situation as a result of their poor educational background. They also had difficulty to comprehend the information shared by the health care professionals. None of the family members reported to have access to formal support resources informing about the nature and management of the

disease. Thereof, children were left alone with several unanswered questions. They were searching for clues to make sense of what their family was going through. Healthy parents either did not provide any information at all or misinformed the children about the condition of the affected parent. Children evaluated the information conveyed by mental health professionals as inconsistent and non-scientific, as well. In fact, the answers they received seem to bring confusion to the already existing ambiguity. For example, Yelda explained her communication with the doctor as:

> Çünkü biz küçüktük ve bunu anlamamız çok zordu. Annem de o dönemde, onun da kendi bir yakın arkadaşı vardı, beraber doktora gitmişlerdi bizim orada. Ve hani o demiş ki çocuklara ilk başta bunu farklı söylemeniz, tutarlı bir neden vermeniz daha iyi olur demişler annem de böyle bir şey söylemişti. Demişti ki böyle böyle bir trafik kazası oldu, yoksa babanız gayet iyi siz de gayet iyisiniz işte sizi etkileyecek bir şey yok bu tarz şeyler. Sonra ben büyüdükten sonra 16 yaşına falan geldiğimde, anneme hani sorgulamaya başladım ne kazası, nerede oldu, niye oldu gibi. Hiç niye ameliyat yok, tedavisi falan. Sonrasında hani kendim de biraz böyle ilaçlarına falan baktığımda hani babamın şizofreni tanı, -şizofreni olduğunu aslında hep hep biliyorduk yani aslında hep bir sorun olduğunu biliyorduk ama hiç üstüne gitmemiştik. Annem hep bizi böyle ekarte etmişti bu şekilde yani. […] Ama dediğim gibi doktorlara da hep sorardım, kendim de araştırıyordum yoktu. Hatta şey demişti bir tanesi bir ameliyatı var işte %95 etkili ama ölüm tehlikesi var demişti bir doktor çok gülmüştüm. Çocuktum çünkü, amacı o an imkansızı söylemekti. Anlamıştım ama işte öyle bundan da bahsetmek istedim. […] Annem de bir şey bilmiyor ki yani, hani annem de bu konuda çok bilgisiz. Sadece işte doktora gidiyor yani dediğim gibi, gittiğimiz psikiyatristler de çok sık değişti zaten ama en son Adıyaman'da bir tane kadın hekim vardı ve o çok ilgiliydi. Hatta ben (hafif gülerek) her gittiğimde küçükken ona şey derdim babam sizce iyileşir mi derdim. O da bana böyle acıyarak bakardı ve derdi ki yani şu an ilaçlarını kullanırsa her şey daha güzel olur Yeldacım derdi. Ve şimdi diyorum ki kendime, kadına niye acı çektirmişim resmen hani her defasında aynı soruyu soruyorum ama bıkmadan usanmadan aynı soruyu soruyorum.

> Because we were little, and it was very difficult for us to understand that. At that time, my mother had a close friend of her own, they went to the doctor together. And the doctor said that 'it would be better to tell to children situation differently in the first place, giving a consistent reason might be better', so she said something like this. She said that 'there was a traffic accident, otherwise your father is fine, you are also fine, there is nothing that will affect you etc'. Then, after I grew up, when I was 16 years old or something, I started to question my mother about the accident, where it happened, why it happened. Why there is not any surgery or treatment or something. After, I examined his medications, I learned that my father has schiz- I mean, actually we always knew that he has schizophrenia, I mean we always knew that there was a problem, but we never thought about it. My mother always excluded us in this way. […] But as I said, I was always asking to the doctors while also searching by myself, there wasn't. In fact, one of the doctors said that there is a surgery which is effective 95% but there is a danger of death as well, to me which I laughed a lot. Because I was a kid. I understood his purpose that he was telling me the impossible. I also wanted to talk about it, too. […] My mother doesn't know anything either, I mean, my mother is also very ignorant about

this subject. She only goes to the doctor, so as I said, the psychiatrists we went have changed very often also, but there was one female physician in Adıyaman, and she was very interested. In fact, every time I went there (by laughing a bit) when I was little, I used to ask her something like, do you think my father would get better? She would look at me like pitying and would say that if he takes his medicine now, everything will be better, Yelda. And I say to myself now, why did I make the woman suffer, you know, I ask the same question every time but without getting tired of that question.

Similarly, Kamuran, an unaffected parent, explained the fear-provoking explanation of the doctor following the diagnosis as:

Doktor bana ilk öğrendiğimde dedi ki, sen şu an 4 çocuğun var. Kocan hezeyan hastalığı. Biz polisliğe devam etmesine izin veremeyiz. Aniden vurur da vurulur da olay sırasında. Cünkü şüphesi var. Ben de dedim, kıskanıyor evet. Bazen oluyordu ki kıyafetini çıkart ben üstüne başına bakıcam senin üstünde bir iz var mı derdi. Öyle şeyleri de vardı. Ondan sonra doktor dedi, sen hayatının kurtulacağını veya ileride sıkıntı yaratmayacağına inanıyor musun dedi doktor. Yeri gelir seni de öldürebilir dedi. Bu hastalık ne kanser ne kalp hastalığı dedi bu geçecek bir hastalık değil dedi.

When I first found out; the doctor told me that ‘you have 4 children now. Your husband has delirium. We can't let him to continue working as a policeman. He might shot somebody and get shot suddenly during an incident. Because he has doubts.’ I said ‘yes, he's jealous.’ Sometimes he would come and say ‘take off your clothes, I'll look at you and check if there's any mark on your body’. Such things were happening. After that, the doctor said, ‘do you believe that his will be saved or will he not cause any trouble in the future?’ He said, ‘he might even kill you too’. He said that this disease is neither cancer nor heart disease, this is not a disease that will pass.

Learning the name of the disease seems to be an important milestone for the offspring as it offers an explanation and framework to the process surrounded by several uncertainty. Still, affected children were not provided additional information except for accidentally hearing the name of the disease. For example, Yılmaz who learnt the name of his mother’s disease after three years later, described this moment as:

Yılmaz: Ee hastalığı da şey olmuştu, tam aklım başıma geldiği süreçte, bir kez annem tekrar psikoz geçirdi. Hastaneye bu kez ben gittiğimde doktor şey demişti mm şizofreni tanısı koyulmuş demişti. Oradan anlamıştım. Şizofreniyi de araştırdım ondan sonra biraz. Ben o zamanlar lise eğitimi aldığımdan dolayı pek doktora falan annemle gidemiyordum. Annemle babam gidiyordu.
Araştırmacı: Peki şizofreni tanısı konulmuş cümlesini duyduğunuz an nasıl yaşandı sizin tarafınızdan?
Yılmaz: Biraz zor geçti ya, şizofreni tanısı biraz da şey olmuştu ee umutlanmıştım hastalığın adını biliyoruz en azından diyip. Ondan sonra araştırdım biraz, hastalığı

araştırdığımda hastalığın ne olduğunu öğrendiğimde de bu umudumun iyimserliğimin boşa gittiğini anladım. Boşa olduğunu.

Yılmaz: Well, her illness, when I just became more clear-headed, my mother had a psychotic attack again. When I went to the hospital at this time, the doctor said she had been diagnosed with schizophrenia. I understood it from there. After that, I also researched about schizophrenia a little bit. Since I was attending to high school at those times I couldn't go to doctors with my mother. My mother and father were going.
Researcher: So, how did you describe the moment you heard the sentence "diagnosed with schizophrenia"?
Yılmaz: It was a bit difficult, the diagnosis of schizophrenia, I mean it also happened like, I was hopeful a bit by naming like that, at least we now know the name of the disease. Afterwards, when I was researched and learned about the disease, I realized that my hope and optimism were in vain and wasted.

As can be seen from Yılmaz's quotation, offspring usually learnt the name of the disease either by their own efforts or accidently which once again highlighted the ongoing secrecy surrounding the disease. It seems that insufficient debriefing of the professionals also resulted in the silencing of the healthy parents, which, in turn, accentuated the lack of communication among family members. Even children themselves hided their parents' condition from their close social network due to fear of stigmatization. For example, Mukaddes, did not share her father's condition even with her husband:

Sonra oradaki doktor, ismini bilmiyorum, sormadım, babanız paranoid şizofreni diyor, teşhis koyup ilaç veriyor. İlaçlarla babamın kafasındaki uğultular geçti. […] Babama teşhis konulduktan sonra çok rahat konuşuyorum artık. Gerçekten. Ben eşimle bile paylaşmadım, eşim daha 5–6 yıl önce öğrendi. Anlatamazdım kimseye. Ama teşhis konulduktan sonra çok rahat konuşmaya başladım. Yani babama teşhis konulduğu için de seninle bu kadar rahat konuşuyorum çünkü artık adı var. Yani ondan önce toplumsal baskılar da var ya işte, çok ağır şeyler. O yüzden çok sakladım ben. En yakın arkadaşım bile bilmezdi okuldaki.

Then the doctor over there, I don't know his name, I didn't ask, says that 'your father has paranoid schizophrenia', diagnosing and prescribing medication. The buzzing in my father's head went away with the drugs. […] After my father was diagnosed (referring to the process of receiving an official diagnosis), I can talk about it comfortably now. Really. I didn't even share it with my husband, my husband learned it 5-6 years ago. I couldn't tell anyone. But after the diagnosis, I started to speak very comfortably. I mean, since my father received his formal diagnosis, I can talk to you so comfortably because now it has a name. I mean, there were social pressures before that, very overwhelming things. That's why I hid it so much. Even my best friends from school didn't know about it.

3.5 Category #5: The Vicious Circle among Secrecy around the Disease & Stigmatization & Lack of Support Resources

This category demonstrates itself as the core constituent of the whole experience of having a parent with schizophrenia. The ongoing secrecy around the disease, stigmatization and lack of support resources together functioned as a vicious circle which, in turn, shaped the perceptions and experiences of the target population at personal, familial and societal levels. In the present category, operations of the components of the vicious circle were discussed interrelatedly since accounts of the participants also represented this triple as nested together.

Ongoing secrecy around the disease manifested itself not only among the nuclear family members but also through the interactions with the outer social context. The first level of secrecy began within the family context. Nuclear family members had varying motivations behind such secrecy. For example, Ziynet had concerns due to the genetic transmission of schizophrenia and believed that talking about the disease out loud might potentiate her children genetic vulnerability. She also had her doubts about such sharing's possible impacts on the attitudes of her children towards their father:

> Ya bir de şöyle bir şey var, evde kendine destek arıyorsun. Faruk da diyorsun baya büyüdü artık, bazı şeylerin farkında yani kaldırabilir bu saatten sonra diyorsun. Yani kendine bir destek çıkmış oluyor ama sonradan da düşünüyorum bu diyorum eğer şizofreni hastalığı ırsiyse kendi oğlumu kendim de böyle şeyler konuşarak diyorum şey yapmak istemiyorum. […] Bazen diyorum hani anlatmak ne kadar doğru anlatmasam mı vs nihayetinde kafalarında bir baba figürü var. İyi de olsa kötü de olsa bir figürü var. Acaba ileride babalarından hani utanırlar mı, utanacaklar mı yani ee benim şeyim o hani. Bir yere gitmezler babalarıyla, çıkmazlar. Bir baba figürü yok kafalarında, babalarıyla çıkıp da dışarıda bir bisiklet top veya başka bir şey oynayan çocuklar olmadılar.
>
> You know, there is also something like this, you are searching for someone to lean on at home. You say, Faruk has grown a lot now, he is aware of some things, so you think he can handle it now I mean, you are getting some support, but then I think about it. I say, if this, schizophrenia is hereditary, I don't want to affect my own son in that way through talking about such kind of things. […] Sometimes, I say how right it is to tell or shouldn't I tell, etc. Eventually, they have a father image in their mind. Whether he is good or bad, there is a figure. I wonder if they will be ashamed of their father in the future, that's my thing. What if they do not go anywhere with their father; they don't go out. They do not have a father figure in their minds, they are not like the kids who go out with their father and play with a ball or ride a bike with.

This quotation reflected the unaffected parents' concern over the genetic side of schizophrenia, which, in turn, led them to avoid communicating about the disease with

their children. Instead of learning offspring's subjective concerns, healthy parents usually abstained from giving concrete information in order to protect their children's well-being. However, such motivation also took its roots from the lack of scientific knowledge regarding the disease. This way of functioning displayed by the unaffected parents sustained and reinforced the burden of stated impediments interrelatedly for each family member. To exemplify, another unaffected parent, Kamuran, described the only explanation she provided to her children when they witnessed to unusual symptoms as:

> **Araştırmacı:** Siz çocuklara ne derdiniz o dönemde, atak döneminde? Hani babanız iyi değil şu anda gibi bir açıklama yapar mıydınız?
> **Kamuran:** Babanız rahatsız falan demiyordum da diyordum ki ama bu adamın ilk şeyinde buna bi şey geliyor. İlk tepkim de bu adamın cini var diyordum. Sürekli öyle diyordum, cini geliyo, cinli mi bu ne diyordum.
>
> **Researcher:** What would you say to children at that time, I mean, during the active attacks? Have you ever made a statement like your father is unwell right now or something?
> **Kamuran:** I wasn't saying that your father is sick or anything, but I was saying that there is something wrong with this, something is affecting him and my first reaction was always saying that 'this man has a jinn'. I was always saying that 'his jinn is coming, he might have a jinn' etc.

From this explanation offered to the offspring, it also becomes obvious that unaffected parents did not know how to convey information about the nature of the disease. Their lack of knowledge led them to give supernatural or inconsistent explanations to their offspring which further increased the already existing ambiguities of the situation. While unaffected parents avoided talking about what was going on, offspring' also refrained from asking questions although they were curious about their parents' condition. In fact, the inconsistent and unreasonable answers of the family members seem to have a role on offspring's silence. For instance, Faruk reflected that:

> **Faruk:** Ya oluyordu böyle sinirli olması, tavrının değişik olması oluyordu. Niye böyle, niye hasta oldu veya neden bu şekilde diyordum da. Ya herkes farklı bir cevap verdiği için hangi cevap doğru olup olmadığını bilmediğim için bütün cevapları reddettim yani. Hastaysa hastadır diye kabul ettim.
> **Araştırmacı:** Farklı cevaplardan kastın neler? Kimler sana farklı farklı cevaplar sundu?
> **Faruk:** Aşağıya indiğim zaman, dedemler der, işte babaannem der büyü yaptılar oğluma derler, askerden sonra geldi böyle oldu derler. Annem der defineye giderdi, definede baya bir şeyler kazardı mazardı orada kafayı bozdu falan derler. Yani bir sürü değişiklik şeyler var yani. Ben direk normal hasta olarak doğuştan gelmiş dedim siz fark

etmemişsinizdir. Çünkü küçük yaşlarında ormanda tek başına çobanlık yapmış bir insan.

Faruk: He was irritable, his demeanor was different. I was asking 'why he is like that, why did he get sick or why he is in that way'. Either everyone was giving a different answer and I didn't know which answer was correct or not, so I rejected all the answers. I accepted that if he is sick, he is sick.
Researcher: What do you mean by different answers? Who has offered different answers to you?
Faruk: When I go downstairs, my grandparents say, my grandmother says that 'they put a spell on my son', they say 'he became like this after the military'. My mother says, 'he used to hunt for treasure, he was digging a lot for things and stuff, so he went crazy there', she says. So, there are many different things. I then directly said that 'probably he was born with the disease, you may not have noticed'. Because he is a person who was a shepherd alone in the forest at his young ages.

To be more specific, spiritual attributions about the causes of schizophrenia demonstrated the lack of awareness regarding the nature of disease among family members that, in turn, complicated the children's meaning making process. Yılmaz accounted on the target issues as:

Araştırmacı: Annenizin hastanede geçirdiği dönemden bahseder misiniz?
Yılmaz: Üzülüyordum. Evde nasıl desem sorguluyordum durumu, neden oldu, benim ne suçum var bu durumda, ne yapabilirim falan yani kendimi suçlu hissediyordum çoğu zaman.
Araştırmacı: Annenizle ilgili bu zihninizden geçen soruları sorar mıydınız yakın çevrenizdekilere?
Yılmaz: E o dönem (gülerek) sormazdım. Şeyden dolayı hani küçüklüğün verdiği bir şey var ya küçüksün seni dinlemezler gibisinden. Çocuk aklını küçümseyen şeyler yani ondan dolayı soramazdım o dönem yani konuşamazdım bunu onlarla.
Araştırmacı: Peki onlar size açıklama yaparlar mıydı?
Yılmaz: Ee annen gelecek derlerdi sadece ama hastalık hakkında onlar da bir şey bilmezdi. Gelecek falan derlerdi. Ben annemin hastanede olduğunu da sonradan anneannemden öğrenmiştim, gelecek diyorlardı ama nerede bilmiyordum. […] Yani bu şeyi onlar nasıl desem şizofreni değil de onlar da benim gibi şeyden düşünüyorlardı, annemin insanlara fal bakmasından. Onlar beni şöyle öğütlüyorlardı annenin fal bakmasına izin verme ee fala karşı böyle bir duruşları vardı.

Researcher: Can you tell me about the period when your mother was taken to the hospital?
Yılmaz: I was really upset. At home, I was questioning the situation, why did it happen, did I make a mistake, what could I do, I felt guilty most of the time.
Researcher: Would you ask these questions about your mother to those around you?
Yılmaz: Well, I wouldn't have asked at that time (laughing). Because of something like, when you are little, it's like they don't listen to you. I wouldn't ask because like they devalue children's mind so I couldn't talk about it.
Researcher: Well, were they explaining something?
Yılmaz: Well, they only used to say that 'your mother will come', but they didn't know anything about the disease either. They were saying 'she will come'. I learned from my

> grandmother later that my mother was in the hospital, they were saying she would come, but I did not know where she was […] I mean, they were considering this not as schizophrenia, but, like me due to my mother's fortune telling. They were advising me as 'don't let your mother to tell fortunes', they had a stance like that against fortune telling.

From Yılmaz's experience, lack of communication again presented itself through the presence of ongoing questions on offspring' mind. Additionally, concerns of not being heard by others in line with the beliefs of being responsible from the disease emerged as the other mechanisms strengthening the vicious cycle among secrecy, stigmatization and absence of support. Another motivation behind offspring's silencing was closely related with the fear fed by the silence of others. As offspring were not able to receive reasonable answers, they became more fearful about what they would hear. To illustrate, Yelda described that:

> Hep biliyordum bir şeylerin normal olmadığını, ben de ablamlar da erkek kardeşim de hep biliyorduk. Ama hani bir şeyi bilirsiniz ama öğrenmek istemezsiniz ya sorgulamak istemezsiniz çünkü öğrendiğinizde kendinizi daha kötü hissedecekmişiz gibiydi çünkü. Evde kimse sormadı. Hani belki ablamlara, yani ben hiç ablamlara bile sormadım neden böyle diye.

> I have always known that something is not normal, me, my sisters, my brother, we all knew it. But like you know something, but you don't want to learn or question it more because when you learn you will be feeling worse, it was like that. Nobody at home have ever asked. Maybe to my sisters, I mean I did not even ask 'why he is like this', to my sister.

The quotation stated above represented the perceived fear of facing with the reality of the disease which, in turn, led to not question the situation and this silence was further strengthened by the others' tendency to avoid communicating about the disease. Offspring also did not explicitly interrogate the situation in order to not upset their healthy parents more. Tarık described his lack of reluctance to ask questions as follows:

> **Araştırmacı:** Peki hiç sordun mu sen bu duyduklarından sonra ya da işte sorsam mı gibi bir düşüncen oldu mu, merak ettiğin şeyler olmuş muydu?
> **Tarık:** Yok hiç sormadım.
> **Araştırmacı:** Sormadın.
> **Tarık:** Merak ettim tabii de bir şey sormadım
> **Araştırmacı:** Seni sormaktan alıkoyan ne olmuş olabilir? Neden sormamış olabilirsin sence?

Tarık: Mm geçer diye medet umdum çünkü. Bir şey sormadım, daha çok üzmek istemiyordum annemi.

Researcher: Well, have you ever asked upon hearing these, or have you ever thought about asking something, were there things that you were curious about?
Tarık: No, I have never asked.
Researcher: You haven't.
Tarık: I was wondering, of course, but I didn't ask anything.
Researcher: What might have prevented you from asking? Why do you think you may not have asked?
Tarık: Because I hoped it would pass. I didn't ask anything; I didn't want to upset my mother more.

Accordingly, not wanting to upset the unaffected parent became another barrier against talking about the disease. Such a concern also represented offspring's observation about the unaffected parent's emotional state and awareness of surrounding family conditions. Thereof, the visible silence surrounding the disease elicited different level obstacles that were steadily perceived and experienced by the affected offspring. The reciprocal relationship between lack of communication and lack of knowledge about the disease also shaped and got shaped by the whole ongoing experience, giving stage to another main component of the vicious cycle, stigmatization/discrimination. Stigmatization revealed itself on several social contexts including nuclear and extended family environment. Stigmatization mainly resulted from the misperceptions about individuals diagnosed with schizophrenia. Besides, society's attitude towards mental disorders in Turkey also eventuated the discriminative attitudes of the external family members. As a result, affected families became more isolated and were not able to receive the instrumental and emotional support they needed. For instance, Ziynet expressed her exhaustion over in-laws discriminating comments and lack of support as follows:

Ya allah aşkına ya görümcemler okumuş insanlar, bilinçli insanlar diyor ki "ayy yenge artık midem bulanıyor, abimi görmek istemiyorum" vah vah yani böyle bir şey söylenir mi? Abimden iğreniyorum, ya yenge ye abim gerçekten çok hasta ne yapabiliriz elimizden ne gelir yok… 24 saat abin beni elin adamlarıyla yatırıp kaldırıyor ben ağzımı açıp bir şey demiyorum size bir orospu dedi diye afedersin iğrenç biri oluyor. […] Ben bunları yaşarken abin için iğrenç demiyorsam, koşturuyorsam, uğraşıyorsam çabalıyorsam bir yerde sizin de elinizi taşın altına koyup da evet yenge haklısın demeniz lazım en azından. E ben bunun üstüne ne diyim gelmeyin o zaman dedim. Gelmiyorlar da zaten, bir abimiz mi var, yengemiz mi var, yeğenimiz mi var bir kapılarını çalayım demiyorsunuz. Aslında benim de bir doktora gitmem lazım.

For God's sake, my sisters-in-law (from her husband's side), they are educated, are conscious people but they say "Oh my sister-in-law, 'I feel nauseous, I don't want to see

my brother anymore" wow, is that such a thing to say? “I feel disgusted from my brother”, what about saying ‘my brother is really sick, what can we help you’, nope. Your brother is constantly accusing me for sleeping with a stranger everday, I don’t even open my mouth and I say nothing, excuse me, but because he called you a bitch one day, he becomes a disgusting person. If I don’t call your brother as disgusting although I am going through all these If I am trying, and working out, you also have to take responsibility and say at least, ‘yes sister-in-law, you are right’. Well, what can I say more on this, I said ‘don’t come if you talk like this.’ They haven’t come anyway, they never say ‘we have a brother, we have a sister-in-law, we have nephews let’s go and ring their doors’. Actually, I need to see a doctor too.

Similarly, Mukaddes expressed their agony and isolation due to the discriminative attitudes of their extended family members as follows:

Mukaddes: Hadi biz çocuktuk. Biz bilmiyorduk. Hiç mi kimse bunun normal bir şey olmadığını fark etmedi? O kadar babamın amcasının oğlu var doktor, zaten şu anda da psikiyatri hastanesinde başhekim, o hiç mi bu çocukların ruh sağlığı iyi değil gibi yani en azından anneme çıtlatsalardı. Yani anneme bir yol gösterebilirlerdi. Yani çok insan var, babamın ailesinde de annemin ailesinde de çok okumuş insanlar var, hiç mi kimse yön gösteremedi. Bizi neden bu kadar huzursuz bir ortama ittiler ki? Üstüne üstlük sürekli alay ettiler, babama ithamları, dedeme ithamları. […] O yüzden şu anda annemin akrabalarıyla hiçbir bağım yok, hiçbirini görmek istemiyorum. Geldiklerinde gidiyorum. Şu anda şizofreni hastası klinikte yatan halam bile benim için onlardan çok çok çok daha değerli. Çünkü onlar bizi hiçbir zaman kırmadılar, hastalardı ama kırmadılar beni. Ama onlar beni çok kırdılar, incittiler. Kimse bir şey demedi yani.
Araştırmacı: Yalnız hissettiniz diyebilir miyiz?
Mukaddes: Evet, annemi de kaderine terk ettiler. Yalnız bıraktılar, beş tane dayım var benim düşünsenize az buz değil, beş tane dayım dört teyzem var. Bu adam bu kadına bu ithamları yapıyor, fiziksel şiddet uyguluyor, ağır yani çok ağır, insan bunlar sebebiyle bırakmaz kardeşini ya! Annem dese ki ben çocuklarımı bırakmıyorum, o zaman bu adamı tedavi ettirelim vs derler ya bizi tamamen annemin tarafı kaderimize terk etti. Babamın tarafında zaten herkes hasta, öyle yalnız kaldık. Annemin tarafı babamın hastalığından dolayı bizi çok ezdiler. Biz çok ezildik anne tarafından akrabalarla, hani işte deli Hasan’ın çocukları gibi ithamlar bize çok yapıldı. Biz o yüzden anne tarafını çok sevmeyiz, çok alaycılardı çok alay ettiler.
Araştırmacı: Dikkatimi çekti Mukaddes Hanım, babanızın psikiyatrist bir kuzeni var
Mukaddes: Evet, üstelikte bu kuzeninin annesi anneme diyor ki “gelin” diyor, “Allahtan sen dışarıdandın yabancıydın da çocukların sağlıklı doğdu”. Yani bunu bile söylüyorlar anneme ama tedavisi için hiçbir şey demiyorlar, adam şu an başhekim ya! Niye demiyorsun ya bu çocuklar risk altında diye. […] Çok yalnız kaldık. Hadi babamın tarafı yalnız bıraktı tamam, annemin tarafı üstüne bir de köstek oldu. Biz kendi sorunlarımızla mücadele etmeye, babamı her şekilde, dediğim gibi babamın şahsi olarak çocuklarına hiçbir zaman zararı olmadı ama hani bir de alay ettiler. Deli, delinin çocukları, işte deli Hasan ne ki çocukları ne olsun. Dışlanmışlık, umursamazlık.

Mukaddes: Come on, we were just kids. We didn't know. Has anyone ever noticed that this was not a normal thing? My father's uncle has a son, he is a doctor, and he's the chief physician in a psychiatric hospital right now. So, he could at least have said ‘these kids’ mental health is not well’, I mean at least if they had mentioned to my mother. They could have guided my mother. There are so many educated people, both in my

> father's and mother's families, why nobody has ever guided my mother? Why did they push us into such a restless environment? On top of that, they constantly made fun of us, accused my father, accused my grandfather. […] That's why I have no contact with any of my maternal relatives, I don't want to see any of them. I am leaving when they come. Even my aunt (from paternal side), who has schizophrenia, currently staying in the clinic, is much more valuable to me than they are (referring to healthy relatives). Because they have never hurt us, they were sick, but they didn't hurt me. But they (referring to healthy relatives) hurt me a lot. So, nobody said anything.
> **Researcher:** Can we say you felt alone?
> **Mukaddes:** Yes, and they left my mother to her fate. They left her alone, I have five uncles, just think about it, I have five uncles and four aunts. This man (referring to her father), making these accusations to this woman, he is using physical violence, I mean very intense violence, one should not leave her sister alone just because of these! If my mother says, 'I am not leaving my children', then they should be saying 'let's get this man treated' etc. My mother's side left us to our fate completely. On my father's side everyone is already sick, so we were left alone. My mother's side humiliated us a lot because of my father's illness. Accusations like 'children of nut Hasan' have been made against us a lot. That's why we don't like my mother's side very much, they were very cynical.
> **Researcher:** Mukaddes, it took my attention that your father has a cousin who is a psychiatrist.
> **Mukaddes:** Yes, moreover, that cousin's mother says to my mother that "bride, thank god you were a foreigner, so that your children were born healthy". I mean they even say this to my mother, but they don't say anything about his treatment, the man is now the chief physician! Why don't you say that 'these children are at risk?' […] We were very lonely. Okay, my father's side also left us alone, but my mother's side also became shackle to us. We tried to struggle with our own problems. So, 'the crazy, children of the crazy, here's crazy Hasan, how could his children be like?'. Exclusion, indifference.

Offspring had not only been affected by the discrimination of external family members but also by the internalized stigmatization displayed by the healthy parents. The reciprocal relation between stigmatization and lack of support potentiated the unaffected spouse's feelings of exhaustion and anger that seem to be displaced to the affected parent. Yelda touched upon this pattern by stating that: "My brother, he had started to behave weird, just like my father. In fact, my mother said something like, 'before his father has died, his son started'…" (*Erkek kardeşim, taşkınlık yapmaya başlamıştı o da, aynı babam gibi. Hatta annem şey demişti hani, babası ölmeden oğlu başladı diye…*). Similarly, Mine explained her discomfort over her mother's stigmatizing attitude towards her father like:

> Mesela bir dönem demiştim ya Diyarbakır'a gittik diye, bu yazdı. Annem, babam gittiği zaman daha mutluydu. Kendi de söylüyordu evin havası değişti, daha huzurlu ve daha mutluyum diyordu. Babam olmadan daha iyiydi yani. […] Bazen hatta, annem "baban deli zaten" gibisinden kelimeler çok kullanırdı. Yani ele alınmadı, o şekilde. Direkt sadece hasta olarak adlandırıyordu yani. Hani şey diyordu annem hep; "onlar kendilerini çok seviyorlar, kendilerine zarar vermezler, babana hiçbir şey olmaz" falan diyordu hep. Ama onu da bilemiyorum.

> For example, as I've told you, once we went to Diyarbakır, it was in this summer. My mother was much more happier when my father was away. She was also saying that 'the atmosphere of the house has changed', she was saying 'I am more peaceful and happier'. So, she was better without my dad. […] Sometimes even my mother used words like "your father is crazy". So, it was not handled. I mean, she was just calling him as 'the sick'. You know, she was always saying; 'don't worry, they love themselves very much, they won't hurt themselves, nothing will happen to your father'. But I don't know that either.

All these quotations reflected how affected parents were positioned both within the nuclear and extended family through the interpretation of offspring. While such positioning sort of undignified the affected parent, the stigmatizing language of the healthy parents particularly added to the confusion of the offspring. While affected parents were subject to negative attitudes at home, they were undignified not by extended family members that, in turn, increased the helplessness and loneliness experienced by the offspring. Hence, having been exposed to discriminatory attitudes at multi-relational contexts further increased offspring's tendency to remain silent and withdrawn. For example, Tülay conveyed that:

> Önemsenmeyen sürekli aşağılanan, o da çok kötü bir şey evin içinde sürekli aşağılanıyor adam. Kimse onu ciddiye almıyor ki, çocuklar falan bağırıyor yani annem de öyle. Gelen akrabalar işte gülüyorlar söylediklerine gülüyorlar. Gülünecek bir şey yok ki aslında, neden gülüyorsunuz, gülünecek hiçbir şey yok. Adam da geliyor işte buraya, babamla iki şakalaşıyor gülüyor çekip gidiyor. Yani kardeşim bir sıkıntın sorunun isteğin var mı, kafanı yoran bir şey var mı çünkü bu adam sürekli düşünceli gibi geziyor evde ya da işte bak sen farklı düşünüyorsun bir yardım alalım bir şeyler yapalım ben senin kardeşinim diyip arkasında durması gerekiyor ama hepsi sanki bana değmeyen yılan bin yaşasın hesabı hepsi köşelerine çekildiler. […] Annem de mesela şey demişti baban Bakırköy'de yattı. Ben Bakırköy'ü görünce direk o canlanıyor gözümde, işte diyor o dönemler çok sıkıntı çektik. Ama hastalıkla alakalı tam net yani şu oldu şunu gördü şu tedaviyi gördü şu ilaçları kullandı falan demiyor. Baban, ben, üç çocuk sürüne sürüne oraya gidiyordum. Çaresiz kaldım, kimse gelmedi, ilgilenmedi işte bu şekilde anlatıyor.

> He is a man, who has been constantly humiliated, it is something really bad that he is getting constantly humiliated in the house. No one takes him seriously, kids are shouting or something, so does my mother. The relatives who come to us are laughing to him, laughing at what he says. There is nothing to laugh, why are you laughing actually, there is nothing to laugh about. Here comes the man, he is joking with my father, laughing, and leaving. I mean, bro, no one asks 'do you have a problem, do you need something, is there anything bothering you, because this man is constantly wandering around home, look you think differently, let's get some help, let's do something', he should say 'I am your brother 'and stand behind him, but they all retreated to their corners, as if the snake

> that did not touch me, long live by the account. […] For example, 'my mother said that your father was institutionalized once in Bakırköy (a psychiatry clinic).' When I see Bakırköy, it immediately comes to my mind her complains like 'we had a lot of trouble at that time'. But she does not say something related with the disease clearly such as the treatment he received the drugs he used. She says 'your father, I, three children were crawling. I was desperate, no one came, nobody was interested', that's how she tells it.

The stigmatization experienced by the offspring manifested itself not only in nuclear and extended family. Affected children had been also exposed to derogatory attitudes of their peers due to their parents' disorder. This is why children did not prefer to share and elaborate on their experiences in their social circle. Besides, the multi-level stigmatization strengthened their sense of isolation that further compromised the already limited support resources. For example, Yelda credited on how her peer's discriminating behaviors shaped the further social contacts that she had as follows:

> Çünkü şey küçükken ben bununla ilgili çok sorun yaşamıştım ilk dönemlerde. Yani şöyle söyleyeyim benim yaşadığım yer küçük bir yerdi, biz o zaman küçük bir yerdeydik. Benim ailemdekiler de, annemin akrabaları diyim, bizi çok, küçüklükten beri bizimle hep dalga geçtiler. Yani dalga dediğim işte senin baban deli, siz delinin çocuklarısınız falan filan. Bu tarz şeyler hep. Kendi sınıf arkadaşlarım. […] Yani şöyle bir şey söyleyeyim size, bizim evimize balonlarla su atarlardı, sonra kapımıza vurup vurup kaçarlardı sınıf arkadaşlarım, ortaokulda olan şeyler bunlar. Hani belki bunlar, aileleri belki o çocukları bir iki kere uyarsa onlar o şeyleri yapmayacak. Ve biz de bunu bu kadar gizli tutmayacağız, ya da gizlemek için çaba sarf etmeyeceğim. Çünkü benim tüm şeylerim, o çocukluk yani, hani gerçekten insanı tek yaralayan o çocukluk travmaları yani. Hoşlandığım çocuk düşünsenize evinize gelip deli deli deli diye kapıya vuruyor yani, anlatamıyorum bile ya, gerçekten (ağlamaklı). Ve biz, konuşmamamızın sebebi de kimseye anlatmamamızın sebebi de bunlardı hep. Ben üniversiteye başlayana kadar hiçbir arkadaşıma söylememiştim. Taa ki tıp okuyan arkadaşım vardı ve o an neden söyledim bilmiyorum ama o an böyle işte benimle arkadaş olduğu için kendimi tuhaf hissetmiştim sanki benimle arkadaş olamazmış gibi. Ve demiştim işte benim babam şizofreni hastası diye sonra o da sadece geçmiş olsun gibi bir tepki verdi ben de böyle biraz afallamıştım açıkçası. Çünkü ben yani zannediyordum ki işte hee falan diyip beni küçümser diye düşünüyordum ama sonrasında fark ettim ki hani olgunlaşma, insanlar olgunlaştıkça bunu daha normal karşılıyorlar.

> Because when I was little, I had a lot of problems at first. So let me put it this way, I was living in a small town, we were in a small town back then. My family members, I would say, my mother's relatives, they have always made fun of us since we were children. I mean, what I call as making fun of is like 'your father is crazy, you are the children of the nuts' and so on. Always these kinds of things. My own classmates. […] So let me tell you something, they used to throw water at our house with balloons, then they would bang on our door and run away. These are the things that have happened during my middle school years. You know, maybe if their families had warned those kids once or twice, they wouldn't have done those things. And we won't have to keep it as a secret or try to hide it. Because all my things, that childhood, you know, those childhood traumas that really hurt the person. Imagine, the boy I like comes to your

> house and bangs on the door by saying ‘crazy crazy crazy’, I can’t even explain, really (crying). And that’s why we didn’t talk and that’s why we didn’t tell anyone. I didn’t tell any of my friends until I started to the college. Until I had a friend who was studying medicine and I don’t know why I said it at that moment, but I think I felt weird because I couldn’t believe he wanted to be my friend. And I said that, ‘my father has schizophrenia’, and he just gave a reaction like get well soon wishes, and frankly I was a little stunned. Because I thought that he would say “hmm” or belittle me, but then I realized that it is maturation, as people mature, they consider it more “normal”. In these ways.

Stigmatization and unavailability of support resources interdependently functioned together increasing the perceived burden of the affected families. The ongoing secrecy reinforced by the lack of awareness complicated the offspring’s making sense of this experience as a whole. Together with internalized stigmas, nuclear family members’ exposure to stigmatization had shaped the offspring self-worth and relating with outsiders. In this context, Tülay’s experience exemplified the interrelation among secrecy, stigmatization, and unavailability of support faced by affected families:

> Zaten hep başkalarının düşüncelerini hep böyle kapatmaya, yani yok öyle bir şey yok ki zatene getirdiğimiz için hiçbir duygu vs paylaşımı olmadı. Hiç demedim. Yani dedim ki onun yapısı öyle, konuşma tarzı öyle hep bu şekilde tepki verdiğim için onlar da orada kapattılar. Hep saklayarak geçti şöyle söyleyeyim, biz korkardık da açıkçası anlayacaklar… Bir tuhaflık var ve anlayacaklar mesela. Ya bana şey derlerdi mesela ya senin baban ne kadar iyi bir adam ya falan derlerdi ben de aa öyle mi gerçekten mi evet öyle falan derdim, oraya hiç kesinlikle açmazdım.
>
> Since we are always trying to cover up others' thoughts by acting as if nothing bad had been happening, so there wasn't any sharing of emotions etc. I never said. I mean, I said ‘that’s his way of being himself, his way of speaking’ is, as I was reacting in this way, they (others) closed the issue at that point, too. We were always hiding, we were also concerned thinking what if they (others) recognized. There is something strange and they will understand. For example, they were saying to me that ‘what a nice man your father is’, and I would be saying ‘is he, really or yes, he is ‘etc. I would never give any detail.

The following category, as the outcome of the vicious circle among secrecy around the disease, stigmatization, and lack of support resources, covered the ways of processing the whole experience of having a parent with schizophrenia.

3.6 Category #6: Meaning Making

Having a parent with schizophrenia by itself brought about several difficulties due to its unusual nature, transformative impacts, and discrete visibility. The ongoing secrecy strengthened by the stigmatization and social exclusion made it difficult for the offspring to process what they were facing as a family. The multi-level ambiguity surrounding the family enhanced offspring's need to comprehend and make sense of such experience. Thus, this category referred to the meanings attributed to parental schizophrenia and the personal lenses of the offspring to reach out conclusions. To some extent, meanings constructed through this experience were dysfunctional since offspring derived those conclusions through blaming, avoidance, denial, withdrawal, and comparison with others.

Offspring's tendency to blame while making sense of their experience was two-sided. On the one hand, they blamed the affected parent for not putting enough effort to reverse the situation. On the other hand, they were also accusing the healthy parent and other family members for annihilating the hope they needed as a child. It was also observed that attributed meanings themselves were bound to inconsistencies due to lack of awareness and communication about the disease. For example, Tülay evaluated her experience as:

> En korkutucusu evet ben hastayım demesi oldu. En korkutucusu oldu çünkü ben onu beklemiyordum. Ben şeyi bekliyordum, kızım evet bende bir rahatsızlık var ama düzelebilirim, neden kestirip attın ki? Yani direk ben hastayım demekle köşeye çekilmek doğru bir şey değil ki. Sonuçta biz çocuğuz küçüğüz yani, tamam lise dönemi ama yine küçüksün 14-15 yani ne bileyim. Şu an kendi çocuklarımı düşünüyorum, çok büyük bir yük yüklemek onların üstüne. Evet ben hastayım, böyle kabul et gibi bir şey oluyor. Neden peki hastasın? Neden? Düzelebilirsin, sonuçta yani onun bir tedavisi var. En kötüsü bu oldu benim için açıkçası, bir de annenizin size sürekli kızım babanız hasta yapacak bir şey yok demesi. Yani bunu duyduğunuzda hep bi neden ya neden bu adam ölmedi ki! Yaşıyor. Neden tedavi görmesin, neden iyileşmesin. İnsanlar kanser oluyor, iyileşiyorlar. Keşke anlatsalardı. […] Dipsiz bir kuyuya attılar bizi ya, bilmiyoruz ki ne var. Ben hala onun acısını yaşıyorum ki hayatımda neden neden diye o muallaklıktan. Artık belirsiz olan hiçbir şeyle uğraşamıyorum, sonunun ne olduğunu kestiremediğim vs. Hayatımı hep planlı yaşamak zorundayım gibi geliyor, hep bir kontrol olması gerekiyormuş gibi farklılıklar olmasın gibi. Sürekli kötü bir şey olacak korkusu artık bize de aşılanmış gibi babamdan. Tedirginlik yani. Korkmaktan korkmak.

> The most frightening aspect of all this experience was the fact that my father said 'yes, I am sick'. It was the worst moment because I wasn't expecting it. I was expecting something like 'my girl, yes, I have an illness, but I can get better', why did you cut and throw it out? I mean, it's not right to go into a corner and accept your fate by saying that

> ‘I’m sick’. After all, we were children, we were young, okay it's the high school phase, but you're still young, around the age of 14-15, so I don't know. I'm thinking about my own children right now, it's a huge burden to put on them. It is like ‘yes, I'm sick so accept it’. Why are you sick then? Why? You can fix it, after all, there is a cure for it. Frankly, this was the worst thing for me, and your mother also constantly tells you that ‘there is nothing to do and that your father is sick’. So, when you hear this, there is always a question as why this man didn't die! He is alive. Why shouldn't he get treatment, why not recover? People get cancer, they get better. I wish they would tell. […] They threw us into a bottomless pit, we don't know what it is. I am still suffering from this pain, from that vagueness as to why in my life. Now I can't deal with anything that is uncertain and unpredictable. It feels like I have to live my life in a planned way as if there was always a need for control as if there should not be any differences. The constant fear that something bad will happen is now instilled in us by my father. I mean, anxiety. To be scared of being scared.

In fact, this quotation reflected the interaction of several internal and external barriers faced by offspring with parental schizophrenia. Attributing the chronic prognosis of schizophrenia to the affected parents’ will had taken its roots from the deficiencies in communication and awareness regarding the disease. Unaffected parents’ helpless attitudes also reflected the lack of social and professional support offered to those spouses. Eventually, blaming both the affected and unaffected parents became evident in the narratives of the offspring. Besides, offspring also criticized their unaffected parents’ way of handling the situation. None of the offspring underlined the impact of having limited access to health care resources at the macro level. To exemplify, Mine blamed her mother for having more than one child, not referring to the problems in the birth planning services implemented in Turkey:

> Yani hasta olduğunu bilmesine rağmen hani belki de baştan hasta olduğunu bilmiyordu ama sonuç olarak anlaşamayacağı, kötü bir insan olduğunu, ona zarar verdiğini biliyordu. Nasıl bu kadar çocuk yapmaya karar verdiğini bilmiyorum ama erkek çocuk sahibi olmak istediğini biliyorum.
>
> I mean, even though she knew that he was sick, maybe was not aware in the beginning that he had been sick, but eventually, she knew that he was a bad person that she could not get along with and that he was hurting her. I don't know how she had decided to have so many children, but I know she always wanted to have a boy.

Interviewed offspring also felt anger due to their unaffected parents’ remaining in the marriage despite the difficulties experienced at home. Correspondingly, they questioned the necessity of sustaining the relationship between parents and blamed their unaffected parent for the long-term impacts of parental schizophrenia. None of

the offspring mentioned the impacts of gender roles or inadequate health care services, rather channelized their anger and helplessness to their parental figures. For example, Mukaddes, touched upon this issue as follows:

> **Araştırmacı:** Ne şekilde evliliğinize yansıdığını düşünüyorsunuz Mukaddes Hanım?
> **Mukaddes:** Nasıl yansıdı, eşim de babam gibi çok sinirli çok çabuk parlar. Diyordum ki annem, babam bağırdığı zaman susmazdı, benim susmam lazım diyordum. Niye çünkü susmazsam daha kötü olur diye gördüm hep evde. Annem susmadı, babam annemi hep dövdü. Ama diyordum ki cevap verirsem ya eşim beni döverse, ha hiç şiddet uygulayan bir adam olmadı eşim ama işte. Hep bunları kendime telkin ederek geçti, annem babam şöyle yapıyordu ben bunları yapmayayım diye. Gerek yokmuş, yokmuş yani. Söyleyeceksin savunacaksın kendini karşındaki adam şizofren değil çünkü yani mantıklı bir açıklamasını yaparsan susuyormuş, onu anladım. Ama 10 yıl kölesi oldum, kötü etkiledi yani. Ha dediğim gibi beni bu şekilde etkiledi, abimi zaten hayatı bitik. Onun çocukları da ayrı. Hepimiz bir şekilde nasibimizi aldık, mesela küçük ablam da bir o kadar kapalı kutu yaşıyor. Ablam da mesela çok öfkeli. O biraz daha bastırmaya çalışıyor abime nazaran ama, o da anneme öfkeli. Bize bunları niye yaşattı, niye zamanında ayrılmadı diye. Neden böyle bir adama katlanıp bizi böyle bir eziyet içinde büyüttü diyor. Sürekli huzursuz bir ortam. Bize bunları neden yaşattı, ayrılabilirdi diyor. [...] Mesela bazen ablalarımla falan konuşuyoruz, büyük ablam diyor ki "allah yardımcısı olsun ya, ben bazen bazı şeylerin vesvesesine kapılıyorum, hani böyle miydi şöyle miydi derken kendimden yoruluyorum. Bu adam 7/24 sürekli mücadele, sürekli bi şeyler var kafasında yani.
>
> **Researcher:** In what way do you think it reflects on your marriage, Ms. Mukaddes?
> **Mukaddes:** How it affected me, my husband is very angry like my father, he becomes really anger in an instant, I was thinking that when my father was shouting, my mother wouldn't shut up, I was saying that I should shut up. That's why, because I always saw at home that it would be worse if I didn't shut up. My mother did not shut up, my father always beat my mother. But I was saying that if I give any reaction, what if my husband beats me, my husband has never been a violent man, but here it is. It has always make myself believe these kinds of things like my mother and father were doing these mistakes so that I shouldn't be doing these things. There is no need. You will tell, you will defend yourself, the man in front of you is not schizophrenic and if you give a logical explanation, he gets quiet, I have understood that. But I was a slave for him (referring to her husband) 10 years, so it affected me badly. But like I said, it affected me that way. For example, my brother's life is already over. His children are also another problem. We all got our share in some way, for example, my little sister lives like in a closed box just as much. She also has anger control problems. She is trying to suppress her anger a little more compared to my brother, but she is angry with my mother as 'why she made us experience these, why didn't she leave him on time?' She asks why she put up with such a man and raised us in such torment. It's a constantly chaotic environment. She says, 'why did she make us go through this; she could have left.' [...] For example, we talk as sisters sometimes, my elder says, 'God help him, I sometimes ruminate on things and get tired of myself even when I say whether it was like this or that. This man is constantly fighting, 24/7, he has issues on his mind all the time.

This quotation was pertaining to the offspring's evaluations about the role of healthy parent and how living with paternal schizophrenia resulted in emotion

regulation problems among affected children. At the same time, the reproach towards the unaffected parent demonstrated itself through prolonged exposure to domestic violence grounding on the paranoid symptoms of the affected parent. Hence, the psychological and behavioral outcomes were considered as derivates of the absence of a grown-up protecting those children from the debilitating effects of parental schizophrenia. Nevertheless, interviewed children still tried to offer a legitimate explanation for the freezing of familial coping strategies. They made downward comparisons with the patients having similar conditions believing that their parent's disorder was worse off. Although they emphasized the unaffected parent's helplessness, even adult children did not refer to the macro level factors explaining the healthy parents' inability to manage the situation effectively. To exemplify, having vented her anger, Yelda continued her account in the following way:

> O zamanlar annem anlatıyor, annemi eve kilitlermiş ondan sonra sürekli dayak, sürekli taciz, sürekli kötü şeyler. Annem de birazcık sahipsiz bırakılmış ve buna mecbur kalmış aslında bu onun seçimi dahilinde olsa bunu kesinlikle asla seçmez. […] Ve benim babamın hastalığı öyle normal değildi hani babası şizofreni tanısı almış arkadaşım vardı onun babası gayet normal görünüyordu ama benim babam çok ağırdı.

> At those times, my mother us tells that, he (referring to her father) used to lock my mother in the house, constant beating, constant harassment, constant bad things. There was no one to protect my mother, in way she had no other choice but being exposed to those things, in fact, she would never have choosen this, if she had any control. […] And my father's illness was not typical, you know, I had a friend whose father was diagnosed with schizophrenia, his father looked quite normal, but my father's situation was very severe.

In fact, all quotations presented so far represented offspring's search for answers regarding causes of their parent's disease and improvement of their family's condition. Children's evaluations were inherently bound with ambiguities due to lack of awareness and knowledge about the disease. It becomes evident that neither adult family members nor professionals did provide age-appropriate and scientific explanations that forced these children to come up with their own personalized answers. While doing so, affected offspring blamed themselves retrospectively for not intervening the situation as early as possible. As they aged, their empathy towards the affected parent increased, giving way to the feelings of guilt. Still, their lack of knowledge regarding the etiology and prognosis of the disease were evident from their

accounts. For example, Tülay (30) expressed her reflections about the difficulties her father had endured during her childhood as:

> Ben mesela şimdi farkına vardım aslında ne kadar zor bir hayat yaşadığının. Çok zordu onun için hayat, yani çünkü görülmeyen bir şeylerle savaştı o ya. Bir şeyle yani kendiyle savaştı bir nevi, e onun için daha zordu. Göremedik ama daha çok acı çekti. […] Yani diyorum ki biz aslında altı kardeşiz hepimiz birleşsek, bir tedavi bir şey olur aslında ama kimse oraya yanaşmıyor ki. Yani kimsenin umurunda da değil, herkes kendi hayatına bakıyor. Yani bu adamı düşünen yok ki, ne yapıyor nasıl vs. Yokmuş gibi. […] Çok garip, ben bunları fark etmekte geç kaldım. Ben bunları işte kendi hastalıklarımla ilgili düşünürken başladım fark etmeye, hepimize farklı yansımaları oldu bunun. Kız kardeşim mesela, hiç misafir sevmiyor ve misafir geldiğinde dolaba saklanıyor, kesinlikle oradan çıkmıyor ve 24 yaşında bunu hala yapıyor inanır mısınız? Abim, hayatı toz pembe görmeye çalışır. Ve o yükleri de yüklenmeye devam eder ama hiç de belli etmez sanki o taşlı yollardan o yürümedi de başka biri yürüdü gibi davranır veya ben mükemmelim ya benim hayatım mükemmel gidiyor gibi. Bir diğeri de mesela böyle babam gibi düşünceleri var, konuşurken ben garip garip bakarım yüzüne derim ki abla söylediklerinde bir mantık yok farkında mısın? Herkesin düşüncesini okur, varsayar. Sende biraz babamlık var herhalde derim. O da böyle, garip düşünceleri var bilmiyorum belki de genden geçiyordur. Geçiyor mu siz daha iyi biliyorsunuzdur?
>
> For example, now I have realized the difficulty of his life. Life was very difficult for him because he fought something invisible. He kind of fought with something, that is, with himself, and it was more difficult for him. We were not able to understand but he got hurt more. So, I'm saying that we are actually six siblings, if we all come together, there might be a cure, would do something, actually, but no one is trying. So, no one cares, everyone is caring about their own life. I mean, nobody thinks about this man, what he is doing, how he is, etc. It's like he doesn't exist. […] I started to realize these while I was thinking about my own problems, it had different reflections on all of us. My little sister, for example, doesn't like guests at all and hides in the closet when guests come, she definitely doesn't come out of there and still does this at the age of 24, can you believe? My older brother tries to see life in pink. And he continues carrying his burdens, but he does not show it at all, as if he did not walk on those stony roads, but someone else did, or I am perfect, or my life seems to be going perfectly. Another one, for example, has thoughts like my father. When she is talking, I look at her strangely and say do you realize that there is no logic in what you say? She reads and assumes everyone's thoughts. I say I guess you look like my father t. He's like that too, has strange thoughts. I don't know, maybe it's passing through genetics. Does it pass, you might know better?

Similarly, Mine retrospectively blamed both herself and her family members for the intolerance against his father's symptoms while giving voice to their own difficulties:

> Annem mesela onun ayrı yemesini istiyor. Onunla yemek yemek istemiyor. Annemin de babama çok kötü davrandığı oluyor yani. Çok kötü sözler sarf ediyor babama yani. Böyle… Bazen yalnız oturduğunda falan üzülüyorum çünkü bi yakın arkadaş ilişkisi falan olmadı babamın şimdiye kadar. Ama insanlarla iyi anlaşıyor baktığın zaman.

> İnsanlar da onu seviyorlar. Çünkü yalnız kalıyor, hani tamam kendisi hasta olduğu için hiçbir şeyi kendi isteyerek yapmadı yüzden babama kötü davranılması falan beni hep üzmüştür. Kendisi de normal bir insan olmak isterdi sonuçta, yalnız kalmak istemezdi. Ne bileyim intihar eder mi acaba yalnızlıktan işte bunalımdan diye düşünüyorum bazen. […]
>
> My mother, for example, wants him to eat separately. She doesn't want to eat with him. I mean, my mother also treats my father very badly. I mean, she's saying very bad words to my father. Like this… Sometimes I feel sad when he sits alone or something because my father has never had a close friend relationship. But when you look at, he gets along well with people. People love him too. Because he stays alone, you know, because he was sick, he didn't do anything voluntarily, so it always upset me that my father was treated badly. He would want to be a normal person himself, after all, he wouldn't want to be alone. I don't know, sometimes I am wondering if he will commit suicide because of loneliness or crisis. […]

Affected children also felt regretful for feeling ashamed of their parents' mental disorder. In fact, their fear of stigmatization led them to dismiss and criticize their affected parents. This is why they hid their parents from the outsiders and felt angry towards them. For example, Tülay expressed that:

> Bir de mesela rezil olma korkusu, ben onu da yeni fark ettim. Babamdan bana kalmış bir rezil olma korkusu yani arkadaşlarım anlamasın işte sürekli babamı uzaklaştırırdım, baba sen gider misin? Sen kendi işlerine bakar mısın gibi. Yani bizi utandıracak diye hep onu sakladık. Resmen eve koyduk sakladık yani ama neden o gene yokmuş hiç olmamış gibi ya da o öyle biri yapısı öyle diyip ötekileştirdik, köşeye attık ki […] Tedaviyi belki kabul etmedi belki hastalığını kabul etmedi ama o da kendince bir savaş verdi.
>
> And for example, the fear of being disgraced, I just realized that too. The fear of being disgraced that has been inherited from my father, that is, I would constantly push my father away so that my friends would not understand his disorder. Father, 'could you please you go, will you mind your own business?' So, we always hid him in case he would embarrass us. It is like we hid him in the house, so we hid him. We really did but why we did so, I mean like he didn't exist, or he never was, or that by saying he is such a person and alienated him and put him in a corner by casting him out, so that […] Maybe he did not accept the treatment, maybe he did not accept his disease, but he also fought in his own way.

Another interesting pattern emerged from the offspring's accounts was the efforts of normalization. Devoid of reasonable explanations, offspring tended to make sense of their experiences through comparing behaviors of their parents with those of their peers' parents. In turn, this downward comparison led children to long for "normal" parent-child interactions. Nevertheless, over time, they started to view parental

symptoms as ordinary deviations from the normative functioning since their parents' behaviors were still their anchor points. To exemplify, Mine shared that:

> Onun dışında hani kimseyle paylaşma gereği duymuyorum. Babamla ilgili bir şey sorulduğu zaman babam hasta diye hiç bahsetmedim. Normal bir babaymış gibi hissediyorum hep. Sadece üzülüyoruz yani çünkü kimsenin elinden gelen bir şey yok. Babamın bakımevine yatmasını da istemiyoruz zaten, annem hariç. Sonuç olarak babamız olduğu için hepimiz seviyoruz onu ama herkese bir şekilde bir zararı oldu yani. Öyle söyleyeyim. […] Hastalık olduğunu biliyorsun ama yine de çok kızgınsın. Kızıyorsun yani. Bilmiyorum ya açıklayamıyorsun çünkü hastalık deyip geçiyorsun ama sonuç olarak her şekilde bir zararı oluyor sana. Bir şekilde kızmak zorundasın.
>
> Other than that, I don't feel the need to share father's condition with anyone. When asked about my father, I never mentioned my father as sick. I always feel like he is a normal dad. […] We're just sad because there's nothing anyone can do. We don't want my father to go into a nursing home anyway, except my mother. As a result, we all love him because he is our father, but he has hurt everyone somehow. I'll say so. […] You know that he's sick, but you are still very angry. You are getting angry. I don't know, you can't explain it as you say it's a disease but as a result, it harms you in several ways. It is like you have to be angry somehow.

Despite perceiving the affected parents as responsible for what they had witnessed, offspring still mentioned their love and affection towards them through acknowledging disease related realities. Still, such a compassion did not exclude the feelings of sadness, guilt, and anger. Consequently, they waxed and waned between blaming and normalization while they were seeking explanations to base their experiences of parental schizophrenia. To illustrate, Tarık (13) tried to make sense of his father's symptoms through early child experiences. Although he accepted the presence of a mental disorder, he still tended to explain those symptoms as maladaptive expressions of anger and hostility and underlined positive attributes of his father. His account also reflected how the unsupportive attitudes of extended family members hampered his meaning making process as follows:

> **Araştırmacı:** Şimdi artık adını biliyorsun, baban şizofreni tanısı aldı.
> **Tarık:** Evet
> **Araştırmacı:** Sence babanın nasıl bir hastalığı var?
> **Tarık:** Mm bizi kötü biri diye tanıyor herhalde bazen. Sinirlendiğinde, bizi kötü biri olarak tanıyor sinirlendiğinde öyle.
> **Araştırmacı:** Peki, sen baban hastaneye yatırıldı ve hasta olduğundan emin oldun. Adının ne olduğunu öğrendin. Nasıl hissettin o ilk anda, ne düşündün?

Tarık: Beklemiyordum hasta olacağını falan tuhaf geldi yani. Herkesin babası da böyle mi yoksa sadece benim babama özel bir şey mi diye, hep şey yani bir hastalık olduğu falan. Genelde kendime sorular soruyorum genelde.
Araştırmacı: Mesela nasıl sorular?
Tarık: Mesela niye böyle diye yani. Niye böyle bilmiyorum neden öyle işte hep kendi aramda bir şeyler soruyorum. Mesela, anne tarafında sadece annemin güçlü olmasını vs istiyorlar. Babam hakkında pek bir şeyleri yok yani, bir şey düşünmüyorlar. İki taraf da çocuklarını düşünüyor, iki taraf da. Daha erkenden hastaneye yatabilirdi babam ya da ee bilmiyorum, çocukken belki bir şey yaşamıştır kötü bir şey o olabilir öyle. Yani bilmiyorum, kimseye babamı sen kötü yaptın demiyorum ya da destek olmuyorsun babama gibi ama öyle işte.
Araştırmacı: Peki şu anda hastanede olmasını nasıl değerlendiriyorsun?
Tarık: Onun için daha iyi, burada olmasından daha iyi. Çünkü haplarını düzenli kullanıyor, daha iyi kendine bakıyor ve sinirlenecek biri olmadığı için de sinirlenmiyor. Bir olay falan yaşamıyor, sinirlenmiyor, kendi kendine bu şekilde kendini daha iyi hisseder. Babam iyi kişi aslında yani çok seviyorum kendisini de bazen sinirlenince kendini kaybediyor sadece.

Researcher: Now you know the name of the disorder, your father was diagnosed with schizophrenia.
Tarık: Yes.
Researcher: What kind of disease do you think your father has?
Tarık: Mm, he probably perceives us as bad people sometimes. When he's angry, he recognizes us as the people with bad intentions.
Researcher: Well, your father was admitted to the hospital, and you made sure that he has a disease. You found out what its name is. How did you feel at that first moment, what did you think?
Tarık: I didn't expect this to be a disease, so it was weird. Whether everyone's father is like that or it is just something special to my father, it's always something like there is a disease or something. I usually ask myself questions.
Researcher: For example, what kind of questions?
Tarık: For example, why he behaves like that? I don't know why it is like that, why is it like that, I always ask myself. For example, on the mother's side, they only want my mother to be strong, etc. They don't think much about my father or anything. Both sides are concerned about their own children, both sides. My father could have gone to the hospital earlier, or I don't know, maybe he had experienced something bad when he was a chils, it could be the case. So, I don't know, I don't accuse anyone like you behaved badly towards my father or you don't support my father, but that's how it is.
Researcher: Well, how do you evaluate his being in the hospital right now?
Tarık: It’s better for him, better than being here (referring to their house). Because he takes his pills regularly, takes better care of himself, and doesn’t get angry because there’s nobody to get angry about (referring themselves). He doesn’t experience an event or something, he doesn’t get angry, he feels better alone that way. My father actually is a good person, I love him very much but sometimes he just loses himself when he gets angry.

3.7 Parentification / Adultification & Ambiguous Loss and Grief

This category covers the role reversals and subsequent losses experienced by the offspring with parental schizophrenia. Interviewed offspring assumed disproportionate responsibilities that were not proportionate to their developmental stages. Simultaneously, they mourned for the familial and personal losses resulting from the perceived absence of the affected parents. Unfortunately, several impediments operating at different levels (e.g., absence of support resources, discrimination, lack of knowledge about the disease) disrupted the meaning-making efforts of the offspring. It seems that their search for answers got stuck between blaming and isolation. Fear of stigmatization and poor public awareness forced them to utilize their already limited resources. Thereof, the absence of internal and external resources eventually halted the coping strategies of the affected offspring increasing the impacts of negative outcomes such as parentification and unresolved grief. For instance, Tülay touched upon this issue as:

> Yani biz artık, şöyle söyleyeyim biz artık ne yapacağımızı bilmiyoruz. Belki de bu hastalıkla yaşayan insanlar ne yapacaklarını, nasıl davranacaklarını, nasıl hareket edeceklerini bilmiyorlar e bilmedikleri için de karşındakine de yardımcı olamıyorlar. Her yönden yani, biz öyle büyüdük yardım edemedik. Ya da nelerle, yani belki o an o çok acı çekiyor. Bilemiyorsun ki yani, çünkü bilmiyordum ki böyle nasıl bir hastalık olduğunu, neyin içinde olduğunu.
>
> Let me put it in this way, we don't know what to do anymore. Maybe other people having and experiencing this disease do not know what to do, how to act, how to behave, and because they do not know, they cannot help the others either. In every way, I mean, we grew up like that, we couldn't have helped him. I mean maybe he's in a lot of pain at that moment. I mean, you don't know, because I didn't know what kind of a disease it was, what he was going through.

Similarly, Faruk described:

> **Faruk:** Yani psikopat gibi görüyor toplum, okuldakilere de yansıtmadım hiç. Arkadaşlarımı da eve getirmedim hiç yani, olmadı.
> **Araştırmacı:** Bunu nasıl değerlendiriyorsun?
> **Faruk:** Yani insan böyle sinirlenir, atıyorum babama deli mi psikopat mı deseler öfkelenir yani karşımdakini de azarlarım yani kavga da çıkabilir.
> **Araştırmacı:** Sence toplumun bu konuda neye ihtiyacı var?
> **Faruk:** Bilgi. Bilgilendirilmeye ihtiyacı var yani hastalığın ne olduğunu nasıl bastırıldığını. Yani hastalıklar hakkında bilgileri direk kaynağından düzgün bir şekilde anlatacak birileri olsa daha iyi olurdu. Herkes farklı şeyler dediği için olmuyor yani birinin dediğini biri tutmuyor.

Faruk: So, society perceive them as psychopaths, I never shared it (referring to his father's condition) at school. I never brought my friends to our house either, it didn't happen.
Researcher: How do you interpret this?
Faruk: I mean, I might get really angry if they call my father crazy or a psychopath, I would be getting angry, so I would scold the person if something like this happens, so there may be a fight.
Researcher: What society needs to know about this?
Faruk: Knowledge. There is a need to be informed, that is, to be informed about what the disease is and how it is treated. So, it would be better if there was someone who would properly explain the information about the diseases directly. It does not work in this way because everyone says different things, so, what someone's saying is not consistent with what others are saying.

In fact, above quotations perfectly capture the offspring's need to be informed and guided by a reliable source to manage the impacts of parental schizophrenia. Nevertheless, families had to find their own ways of coping as they were unable to receive either formal or informal support throughout the process. Amongst others, denial, avoidance, and withdrawal emerged as the most prominent strategies employed by the affected families to handle disease-related difficulties. For instance, Yelda defined as:

Yelda: Ama dediğim gibi konuşulmaz bizim ailede bir şeyler anlatılmaz. Normalmişiz gibi davranmaya çalışırız her zaman. Yani bir şeyleri bildikçe daha çok üzülüyor insan. Yani bir şeyleri bilmeyince daha az hasar aldık ya da daha bilemiyorum hani anlatamıyorum bazı şeyleri ama bilinmemesi şu an daha iyi gibi keşke ben bazı şeyleri hiç bilmeseydim. […] Arkadaşlarım gayet iyiler bana karşı, hiç soru sormuyorlar çünkü niyeyse soru sormaya biraz izin vermiyor gibiyim. Bilmiyorum hani o tepkiyi nasıl yapıyorum bilmiyorum ama o an karşıdaki kişiye öyle bir bakıyorum ki ya da işte öyle bir temas kuruyorum ki hani o bir şeyleri sormaya cesaret edemiyor gibi.
Araştırmacı: Aslında sormalarını da istemiyorsunuz
Yelda: İstemiyorum, diyorum ya bu denli ilk kez size anlatıyorum. Size de niye anlatmak istiyorum çünkü siz zaten yabancısınız, belki siz benim öğretmenim, hocam olsaydınız size anlatmazdım. Ama böyle sanırım artık birine anlatmam da gerekiyordu benim. Yani şu an size bunları anlatıyor olmamın tek sebebi şu an karşımda olmamanız belki de hani karşımdasınız ama sanal bir ortam ve belki de ben sizi bir daha hiç canlı yüz yüze göremeyeceğim. Bilmiyorum, yeni bir şey öğrenmekten korkuyorum.

Yelda: But as I said, in our family, things are not talked about, things are not spoken. We always try to pretend like we were normal. In other words, the more you know about something, the more you get upset. I mean, we got less damage when we didn't know something, or I don't know yet, I can't explain some things, but it's better not to know right now, I wish I didn't know some things at all. […] My friends are fine towards me, they don't ask any questions at all because for some reason, I don't allow them to ask questions. I don't know, I don't know how I react but at that moment I look at the other person in such a way that like I make such a contact that he does not dare to ask anything.
Researcher: Actually, you don't want them to ask either.

> **Yelda:** I don't want to; I'm talking about this for the first time, I'm telling you. Why do I want to tell you, because you are already a foreigner, maybe if you were my teacher or professor I wouldn't have told you either. But like that, I guess I had to tell someone now. I mean, the only reason I'm telling you all this right now is that you're not in front of me right now, maybe you are, but it's a virtual environment and maybe I will never see you face to face again. I don't know, I am afraid of learning something new.

To conclude, societal and political impediments led these families to function maladaptively while coping with the implications of parental schizophrenia. Families eventually exhausted their own psychosocial resources due to the chronicity of the disease which in turn resulted in the development and maintenance of dysfunctional coping strategies. The result of this multilevel process is two-folded for the affected offspring. On the one hand, they were exposed to age-inappropriate tasks and duties at home. On the other hand, they tried to mourn for the various invisible losses brought by parental schizophrenia.

3.7.1 "Parentification and Adult-like Behaviors"

This part covers the age-inappropriate responsibilities imposed on offspring due to the disease-related absence of their parents and the stigma-induced isolation of the family. Having provided constant assistance and care, not only the affected parents but also the unaffected parents' absence became evident in the accounts of the interviewed children. As a result of the chronicity of the disease, caregiver roles of the unaffected spouses overshadowed the parenting duties and role reversals demonstrated themselves. The limited knowledge regarding the nature of the disease and the absence of external support made it difficult for healthy parents to sustain their parenting endeavors. Lack of formal and informal support eventually led those families to utilize the within family resources. Hence, affected offspring started to assume adult-like responsibilities at an early age. They were involved in the care of the affected parent and provided both instrumental and emotional support to the other family members. For instance, Sevinç explained such role reversals in the context of maternal schizophrenia as:

> Ablam zaten birazcık vurdum duymazdı. Ben ablalık yapıyordum daha doğrusu öyle diyeyim. E babam zaten küçükken menenjit geçirmiş kafası yerinde olan bir insan değildi. Birazcık şey gibiydim yani aileyi toplayan gibiydim daha çok. Onlar sadece maddi geliri çeviriyorlardı, ben hepsini çekip çeviriyordum. Zaten küçüktüm, 18

yaşındaydım daha yeni reşit olmuştum. Sadece doktorun söyledikleriyle, doktorlardan öğrendiklerimle uygulamaya çalıştım. […] Annene çocuğunmuş gibi bakmak, kendi çocuğuna annelik yapmaktan farksız yani ama çok üzülerek baktığım bir çocuk. Gerçekten çok zor, ağır bir sorumluluk. Artık bir şekilde evde yemeğine suyuna katıyordum ilaçlarını içsin diye zorla başında bekleyip ama içmiyormuş ağzında bekletip ben ayrıldığımda yanından, çıkarıyormuş yani. Ben sanki çocuklarımı korur gibi evde ekstra da onun için önlemler alıyordum. Tehlikeli maddeleri vs erişemeyeceği yerlere koyuyordum. […] Açıkçası o hastanedeyken çıksın istemiyordum baş edemiyordum ki oradaki kadar iyi bakamadığımı biliyordum çünkü. Kalsın istiyordum hastanede. Çok sabır istiyor çok.

My sister was a little bit carefree anyway. I was like the older sister, I should say. Well, my father was not a sane person either, he had meningitis when he was a child. I was like someone who was holding the family together. They were bringing money, I was the one managing them all. I was very young, I was 18 years old, I had just attained my maturity. I just tried to apply what the doctor said, what I learned from the doctors. […] Caring for your mother as if she had been your child, is not different than mothering your own child, but she is a child that I look after with great sadness. It's a really tough, heavy responsibility. I was adding her medications to her food and water at home, I was waiting beside her to make sure that she took them all but she was resisting, she was keeping it in her mouth and taking it out when I left. I was taking extra precautions for her at home as if I had been protecting my children. I was putting dangerous materials away to the places where it was inaccessible to her. […] Frankly, while she was in the hospital, I wasn't wanting her to leave the hospital. Because I wasn't able to cope alone, and I knew I couldn't take care of her as good as she was cared in hospital. I was wanting her to stay in the hospital. It takes a lot of patience really.

Similarly, Mine described how she supported her mother in the care of his father as:

Ve annem bana şey derdi, sen gizliden ilacını bir suya gizliden at, ilacını ver o şekilde uykusu gelir, yaparsan sakinleşir derdi. O şekilde sakinleştirirdim babamı. Ve bu bıçak saklama olayı çok oldu bizde. Hani sadece bıçak da değil zarar verebilecek her şey. Kavgalar olduğu zaman da genelde küçük olsam da etrafı ben sakinleştirmeye çalışıyordum. Ablam falan çok panik oluyordu çünkü böyle, bir şekilde ayırmaya çalışıyorsunuz iki tarafı da. E ben bir yandan ablamı bir yandan ortamı sakinleştirmeye çalışıyordum. Bu konularla ilgili ben hep sakindim yani şimdiye kadar. Hala daha sakinim. Çünkü bir kişinin ortalığı sakinleştirmesi gerekiyordu (gülüyor). Yoksa çok panik ortamı oluşuyordu o zamanlar. Bu yüzden hep bir şeyler ertelendi işte ben okulumu erteledim, başka şeyler vs yani şu anki durumumuz daha iyi olabilecekken daha kötü durumdayız. Maddi olarak da. Her açıdan kötüydü.

And my mother used to say to me that, ‘you secretly put the medicine in his water, make him take his medicine in this way, he would eventually get sleepy, if you do it like that, he would calm down’. That was how I calmed my father down. And this putting-the-knives-away thing happened a lot. You know, not just the knife, but anything that can cause harm. When there were fights, even though I was younger, I was trying to calm the people. Because my sister was panicking or something a lot like that, so you're trying to separate both sides somehow. Well, I was trying to calm my sister on the one hand and the environment on the other. I have always been calm about these matters, that is, until now. I'm still calm. Because someone had to calm things down (laughing). Otherwise, there would have been a very panicky atmosphere at those times. That's why

> things have always been postponed, I postponed my school, other things etc. While our current situation could have been much better, we are in a much worse situation now. Financially too… It was bad in every way.

As can be seen from the above quotations, the parenting responsibilities of the offspring were not limited to management of the disease-related needs of the affected parents. They also functioned as a negotiator at home due to the constant conflicts triggered by the psychotic symptoms. In a house where emotional instability was predominant, children were left with no option but staying calm and establishing peace. For example, Tarık, 13 years old, emphasized that he was not angry due to his father's condition thanks to his calm and easy personality: "I wouldn't be angry, but I mean, I'm not usually annoyed person anyway. Sometimes I get angry as a joke, but I don't get angry again" ("*Sinirlenmezdim ama yani ben zaten genelde sinirli biri değilim. Şakasına bazen sinirlenirim, sinirlenmem yani bir daha*"). Having been left alone by the system and close relatives, anger was one of the dominant feelings displayed by the affected parents. They usually had difficulty to regulate their emotions, failing to perform caregiving and parenting duties adequately. Accordingly, offspring seem to take a counter position as a negotiator and protector to fulfill the instrumental and emotional needs of their parents and siblings. Still, interviewed offspring seem to feel satisfied with assuming adult-like responsibilities as they were skillful enough to manage such difficulties at a young age. For instance, Faruk described her authority on his father as follows:

> Küçük yaşlarında ormanda tek başına çobanlık yapmış bir insan. Küçük kaç yaşında çocuk, 6 yaşında koyunları verip dağa göndermişler çocuğu, şimdi o çocuğun ne kadar sağlıklı olabileceğini tahmin edemezsin. Babama biraz daha böyle şey davranıyorum komutan gibi düşünün, sade ve kesin şekilde konuşurum. […] Böyle kavgaya tutuşacakları zaman ortamı yumuşatmaya çalışıyorum elimden geldiği kadar. Bir de kardeşimi genelde ortamdan uzaklaştırırım mesela, o bizim olduğumuz ortamdaysa Tarık'ı öbür odaya falan gönderirim ya da öbür odaya çekiliriz.
>
> He was a person who had worked as a shepherd alone in the forest at an early age (referring to his father). He was a very the little boy, when he was 6 years old, they gave him the sheep and sent him to the mountain, now imagine how healthy that child would be. I treat my father a little more like this, think like a commander, I speak simple and assertive. […] I try to soften the atmosphere at home as much as I can when they get into a fight like this. Also, I usually remove my brother from the environment, for example, if he is there with us, I send Tarık to the other room or something, or we retreat to the other room.

Likewise, Yelda expressed that:

> Evet ben zaten yani meraklı olduğum için mi artık ya da hep bir şeylere dahil oldum yani. Mesela babam kimseden ilaç almaz, bir tek ben ve annemden alır. Çünkü hani her şeyde ben hep yanında durmak istedim niyeyse. Anneme diyordum ben de geleceğim diye, annem de gel diyordu en azından bir şey olsa o ya da ben tutarız, diğerimiz eczaneye gider falan. Bir de biz babamı yalnız da bırakamıyoruz aslında, hep birisi evde olmak zorunda ya da işte tamamıyla yalnız bırakmıyoruz. İki üç saat maksimum. […] Yani bir de kardeşimle birbirimize şunu derdik, bir şey olursa bağır, yani beni çağır bağır gelirim ben koşarım. […] Ben aslında çok daha güçlü olduğumu hissediyorum. Mesela beni kolay kolay hiçbir şey üzemez, kolay kolay dediğim mesela arkadaşımı, normal benim yaşıtımdaki bir kızı üzen bir durum beni teğet geçiyor gibi. Bunu kendimi şey için söylemiyorum açıkçası, bu gerçekten öyle olduğu için. Yani mesela nasıl desem gündelik sorunlardan çok etkilenmem mesela daha mutluyumdur, her zaman mutluyumdur hatta daha gülerim.
>
> Yes, I mean, maybe it is because I tend to take responsibility, I always involved into something. For example, my father does not accept medicine from anyone, he only takes it from me and my mother. Because for some reason, I always wanted to stand beside him in everything. I was saying to my mother that 'I would come too', my mother also wanted me to come, if something happens, either she or I would cover it, and the other one would go to the pharmacy or something. Also, we can't leave my father alone either, someone has to be at home all the time or we don't leave him completely alone. Two to three hours at maximum. […] I mean, my brother and I used to say to each other, 'if anything happens, shout, call out for me, I'll come, I'll run.' […] For example, nothing can easily upset me, for example, a situation that upsets my friend, who is a normal girl of my age, seems to be tangent to me. I'm not saying this to make myself like anything, frankly, because it really is like that. For example, how can I say, I am not affected by the daily problems, for example, I am happier, I am always happy, I even laugh more.

Another dimension of parentification experienced by the target offspring revealed itself as taking the position of decision-maker in the family. As the psychotic nature of the disease impaired the decision-making abilities of the parents, affected children had to make decisions beyond their ages to sustain the optimal functioning of the family. Some of these decisions were related to the well-being and care of the siblings, while others were about the improvement of economic conditions. Mukaddes touched upon that feature as: "A lost childhood, you have to always think like an adult. I mean, your father is like a child anyway" ("*Yaşanılmamış çocukluk, hep büyük gibi düşünmek zorundasın. Yani baban çocuk gibi zaten*"). Similarly, Tülay described the same situation as:

> Bir baba olarak yani ne bileyim, en basiti ders çalışırken gel beraber ödev yapalım yok ki bunların hiçbiri yok ve sürekli siz karar merciisiniz. Yani abim keza çok çabuk sanki böyle evin babasıymış gibi rolü üstlendi, herkes ona mesela biri düşsün burnu kanasın ona söylüyor. Ben yolda kaldım ona söylüyor mesela hepimiz düşünün beş kardeşin beşi de ona. Ya zaten şöyle söyleyeyim abim şu an 32 yaşında görseniz 45 dersiniz. Yani yaşlandı. Tarih öğretmeni kendisi, ama yoruldu. Hayat yordu.
>
> I don't know, the simplest is that, while studying, as a father you say 'let's do your homework together', we don't have such interactions, and you are always the one making decisions. I mean, my brother also took on this role very quickly as if he was the father of our house, for example, if someone falls and his nose bleeds everyone tells him. Everybody tells him everything, for example, 'I'm stuck on the road', think of all five siblings that they are all telling him everything. Let me tell, my brother who is 32 now, if you saw him, you would say he is 45. So, he has been aged faster than his time. He is in fact a history teacher, but he's tired. Life exhausted us.

All of these quotations reflected interviewed offspring's obligatory entry into adulthood out of familial necessities arousing from parental schizophrenia. The psychological absence of parents and lack of external support positioned offspring as the negotiator, the decision-maker, and caregiver in the new family system. Unfortunately, these new roles took their tools on children's well-being through multiple losses experienced throughout the process.

3.7.2 "Ambiguous Losses and Unresolved Grief"

Grieving surrounded the offspring not only through the lost childhood but also through the loss of the old but normative experiences regarding parental and familial interactions. The psychological absence of the affected parent resulted in mourning for the relational losses such as loss of intimacy and support. Grieving upon those losses simultaneously grounded on the uncertainties regarding fulfillment of the parental roles. Offspring seem to suffer most due to losing conventional family experiences (e.g., having a cup of coffee together) as a result of parental schizophrenia. In other words, longing for normality showed up as a repeated theme in the narratives of the target family members. For instance, Yılmaz expresses as:

> **Araştırmacı:** Peki Yılmaz Bey, birisi sizden şizofreni tanısı almış bir ebeveynle büyümenin nasıl bir deneyim olduğunu tek bir cümle ile açıklamanızı istese ona ne dersiniz?
> **Yılmaz:** Eksik hissettiriyor insana
> **Araştırmacı:** Eksik
> **Yılmaz:** Evet. Biraz da özlem duyduruyor insana çünkü nasıl desem o 14 yaşından önceki süreçte annem (hafif gülerek) güzel yemekler yapardı bana. Ailece oturur yemek

yerdik, yani bir de evimiz daha kalabalıktı. O dönemde benim öğretmenlerim gelirdi eve, komşularımız gelirdi. Fal baktırmaya gelirlerdi anneme. Hatta şöyle olurdu, ben kahve kokusu aldığımda annem fal bakarken o an çok öfkelenirdim. Ondan sonra annem fal bakmayı bitirdi, hastalandı sonra ben kendim kahve içmeye başladım. O dönemi de biraz özlüyorum gibi. Ev kalabalıktı, ses vardı en azından.

Researcher: Well, Mr. Yılmaz, if someone asked you to describe in one sentence what it was like to grow up with a parent diagnosed with schizophrenia, what would you say to them?
Yılmaz: It makes you feel you are lacking.
Researcher: Incomplete.
Yılmaz: Yes. It makes you also yearn for a bit because, how can I say, before the age of 14, my mother used to cook good meals for me (laughing a little). We used to sit down and eat as a family, and our house was much more crowded too. At that time, my teachers would come to our house, our neighbors would visit. They used to come to my mother for fortune-telling. In fact, it was like, when I smelled the coffee, while my mother was fortune-telling, at that moment I was feeling like very angry. After that, my mother stopped fortune-telling, got sick, and then I have started drinking coffee myself. It's like I miss that period a little bit too. The house was crowded, but at least it was lively.

Similarly, Tarık described the impacts of his father's absence as follows:

Babamın hasta olması yani, bunun da geçip gideceğini şey mmm umuyorum yani bir an önce atlatmasını falan istiyorum. Yani babamın yokluğunu falan çok hissediyorum bazen, sevgisine ihtiyacım var. Günlük yaşantımda hep hissediyorum, babam olmaması kötü bir şey yani. Hastalık kötü bir şey. Babamın hasta olduğunu öğrenmek yani üzücü oldu, aramızda da yok. […] Hayatım daha farklı olurdu herhalde bilmiyorum yani, (sesi titreyerek) babam hasta olmasa gitmez aramızda olurdu yani. Daha samimi olurduk yani birbirimizle çok fazla muhabbetimiz olurdu daha fazla konuşurduk. Çok fazla sohbet ederdik çok fazla şey yapardık. En zorlayıcı yanı da çevresindeki karşı, ee çevresindeki insanlara karşı çok zararlı olması ve kendine de istemeyerek çok kötü davranması yani kendi de istemeyerek (ağlıyor) bir şeyler yapması.

I mean, my father being sick, I hope this situation will pass too, mmm, I mean, I want him to get over it as soon as possible. So, sometimes I feel the absence of my father, I need his love. I always feel his absence in my daily life, not having a father is a bad thing. Illness is a bad thing. It was sad to learn that my father is sick, he is not with us either. […] I don't know if my life would have been different, I guess, I mean (his voice trembling), I mean, if my father hadn't been sick, he would have been with us. We would be more intimate, I mean, we would have a lot of conversation with each other, we would talk more. We would be talking too much; we would be doing several things together. The most challenging aspect is that he is very harmful to the people around him and also to himself, he treats others very badly, that is something he does (crying) unintentionally.

As it can be seen from the above quotations, absence of parental affection and guidance together with the loss of former living conditions contributed to the yearning

for normality. Even though parents were alive, children's accounts occasionally included some expressions implying the death of their affected parents. In fact, utilization of such a language might be closely related with the continuous losses and unresolved grief experienced by the offspring. The affected parents' failure to function normatively also led to the development of an imaginary parental figure. Over time, children admitted that they started to believe this make up scenario to cope with the negative feelings resulting from the psychological absence of their parents. These imaginary scenarios also protected them from being stigmatized by their peers. For instance, Yelda described this pattern as:

> Yani ben zaten hep yalan söylerdim herkese babam göreve gitti gibi. Yani öyleymiş gibi davranırdım. Annem bunun için bir kere bana tokat atmıştı aslında yani çünkü ben çok yalan söylemeye başlamıştım ve o yalanlara bir de kendimi de inandırmaya başlamıştım. Arkadaşlarımın yanında böyle bir mevzu geçmişti ve annem gözümün içine bakmıştı ama asla bozuntuya vermemişti. Annemin o an orada bir şey söylemesinden çok korkmuştum çünkü ben babam göreve gitti diyordum. Evet gelecek ama yakında az kaldı falan dedi sadece. Babamla ilgili kendi hayal dünyamda yaşıyordum, kimseye söylemiyordum. Biz de şuraya gittik, babam bana bunu aldı falan diyordum halbuki öyle bir şey yok. Bunu lisede de yaptım çünkü yani niyeyse biri vefat ettiğinde dersiniz ki vefat etti ama biri varken yoksa bunu anlatmak çok imkânsız. Ve sürekli anne diyormuşum. Arkadaşım vardı, bir gün dedi ki sen neden sürekli anne anne diyorsun hiç babandan bahsetmiyorsun dedi. Sonra ben de benim babam çok gizemli bir adamdır falan dedim. Hani bu şekilde daha farklı farklı yalanlar, hep yalan söyledim yani ben. Çünkü bunu sanki kapatmak zorundaydım. Kendi hayal dünyamda yaşıyordum. Dediğim gibi üniversiteye geçtikten sonra ben artık bunun saçma olduğunu fark ettim. Biraz geç oldu ama sanırım bu şekilde kendimi kandırıyordum.

> I mean, I always lying to everyone like 'my father went on a duty'. So, I was acting like this is real. Actually, my mother slapped me once for this, because I started to lie a lot and I started to make myself believe to those lies. Such an issue had been a topic with my friends once and my mother looked me in the eye, but she did not say anything there. I was very afraid that my mother would say something at that moment because I was saying that my father had gone on duty. Then, she said, 'yes, but he will come soon, it's almost time'. I was living in my own fantasy world about my father, by not telling anyone. I was saying things as 'we went there, my father bought me this or something', but there were no such things. I did this in high school, too because for some reason, when someone died, you say that 'he passed away', but it is very impossible to tell when someone is present and also not present. And I was always talking about my mom, one day a friend of mine said 'why do you always talk about your but never talk about your father'. And then I said, "My father is a very mysterious man ". So, different lies like this, I've always lied, I mean. Because it was like I had to cover it up. I was living in my own imagination. As I said, after I went to university, I realized that this is ridiculous. It has happened a little late, but I guess I was deceiving myself that way.

Yelda distanced herself from her father's mental illness by creating an imaginary healthy parent and lied to others to avoid stigmatization. The reason for her lying stemmed from the need to cover up the disease from the external world. In a way, through establishing and believing in a fantasy world, they tried not being an outcast in their social network. However, to cover up such a fact also demonstrated the unresolved grief and longing for a parent without schizophrenia.

Without any exception, all interviewed children had difficulty describing a stable relationship with their affected parents. The relationship itself was bound to several ambiguities due to the rapidly changing prognosis of the disease. To be more specific, frequent psychotic attacks and negative residual symptoms impaired parents' communication and interaction with their family. They became irritable and withdrawn depending on the course of the disease and were not able to attend to the family practices and rituals. Thereof, offspring felt as if their parents had not been present at home during their childhood. For example, Faruk clarified such interaction as:

> Babam genelde sevecen yaklaşır böyle yardımsever insandır da bu son hastalığında böyle sevecenliğini kaybetti. Biraz daha böyle agresifleşti. […] Normalde arada aklıma geliyor ama sonra gidiyor yani sanki evde hiç yokmuş gibi. Öyle devam ediyoruz yani üç kişilik bir kişi olarak devam ediyoruz evdekilerle. İlacını içtiği gibi uyur yatardı, belki ilacını kullanmamış olsaydı yani hasta olmasaydı bizimle vakit geçirirdi. Pek vakit geçiremediğimiz için böyle biraz soğuğuz. Bazen beraber dışarı çıkardık, dışarı götürürdü dolaştırmaya falan o zaman iyi olurdu ama üstünden birkaç gün geçtikten sonra tekrar soğurduk yani. Ara sıra o da işte 3-4 sene önce çıkmışımdır belki en son.
>
> In fact, my father is, generally really affectionate, and he is a kind person, but he lost his kindness in his last episode. He became more aggressive. […] Normally, it comes to my mind from time to time, but then it goes away as if he wasn't at home at all. We continue like that, that is, we continue our life as three people at home. He would sleep when he took his medicine, maybe if he hadn't used his medicine, that is, if he hadn't been sick, he would have spent time with us. We're a little distant like this because we don't have much time to spend. Sometimes we used to go out together, he would take us out for a walk or something, those times were nice, but after a few days, we were becoming distant again. It is also occasionally, maybe the last time I went out with him was 3-4 years ago.

Similarly, disruption of the normative functioning of the family resulted in the yearning for the normality. Interviewed children felt like outcasts particularly when they observed their peer's interactions with the parental figures. At those times, they compared their experiences with those of others, grieving for the multiple losses

brought by parental schizophrenia. They felt envious, and sorrowful because parent's disease had robbed of their chance of concerning about mundane things. For example, Yelda stated as:

> Üniversiteye ilk geldiğim zaman, bir arkadaşımın babası bana çok iyi davranmıştı. Ve ben hayatımda hiç öyle bana baba gibi davranan birini görmemiştim ve o vefat edince çok çok üzüldüm. Çünkü ben şeyi düşündüm acaba ben çok imrendim de adama nazar mı değdirdim hani benim yüzümden mi düşündüm. Ama ben bilmiyorum yani babam nasıl biri olurdu bilmiyorum. Ama tabii ki bence daha güzel olurdu en azından böyle normal kaygılarım olurdu diye düşünüyorum. Hani böyle işte saçımı önemserdim, tipimi önemserdim ee ne bileyim belki derslerim falan benim kaygılarım olurdu. Ama benim kaygılarım hep böyle saçma sapan şeyler oldu yani. İnsanlarla aynı şeyleri düşünmeyi isterdim, aynı sorunlarım olsun isterdim.

> When I first came to college, a friend's father treated me very well. And I have never seen anyone who treated me like a father in my life, and when he passed away, I was very, very sad. Because I thought about something like ', did I put the evil eye on the man because I was so much envious', I thought he died because of me. But I don't know, so I don't know what kind of person my father would be (without the disease). But of course, I think it would be better, at least I would have such normal concerns. For example, I would be concerned about my hair, I would be concerned about my apperance, I don't know, maybe I would be concerned about my classes or something. But my concerns have always been about such ridiculous things. I would like to think and live like other people, I would like to have the same problems.

The given quotation presented the offspring's tendency of self-marginalization due to the envy she had for a healthy parental figure. Self-marginalization in a way reinforced children's sense of feeling like an outcast for not having a typical family environment. Role reversals in the family system increased grieving upon the loss of normative parental interaction and resulted in feelings of anger and frustration. Offspring felt resented for the missed opportunities and loss of their position as the children of the family. Their searching for answers never reached a closure since the parental disease demonstrated itself with continuous ambiguities. To exemplify, Mine described her never-ending search for answers throughout her childhood as:

> Ben hep kızıyordum çünkü, neden babam böyle, neden düzgün bir babam yok, neden babam olduğunu hissedemiyorum… Hala hissedemiyorum mesela. Hep annem, hep annem. Babam olduğunu hiçbir zaman hissetmedim gerçekten. Hep özeniyordum, hatta hala özeniyorum güzel baba-kız ilişkisi gördüğüm zaman. Üzülüyordum mutlu bir aile yaşantısı olan arkadaşımı gördüğüm zaman. Hani "Benim neden böyle değil? Benimki niye bu şekilde? Biz niye bunları yaşamak zorundayız?" gibisinden. Hep düşündüm, hep üzüldüm yani. Sürekli böyle mi kalacak, hiçbir zaman geçmeyecek mi, biz hiç mutlu olamayacak mıyız, düzelmeyecek mi hiçbir şey vs. Daha sorumluluk sahibi bir

baba olurdu. Hem babalığını hem kocalığını yerine getirirdi diye düşünüyorum. Başka çevremiz olabilirdi. Psikolojik açıdan daha iyi olurduk. Bu kadar şey yaşamazdık sonuç olarak daha mutlu, daha huzurlu bir yaşam olurdu genel olarak. Başka bir şey farklı olmazdı herhâlde, zaten bunlar yeterli diye düşünüyorum. Nasıl bu kadar sakin kalmışız, hepimiz nasıl buna dayanmışız. Onca şeyi atlattıktan sonra bu şekilde hayata devam etmek, bir şeyler yapmak garip geliyor yani, garip hissediyorum şu an.

I was always angry, why father is like this, why I don't have a typical father, why I can't feel that he is my father... I still can't feel it, for example. It's always mom. I never really felt that I have a father. I always envied, and I still do, when I see a good father-daughter relationship. I was sad also when I saw a friend who has a happy family life. I always thought like "Why is mine not like this? Why is mine like this? Why do we have to go through these things?" so I was always sad. "Will it stay like this forever, will it never pass, will we ever be happy, will nothing ever get better" etc.? […] He'd be a more responsible father. I think he would have fulfilled both fatherhood and spouse roles. We could have had another environment. We would be better psychologically. We wouldn't have been experienced this much, as a result, we would have a happier, more peaceful life in general. I guess, nothing else would have been different, I think these are enough anyway. How did we remain so calm, how did we all endure that? After going through all that, it feels strange to continue in life like this, to do something, so I feel strange right now.

Indicating their continuous grieving and confusion, some offspring admitted thinking about the physical death of their affected parents. They questioned how they would be reacting when the day had come. They viewed death as a closure as it would end up their search for normality. At the same time, they felt guilty of having those thoughts since they still loved their parents and did not want to lose them. Offspring were also concerned about the loss of the unaffected parent which might lead them to undertake the whole caregiving burden in the family. In addition to their existing responsibilities, worrying about the possibility of being the only caregiver seems to increase their ambivalence towards the affected parent. To illustrate, Yelda described her ambivalent feelings towards his father in the context of parental loss as:

Yelda: Ben fark ettim ki, ben geceleri uyumadan önce babam ölürse nasıl tepki veririm diye düşünüyormuşum. Hani bunu hep yapıyormuşum aslında ben, hani hatta geceleri ağlanır ya annem ölürse napıcam gibi ama ben hiç düşünmedim annem ölürse naparım gibi ama babam öldüğünde nasıl tepki vermem gerekir diye hala da düşünüyorum açıkçası.
Araştırmacı: Bunu nasıl değerlendiriyorsunuz?
Yelda: Yani ölmesini istersiniz ama bir yandan ölmesin diye çaba sarf edersiniz. Yani bunu söylerim herhalde. Böyle söylemek de kötü hissettiriyor ama dediğim gibi kaybetme korkum yok değil çokça var hatta bu da beni eskiden buna da çok kızardım derdim ki bu adam böyle böyle yapmış ya sen niye böyle davranıyorsun niye bu kadar saygılı davranıyorsun üzülüyorsun ama bir yandan da sonuçta o

kişi senin baban yani. Kaybetmek istemiyorsun işte başına bir iş gelirse çok kötü oluyoruz yani erkek kardeşim de böyle. O yüzden böyle hem çok agresifiz hem değiliz çok garip bunu anlatmam biraz zor galiba. […] Hep düşünüyorum dedim ya, geceleri babam ölürse nasıl tepki veririm diye. Ama annem ölürse ne yaparım bunu şimdi düşündüm. Öyle bir durumda bütün sorumluluk bana geçecek, ben babama tümüyle bakmak zorunda kalacağım. O zaman ben ne yaparım.

Yelda: I realized that before I went to sleep at night, I was thinking about how I would react if my father had died. Now I realize I had always been doing this, you know, sometimes one cries about what would I do if my mother dies, but I never thought about what I would do if my mother died, but I still think about how I should react when my father dies.
Researcher: How do you evaluate this?
Yelda: So, you want him to die, but at the same time you try to save him so that he does not die. So, I guess I'll say that. I also feel very bad talking about this, as I said, I also have a fear of losing him. In fact, I used to be very angry with myself about this, by saying to myself this man did it like that, why are you behaving like that, why are you behaving so respectfully, and you are getting upset, etc. But on the other hand, that person is your father after all. You don't want to lose, if something happens to him, we feel very bad, my brother feels in the same way. That's like, we're both so angry and not, it's so strange, I guess it's a little bit hard to explain. […] As I said I always think about how I would react if my father died, at night. But now I've thought about what I'd do if my mother died. In such a case, I have to take all responsibility, and I will have to take care of my father completely. Then what will I do?

Interestingly, offspring tended to compensate for the parent's unfinished dreams while the affected parent was still alive. It seems that the career path chosen by the offspring was one of the ways of fulfilling for what had been missed by the affected parent. While grieving upon the familial losses, offspring simultaneously positioned themselves as someone who had carried the legacy of the affected parent. To be more specific, making up for what's missing became the motivation for offspring to cope with the uncertainties resulting from the simultaneous presence and absence of their parents. For example, Tülay expressed her career choice as a police officer in the following way:

Mesela şey diyordum hep, neden polis bi insan bu kadar güzel bir mesleği varken bırakır. Ben mesela polisliğe hazırlanıyorum şu an, benim için kocaman bir ukte yani. Onun tamamiyle görevini yerine getirememiş olması yaşını doldurup görevini yerine getirememiş olması ya da işte yani bir şeyleri tamamiyle başaramamış olması. O zamanlar ona çok kızardım yani en çok şeyi hatırlıyorum işte babalık görevlerini yerine getirmiyorsun, bizimle ilgilenmiyorsun işte bize sen neden para vermiyorsun, neden bize annem para veriyor.

For example, I was always questioning, why would a person as a policeman leave his profession when he has such a beautiful profession? For example, I'm getting ready to be a police officer, it's a huge knot for me right now. The fact that he has not completely fulfilled his duty, not having retired by age and has not fulfilled his duty, or that he has not completely accomplished something. At that time, I was very angry with him, so I vividly remember asking, ‘you don't fulfill your fatherhood duties, you don't take care of us, why you don't give us money, why my mother does give us money’ etc.

CHAPTER 4

DISCUSSION

In the present study, eight offspring who had a parent with schizophrenia and two parents with spousal schizophrenia were interviewed to investigate the operations of psychosocial, political, and cultural structures in explaining ambiguous loss experiences of offspring with parental schizophrenia. A qualitative design and particularly the Grounded Theory approach, was utilized to delineate multilevel mechanisms of parental schizophrenia in the sociopolitical context of Turkey. Our results indicated that witnessing parental schizophrenia is overwhelming by itself due to challenges in the management and comprehension of the disease. It is associated with several personal, familial, and political impediments that function interrelatedly, maintaining and strengthening the loss and parentification experiences of children. A model comprising psychosocial and political mechanisms of ambiguous loss and parentification was obtained from the participants' accounts, and seven interdependent concepts emerged: (1) the atypical nature and prognosis of the disease, (2) impediments to the home environment, (3) impediments with the external family members (4) socio-politic impediments, (5) interrelation of secrecy, stigmatization, and lack of support resources, (6) meaning-making process, (7) adultification/parentification along with (8) the experiences of ambiguous loss and chronic grief.

Schizophrenia is a mental illness that affects not only the patient but also the family members' functioning in several domains of life (Chen et al.,2021; Gater et al., 2014). Despite its pervasive effects, families tend to hide the affected patients' diagnosis due to fear of stigmatization and exclusion. Children's welfare is strongly context-dependent, and exposure to stigmatization adversely affects their well-being (Chan & Chau, 2010). However, there is a paucity of research regarding the psychosocial processes of discrimination in the context of parental schizophrenia. Existing studies

usually evaluated the experiences of family members in general (Caqueo-Urı´zar et al., 2017; Shiraishi & Reilly, 2019) or worked with children having parents with different mental disorders (Barnwell, 2019; Gatsou et al., 2017; Lincoln et al., 2017). To the researchers' knowledge, only a few qualitative studies have been focusing mainly on the psychosocial functioning of affected offspring by considering the families' social, political, and cultural contexts (Kadish, 2015; Kahl & Jungbauer, 2014). Hence, we hope the current study will contribute to this gap in the literature, expanding upon the existing findings about family members' experiences of schizophrenia. In the following section, the conceptual components of the model were discussed interrelatedly in light of the current literature. Afterward, psychosocial and clinical implications, limitations and future suggestions for research were provided in detail.

4.1 Impediments at Home, Impediments with Close Relatives, and Impediments in the Socio-Politic Realm

One of the main findings of the current study was that children with parental schizophrenia experienced interdependent impediments in the nuclear and extended family context that were maintained and strengthened through societal and political barriers. Impediments began within the home environment and were influenced by the relationships with close relatives. Ineffective implementations of social policies and lack of awareness cumulatively reinforced those impediments in the family context. Eventually, family members felt isolated and excluded, not engaging in any advocacy that further sustained the societal silence about their conditions.

Impediments at home were triggered mainly by the unpredictable and chronic nature of schizophrenia and the caregiver burden. The presence of symptoms deviated the affected parent from the normative functioning leading to feelings of exhaustion and anger among healthy parents. This finding partly corroborates with the previous research documenting that, mothers having spouses with schizophrenia experienced extreme levels of burden and exhaustion due to being the primary caregiver in the family system (Bloch et al., 1995; Cassidy & Callaghan, 2001; De Haan et al., 2004; Wright, 1994). Our findings added that the burden of the healthy parents sustained the offspring's confusion regarding the disease and the position of their affected parents.

Devoid of social support, healthy parents openly displayed their hostility towards their spouses in the presence of children. In turn, children avoided asking questions to not overburden the unaffected parents engaging in a meaning-making process all alone. This result might be partly explained by the impacts of Expressed Emotion (EE) on children with parental schizophrenia. The concept of EE refers to the emotional exchanges among family members in the context of schizophrenia (Zanetti et al., 2018). It involves family members' hostility, criticism, and overprotection towards the patient due to attributions of the disease and perceptions of caregiver burden (Wearden et al., 2000). Accordingly, family members with greater stress and burden were more likely to have increased levels of EE that exacerbated the symptoms of the affected patients (Ma et al., 2021). It was well-established that higher levels of EE predicted an increased number of relapses among patients with psychosis (Cechnicki et al., 2013; Ma et al., 2021). Besides, caregiver burden was further eventuated by EE, creating a vicious cycle between perceived burden and negative mental health outcomes (Manao & Pardede, 2019). Although extensive research has documented the impacts of EE on patients' and caregivers' outcomes (Hajebi et al., 2019; Onwumere et al., 2018) to the authors' knowledge, no single study has addressed how healthy parents' EE has shaped the psychosocial experiences of children living with parental schizophrenia. The limited number of studies available in the literature only indicated that parents with mental disorders (e.g., depression and schizophrenia) have greater levels of EE towards their child's problematic behaviors, and EE might be one mechanism explaining the intergenerational transmission of psychological symptoms across generations (Bolton et al., 2003; Gregg et al., 2021).

The question here is, why did children with parental schizophrenia experience greater stress, barriers, and grief in response to the hostility and burden expressed by their healthy parents? Although the mechanisms are still unclear, one explanatory framework might be related to the Attribution Theory (Gregg et al., 2021). Attributions mainly refer to the beliefs about the causes and consequences of behavior, and these beliefs are predictive of one's attitudes and behaviors towards others (Gregg et al., 2021). Related literature indicated that parents with high EE are more likely to engage in critical and hostile comments about their children's behavior, thereby increasing the negative atmosphere in the family (Bolton et al., 2003; Fahrer et al., 2022). Based on

Toxic Family Stress models (Peris & Miklowitz, 2015), it can be inferred that the chronic and sustained stress aroused from the negative interactions between parents with schizophrenia and their spouses might have interacted with the psychosocial vulnerabilities of the children living with parental schizophrenia.

While instrumental and emotional needs of offspring were left unseen, offspring tended to silence more and postponed their needs in order to not burden their already overwhelmed parent. The relationship quality between children and affected parents was also compromised due to difficulties related to active psychotic attacks and recurrences. Eventually, offspring reported incidences of neglect and subsequent isolation while conveying their experiences. A comparison of these findings with those of other studies confirms that children living with a family member having schizophrenia are at greater risk of being subjected to maltreatment and other negative parenting practices (Blakeman et al., 2019; Chan & Chau, 2010; Nieto-Rucian & Furness, 2019). Family routines and communication become restrained due to the caregiver burden decreasing the chance of caring for the healthy members of the family (Magliano et al., 2005). Cases of domestic violence were also evident in such families (Kageyama et al., 2015), suggesting that the person with the diagnosis is the victim of violence rather than the perpetrator (Desmarais et al., 2014; Tsigebrhan et al., 2014). Nevertheless, our participants revealed that domestic violence was performed by the parent with psychosis due to the persecutive delusions of the disease. In fact, the impacts of gender roles might be the cause of this difference because our participants generally conveyed their experiences regarding paternal schizophrenia.

Barriers encountered at home not only stemmed from the frustration of the relational and emotional needs of the family members. Instead, such impediments were also exacerbated by the economic deprivation accentuated by the prognosis of parental schizophrenia. As heavily stated in the literature, the onset of the disease usually disrupts the working life of affected parents resulting in lower wages and economic losses (Ranning et al., 2018; Ranning et al., 2016). In our study, all participants with paternal schizophrenia highlighted the economic frustration due to their fathers or husbands having lost their job as a result of the chronic nature of the disease. This finding once again might indicate the differential impacts of gender roles on the financial strain resulting from parental schizophrenia. The father figure is usually the

breadwinner of the family in Turkish culture (Sakallı Uğurlu et al., 2021), consistent with the gender norms imposed by society. Therefore, the diagnosis of paternal schizophrenia might have created a particular risk for the economic conditions of the affected families.

The current study yielded that the troubled relationships with the extended family members exacerbated the already existing impediments experienced by those families at home. Families shied away from their social environment due to the absence of support and the presence of ignoring and rejecting attitudes of close relatives. In-laws either denied the seriousness of the condition or perceived disease-related challenges as normative marital conflicts. They also attributed symptoms to religious and spiritual causes, exacerbating families' sense of not being understood. Thereof, family members felt rejected, helpless, and subsequently isolated from their environments. Consistent with the existing findings in the literature, the instrumental and emotional needs of those parents and offspring remained unmet (Caqueo-Urı´zar & Gutie´rrez-Maldonado, 2006; Gutie´rrez et al., 2005; Leff, 1994; Singhai et al., 2022). In fact, loneliness and isolation have a self-perpetuating nature in the context of schizophrenia (Rocha et al., 2017). As the disease narrows down the social interactions, patients withdraw from their environments, limiting their chance of benefiting from mitigating factors. Their symptoms intensify in the absence of buffering factors, and they become more isolated from their social networks (Gayer-Anderson et al., 2013; Rocha et al., 2017). Nevertheless, it is essential to note that loneliness in schizophrenia is associated with several different level factors, such as low self-esteem, presence of paranoid symptoms, risk of stigmatization, and lack of awareness (Chrostek et al., 2016; Lamster et al., 2017; Rocha et al., 2017).

Developing countries like Turkey usually fail to provide sufficient community mental health resources to families with schizophrenia due to strains on their economies (Lippi, 2016). With the deinstitutionalization movement, governments are obliged to provide community resources to both patients and their families in the management of the disease. Despite this, families with schizophrenia complained about ill-defined health care services. They are not aware of the availability of such services either (Duckworth et al., 2014; Lippi, 2016). Supporting these findings, interviewed families were suffering from a lack of knowledge regarding the nature of

the disease, and they were not aware of community health services. As a result, family-level impediments were magnified, resulting in more intense feelings of helplessness and loneliness. Our participants also reported the unavailability of scientific knowledge even from the doctors during the course of the disease. The confusion and ambiguity around the families increased (Boss, 2000), which exacerbated the barriers that were already existing in the nuclear and extended family context. In addition to having been isolated from the social environment, health policies were also sort of isolating families from society through a lack of scientific debriefing and unavailability of community mental health services aiming to increase the quality of life of families with schizophrenia. Consistent with the previous studies, the present study highlighted the significance of expanding the understanding and awareness to decrease the perceived struggles of other family members without a diagnosis of schizophrenia (Dixon & Lehman, 1995; Fischer et al., 2002; Lippi, 2016; McFarlane et al., 1995). However, deficiency in communication seems to be another dominant barrier both within and outside the family system (Lee et al., 2005).

All in all, the aforementioned impediments taking place in the home environment, in relationships with extended family members, and in the socio-politic system were interdependent influencing and being influenced by each other. Obtained findings showed the impossibility of separating these barriers in evaluating and understanding the impacts of parental schizophrenia.

4.2 The Vicious Circle among Secrecy around the Disease & Stigmatization & Lack of Support Resources

Another key finding of the present study is the operation of a vicious circle of secrecy, stigmatization, and lack of support resources. These triples are nested in the center of the whole experience of having a parent with schizophrenia maintaining and strengthening the interdependent relationships among three types of barriers (i.e., at-home barriers, extended family barriers, and socio-political barriers). In other words, the vicious cycle has shaped the perceptions and experiences of the affected offspring at different levels (e.g., personal, familial, and societal levels).

Our results indicated that unaffected parents were reluctant to inform their children about their spouses' condition for several reasons. Consistent with the literature, they had concerns about the genetic transmission of schizophrenia (Lee et al., 2006; Montersen et al.,1999), and their fear led them to limit disease-related communication with the offspring. It was also observed that healthy parents' fear was exacerbated by their lack of knowledge regarding the etiology and transmission of the disease. They also avoided sharing information to prevent children from being negatively influenced by the parent's psychiatric state. These findings highlighted the importance of increasing families' knowledge and awareness regarding the disease, as stated heavily by the previous studies (Connor et al., 2016; Tamizi et al., 2020). According to existing findings, families with schizophrenia are either unaware of the availability of community health services or experience barriers to accessing such services (Angermayer et al., 2003; Lippi, 2016). They also complained about the lack of state-based support regarding effective and manageable health care services (Angermayer et al., 2003). Devoid of information and community support, they feel alone while dealing with the challenges brought by the disease (Angermayer et al., 2003; Lippi, 2016). At this point, it can be concluded that the secrecy maintained by the healthy parents was reinforced by the lack of knowledge regarding managing the disease and the absence of community resources available to them.

Not surprisingly, interviewed offspring reported their need to know about their parents' condition to decrease ambiguity and unpredictability brought by the disease. Yet, they had their own motivations to sustain their self-silencing behaviors. They did not want to upset the unaffected parent, who was already overwhelmed. They were also afraid of the possible answers they would get and had concerns about not being heard by others. Eventually, all family members felt alone with several questions in their minds due to the lack of communication between each party (i.e., healthy parent, affected parent, and the offspring). This secrecy, in turn, magnified the burden of the existing impediments for each family member. Healthy parents did not know how to provide information about the disease. and offered inconsistent and supernatural (e.g., a parent with a diagnosis is under the influence of a spell and jinn) explanations to their offspring. Hence, secrecy around the disease increased the ambiguities surrounding the families. However, to the authors' knowledge, no study has ever

investigated the impacts of secrecy on the meaning-making process of offspring with parental schizophrenia.

According to our results, another interdependent component that explains the self-perpetuating cycle between secrecy and lack of resources is stigmatization. It was well-established in the literature that families with schizophrenia are subjected to various forms of stigmatization due to the unusual manifestation of the symptoms and so-called violent tendencies of the patients (Koschorke et al., 2017; Wang et al., 2021; Wong et al., 2009). Unfortunately, such discriminative acts were associated with lower quality of life and increased guilt and isolation among affected family members (Catthoor et al., 2015; González-Torres et al., 2007). Our study also supported these findings suggesting that offspring with parental schizophrenia were exposed to stigmatization in various social contexts (e.g., within the nuclear and extended family, in peer relationships) due to the misperceptions and lack of awareness regarding schizophrenia. Exposure to multi-level stigmatization led offspring to assume a distant stance preventing them from sharing their experiences with others. Therefore, consistent with the previous findings, concealment eventuated the feelings of isolation and jeopardized reaching for the possible support resources already scarce (Phelan et al., 1998; Reupert et al., 2021). Societal evaluations of seeking support for mental illnesses seem to be another core theme of discriminative and stigmatizing attitudes among interviewed families. In collectivistic cultures, interdependence and familial support are regarded as important traditions during challenging times (Han & Shavitt, 1994). Despite this, interviewed family members complained about their relatives' excluding attitudes throughout the management of the disease. Consistent with the existing findings, they were surrounded by feelings of worthless, rejection, hopelessness, and helplessness (Kuipers, 1993; Sirey et al., 2001). The interaction between stigmatization and lack of support also reinforced the feelings of exhaustion and anger of the healthy parents leading them to use stigmatizing language towards their affected spouses.

All in all, the absence of support resources and exposure to stigmatization functioned interdependently, exacerbating the perceived burden of the affected families. Lack of knowledge and fear of stigmatization are the core constituents of the whole experience resulting in the concealment of the disease and withdrawal from

social relations. The vicious cycle of secrecy, stigmatization, and absence of support complicated offspring's attributions regarding parental schizophrenia.

4.3 Meaning-making Process

The present study mapped out several barriers beginning with the onset of parental schizophrenia. The distinctive nature, transformative impacts, and discrete visibility of the disease led offspring to be stigmatized and socially excluded. Multi-factorial impediments and unresolved ambiguity around the families increased offspring's need to process and make sense of such experiences. Hence, the current study revealed the meanings of attributions given to parental schizophrenia via the subjective lenses of offspring. Unable to receive consistent and educated answers from parents, relatives, and the health care system, offspring in our study ended up with conclusions through engaging in maladaptive attributions (e.g., blaming, avoidance, denial, withdrawal, and comparison with others) regarding the cause, prognosis, and implications of the disease. Besides, exposure to stigma also disrupted their meaning-making process through the infliction of helplessness and self-blame.

Narratives of offspring reflected their search for an explanatory framework on the causes of parental disease and amelioration of their family's circumstances. Offspring's tendency to blame emerged as two-sided (i.e., accusing the affected parent for not fighting to reverse the situation, and blaming the healthy parent and close relatives for destroying the hope they needed as a child). Unable to reach reliable information, they momentarily channelized their anger to the affected parent perceived as responsible from the burden and stigmatization. In turn, offspring suffered from difficulties with their emotion regulation skills evaluating their experiences as worse than the others from similar backgrounds. Over time, the offspring's tendency to blame turned inwards and demonstrated itself with guilt due to the failure of early intervention to parents' symptoms. These results corroborate the findings of a great deal of the previous work in expressed emotion literature among families with schizophrenia. As mentioned, EE was initially developed to assess the emotional exchanges among family members with schizophrenia (Amaresha & Venkatasubramanian, 2012; Barrowclougha & Hooley, 2003). According to Attributional Model, EE basically comprises family members' efforts to bring

explanations regarding the causes, prognosis and outcomes of the disease (Barrowclougha & Hooley, 2003). Low EE individuals tend to views symptoms and problematic behaviors as part of a disorder and come up with adaptive explanatory frameworks. By contrast, high EE individuals try to exert control over the situation through changing the patient instead of legitimizating the symptoms and searching for available sources (Vasconcelos et al., 2013). Consequently, they display hostility, criticsm and overinvolvement throughout the management of the disease (Barrowclougha & Hooley, 2003; Amaresha & Venkatasubramanian, 2012).

It was well-established in the literature that family members are more likely to engage in EE in the presence of high anxiety and caregiver burden (Barrowclougha & Hooley, 2003; Vasconcelos et al., 2013). Although existing findings are largely based on perceptions of spousal and parental caregivers, similar attributional styles also emerged in the current study for the offspring with parental schizophrenia. According to the Locus of Control Model (Rotter, 1954), individuals low on internal locus of control (ILC) believed that their efforts would be unsuccessful in exerting control over a challenging situation and believed the consequences of the events are determined by external agents who hold the power (Vasconcelos et al., 2013). Accordingly, low ILC has been found to be associated with high EE among families with schizophrenia (Bentsen et al., 2011; Vasconcelos et al., 2013). Supporting this, our findings revealed that offspring waxed and waned between adaptive and maladaptive attribution styles. Neither professionals nor other adult family members offered consistent age-appropriate explanations to the offspring with regard to parental schizophrenia. Therefore, offspring's hopelessness and blaming attitudes might be accounted for by the lowered locus of control due to lack of information, absence of available resources, and the presence of stigmatization. However, a note to caution is due here. Offspring were still much more flexible in their attributions regarding their parents' mental illness. Compared with healthy parents, they were more compassionate and empathetic towards the affected parent indicating the importance of child and adolescent-focused intervention programs aiming to spread awareness regarding parental symptoms.

Childhood is a period where offspring construct representations about self, others, and the world through interacting with others (Eccles, 1999). However, children in the present study were left all alone in their efforts to make sense of their

experiences. They only reached conclusions through comparing their parents with those of peers' and tried to view parents' symptoms as ordinary deviations. To be specific, they tended to normalize their affected parent's symptoms to handle several ambiguities surrounding their families. All human beings are in need of control and predictability in their lives (Affleck et al., 1987; Prenda & Lachman, 2001). Yet, this need might be much more pronounced for children and adolescents as their belief systems are not well-established yet (Ollendick et al., 2014). Thus, more research seems necessary to understand children's unique developmental needs with regard to comprehension of disease-related difficulties in order to inform possible psychosocial intervention programs.

To sum up, the current study is one of the first studies which particularly focused on the meaning-making processes of children with parental schizophrenia. Hence, the building blocks of this component once again revealed the significance of awareness and knowledge regarding schizophrenia. Offspring were waxing and waning with possible scenarios to base their experiences on because they have been simultaneously exposed to several impediments operating at different levels (e.g., absence of support resources, discrimination, and lack of knowledge about the disease).

4.4 Parentification & Ambiguous Losses and Grief

Obtained findings together indicated two interrelated psychosocial outcomes in relation to the role reversals and subsequent losses. Accordingly, parentification and ambiguous losses and grief emerged as the main outcomes of the current study. While these outcomes show similarities with the previous studies inquiring about parental mental illnesses (Mechling et al., 2018; Mechling, 2016; Misrachi, 2012), the current study differentiates itself by specifically focusing on offspring's experiences in the context of parental schizophrenia.

The scarcity of internal and external resources shaped the meaning-making process and coping strategies of the target offspring. Manifestation of interdependent barriers through the operations of secrecy, stigmatization, and unavailability of resources led them to find their own ways to handle disease-related difficulties. Amongst others, the need to be informed and assisted by a reliable source was manifested as the most pressing concern due to several ambiguities surrounding

families. Hence, offspring neither had sufficient information regarding the management of the disease nor were provided emotional and instrumental support by informal networks. Eventually, they started to assume age-inappropriate responsibilities within the family system while simultaneously coping with the invisible losses stemming from the nature of the disease.

4.4.1 Parentification

Parentification was explained by Jurkovic (1997) as a two-sided concept including instrumental and emotional domains (Jurkovic, 1997). Instrumental parentification is described as children' undertaking functional tasks (e.g., making money, handling household chores, taking care of their siblings etc.) that are disproportionate to their developmental stages. Emotional parentification, on the other hand, refers to the tendency of children to compensate for the emotional or psychological needs of their parents (Boszormenyi-Nagy & Spark, 1984).

The findings of the current study revealed several similarities with the existing literature investigating parentification and its influences on children's well-being. Previous research has pointed out that children with parental psychopathology (e.g., depression, Alzheimer's disease, etc.) are at greater risk of parentification (Svanberg et al., 2010; Van Loon et al., 2017); due to the psychological unavailability of the parents and disruptions in the family system (Backer et al., 2016; Brankin, 2015; Earley & Cushway, 2002; Macfie et al., 2005). However, studies specifically sampling offspring with parental schizophrenia are quite limited.

The chronicity and unpredictability of the disease resulted in a significant caregiver burden among family members with schizophrenia. Caregiver roles and duties depleted the already limited resources of the family members leaving no energy for other caring tasks (Arun et al., 2018; De Haan et al., 2004; Jungbauer et al., 2004). Consistent with these findings, interviewed children in our study reported assuming age-inappropriate responsibilities (e.g., monitoring medication adherence, working outside the family, negotiating the conflicts between parents) because their unaffected parents had been already overwhelmed by the caregiving responsibilities. Lack of support resources (Lee & Seo, 2020) and presence of stigmatization (Gonzales et al., 2018) together might also have pushed these children to perform adult like tasks to

maintain family functioning. Supporting our findings, a growing body of evidence pointed out to the loneliness and isolation experienced by patients with schizophrenia and their family members due to being marginalized by the society (Gonzales et al., 2018). In turn, affected families further withdraw from the social environments as a self-defense decreasing their chances of receiving the formal and informal care that is already limited (Lee & Seo, 2020; Xanthopoulou et al., 2022). Thus, the conjoint effect of fear of stigmatization, unavailability of the resources and social exclusion might explain why the offspring in our study had undertaken the unfulfilled roles and duties that were expected to be performed by adults. According to existing research, parentification developed either through the transference of the responsibilities from the parent to the children or offspring internalizing these responsibilities or both (Aldridge, 2006; Mechling, 2011). However, our participants' parentification experiences might not be accounted only by the combination of these pathways. Since the system itself prevented these families from accessing to formal and informal support resources (Xanthopoulou et al., 2022), children might have been involuntarily parentified to manage disease-related difficulties all by alone.

In conclusion, offspring with parental schizophrenia not only suffered from disease-related challenges but also due to deprivations of instrumental, informational, social, and emotional needs. They referred to their experiences as sustainment of ongoing efforts for compensating for these deprivations. Barnett and Parker (1998) defined one of the motivations behind assuming such responsibilities and providing care to others as a way to form a sense of relatedness (Barnett & Parker, 1998). In that regard, not only missed childhood but also losses associated with the involuntary entry into adulthood seem to have converged with the grief experiences of children as the parents became psychologically absent as a result of pervasive neurological destruction.

4.4.2. Ambiguous Losses and Unresolved Grief

Boss (1999) defined ambiguous loss as "an incomplete, uncertain loss of a loved one, where ambiguity interferes with meaning-making, causing lack of resolution" (p.3). There are two types of ambiguous loss (e.g., physical and psychological), and the psychological type is relevant to the present study (Boss & Harris, 2021). A loved

one is present physically but absent psychologically, converging with the manifestation of schizophrenia. In that regard, the current study is one of the first to focus on the ambiguous loss experiences of offspring with parental schizophrenia. Despite stating the relevance of ambiguous loss theory in severe mental illnesses (Hasbun, 2019; Mechling et al., 2018; Ormandy, 2020), it is interesting that schizophrenia is rarely studied. As the findings of the current study and literature have suggested (Betz & Thorngren, 2006; Craig & Moore, 2019), the isolation of these families from the social context might have resulted in the invisibility of ambiguous loss experiences of offspring with parental schizophrenia. Existing studies mainly referred to the ambiguous loss experiences of families with Alzheimer's disease, addiction, immigration, and foster care abandonment (Cutillo-Schmitter, 1996; Dupuis, 2002; Frank, 2008; Landau & Hissett, 2008; Mitchell, 2016). By contrast, family members with schizophrenia have usually been researched from a caregiver burden perspective (Hsiao et al., 2020; Shiraishi & Reilly, 2019).

Findings of the current study revealed that offspring grieved not only for their missed childhood but also for the loss of the old, conventional family and parental interactions (i.e., intimacy, support, togetherness, having a cup of coffee together, etc.). Offspring's grief reactions were exacerbated by ongoing uncertainties due to the unpredictable nature of the disease leading to further confusion and isolation in our families. Supporting this, existing literature also documented the disruptive effect of schizophrenia on family arrangements, roles, and boundaries (Awad & Voruganti, 2008; Madianos & Economou, 1994; Teschinsky, 2000). This might be why "longing for normality" was one of the most repeated themes of ongoing grief experiences of the interviewed children. Despite the fact that the parent with schizophrenia was alive, offspring conveyed their experiences by utilizing a language as if their parents had already died, evidencing the discourse of psychological absence. At the same time, they referred to their affected parents by expressing compassion which reflected the confusion stemming from the physical presence of the affected parent. Such two-sidedness in the language was interpreted as one of the target families' root causes of confusion and immobility. Boss (2000) also associated this double limbo with the freeze of the grief process (Boss, 2000), accounting for the helplessness explained by the offspring in the current study. Some offspring stated thoughts regarding the

possible death of their affected parents and felt unsure about their reaction when the day has come. In other words, unresolved grief comes into prominence in offspring's lives. As it was previously explained in the meaning-making process, the offspring's need for cognitive and emotional attributions was prevented through operations of psychological, familial, and political barriers. Supporting these, existing studies have touched upon the importance of increasing awareness and knowledge to not only clarify the uncertain losses but also to integrate them into the survivors' narratives through re-interpretation (Boss, 2006; Markell & Hoover, 2010).

In collaboration with the previous findings (Badcock et al., 2020; Krupchanka et al., 2016; van der Sanden et al., 2014), interviewed families expressed their loneliness due to being excluded from formal and informal support networks. This isolation seems to hinder their meaning-making process about the losses they experienced. Meaning-making in response to adverse events like death has a central role in adaptation to the losses (Neimeyer, 2000). However, outcomes of meaning-making are two-sided because not every meaning established eases pain and distress (Park, 2010). Accordingly, the meaning-making efforts of the affected offspring seem to be hindered by secrecy, stigmatization, and lack of support resources. They tended to establish a framework through comparing their parents with those of their friends and based on the inconsistent information provided by the family members and health care professionals. Yet, these efforts further intensified their sorrow and envy. Besides, magical thinking was obtained as one strategy to cope with the ambiguous loss-related outcomes by the current study. Magical thinking was defined as a way to increase control over challenging events and it is usually adopted when one is struggling with limited knowledge and the motivation to establish an explanatory framework (Brewin, 1988; Friedland & Keinan, 1991). Existing studies proposed that the adoption of magical thinking is associated with less psychological stress but a greater sense of control (Fisher, 1986; Lazarus & Folkman, 1984). The proposed manifestation of magical thinking was also employed by the interviewed offspring with parental schizophrenia. The psychological absence of the affected parents in the conventional sense negatively influenced the psychological well-being of the offspring. Hence, they created an imaginary parental figure to cope with not only the psychological absence

of the parent but also with their negative feelings. The creation of such a symbolic figure also decreased their chances of being exposed to stigmatization by their peers.

Finally, the political barriers with regard to accessing community mental health resources prevented offspring from engaging in adaptive re-framing. Although existing research documented families' insufficient access to community mental health resources (Tristiana et al., 2018; Berry & Haddock, 2008), to the authors' knowledge, our study is the first that documents the contributing role of socio-political factors on the meaning-making efforts of children while dealing with uncertain losses brought by parental schizophrenia.

4.5 Psychosocial and Clinical Implications of the Study

To the author's knowledge, the current study is the first qualitative research that attempted to discover the ambiguous loss experiences of offspring with parental schizophrenia in Turkey. The findings of the current study shed light on the interdependent relations among psychological, social, and political dynamics that shaped the functioning of families and offspring with parental schizophrenia. Hence, there emerged an immediate need to eliminate the psychological and social impediments surrounding the target population to increase adaptive functioning and combat with debilitating impacts of parentification and unresolved grief.

Psychosocial implications start with the necessity of providing consistent scientific knowledge to increase awareness about schizophrenia both for nuclear family members and society in general. Our participants' accounts indicated that even mental health professionals did not provide sufficient information about the nature and psychosocial management of schizophrenia. Offspring and unaffected parents were left on their own to handle disease-related difficulties without formal assistance. Therefore, systematic delivery of such information and assistance through community mental services seems to be the most prominent issue to be addressed by governmental policies. Psychoeducation programs might also be implemented in different public settings (e.g. schools and public health centers) to increase the visibility of the disease and to address the psychosocial needs of the affected families. In turn, stigmatization can also be prevented to some extent through delivery of knowledge and direct contact

with such families. In fact, training aiming to increase knowledge and awareness about schizophrenia would not only be advantageous for family members but also for outsiders. Such interventions will provide an opportunity for all to interact with each other which might be helpful in eliminating the prejudices against these families.

Lack of arrangements and limitation of health services both created and reinforced the impediments surrounding the family members with schizophrenia. One of these arrangements that need to be improved by state-based policies is the disability retirement subject in Turkey. Due to the disease, the working life of affected parents comes to an end. The wages of disability retirement are inadequate to cover both the family expenses and the costs of reaching and benefiting from health care services. Hence, offspring are getting a job by putting their own academic priorities behind starting from early ages. Financial support policies for people with disabilities have to be considered and rearranged. Supporting such families both psychologically and financially might decrease the excessive responsibilities undertaken by offspring who have been already facing with multilevel impediments (e.g. lack of parental affection, lack of support). Hence, as the present study reflected the interrelatedness among impediments, psychoeducation and interventions programs should be implemented together with better policies about mental health services and development of national campaigns to combat misconceptions and discriminative acts.

The current study also provided valuable insights with regard to psychological processes underlying ambiguous loss experiences of children with parental schizophrenia. In that regard, the experience of uncertain losses and unresolved grief in several domains (e.g., loss of normalcy, childhood, affection with parental figures, etc.) is suggested to be worked by mental health professionals through the integration of the meaning-making component. Boss (2000) also referred to the importance of communication and dialectic thinking to decrease psychological distress caused by never-ending ambiguities (Boss, 2000). Yet, children are left alone in their meaning-making efforts due to the secrecy around the disease and not seeking informal help. Our findings also revealed the employment of maladaptive mechanisms such as denial, ignorance, and blaming among affected offspring. Since the present study revealed apparent secrecy and lack of communication among target family members in addition to the difficulties caused by these shortcomings, the importance of providing

information, especially to the unaffected/healthy parent should be considered by professionals. Starting from the nature of the disease and ways to cope with disease-related experiences to the significance of possible sharings with children. Professionals might also offer support in order to create a bridge between the expectancies of both healthy parents and offspring to enhance the adaptive functioning of each party regarding spousal and parental schizophrenia. At the same time, paying attention to the nature of such relations regarding the developmental period of offspring should be observed and intervened, when necessary, by professionals. In that regard, with the empowerment of healthy parents, meaning making processes of children also might be facilitated. Besides, those services might also be reinforced by providing brochures that are informative and awareness-raising regarding schizophrenia in mental health centers and other social areas.

Accordingly, clinicians should refer to the interrelation among the personal, social, and political dynamics to decrease self-stigmatization and self-accusations. Such a perspective evaluating not only the personal but also societal dynamics might enhance communication and might result in an adaptive meaning-making process while working with unresolved grief in the context of parental schizophrenia.

4.6 Limitations and Directions for Future Research

The present study has some limitations which might have had influences to some extent on the nature of the obtained data and the proposed theory at the end. First of all, the number of participants is limited to ten individuals in total, including eight offspring with parental schizophrenia and two mothers with spousal schizophrenia. Although the current study meets with the standards of the grounded theory approach regarding the minimum expected number of participants in a study. Future studies might be conducted with larger populations especially with offspring to understand and reveal the functioning of parental schizophrenia in a deeper and more comprehensive manner. Besides, each participant was interviewed only once. Despite the repetition of obtained data at its core as the research process continued, some of the participants might have needed to involve interviewing process more than once. Moreover, some of the participants defined their experience as the first time they are talking about their parents' disease which might also influence the nature of obtained results. Hence, further studies should be considering such effects in the arrangement

of interviews. Secondly, the age interval of the offspring in the present was kept wider due to the difficulties in reaching out to the offspring with parental schizophrenia and the time constraint. Hence, data was shaped more retrospectively in its nature. In that regard, future studies should be formed by considering the age range accordingly in order to discover differences and similarities in offspring's experiences by including prospective data if it is necessary. Besides, the present study aimed to discover and understand the experiences of individuals with parental schizophrenia at its core, multi-dimensionally. Hence, findings revealed themselves explanatorily. However, there are still unseen components regarding the effects of having a parent with schizophrenia on the offspring's inner world. For example, the functioning and meaning behind the defense mechanisms of offspring; how parental psychosis influences offspring in a deeper manner; how attributions of offspring shape the sense of self and flow of loss and grief, etc. Future studies might be designed by aiming to catch dynamics in the inside world of the offspring rather than the outside surroundings. Finally, the current study mostly included offspring with paternal schizophrenia unintentionally. As societal gender norms are affecting the family dynamics, maternal schizophrenia might reveal different outcomes in that regard. Therefore, future studies can be conducted by increasing the number of offspring with maternal schizophrenia as well.

Since the present study is the first which conducted in Turkey regarding parental schizophrenia, the established theory at the end can be improved via the considerations and implementations of the aforementioned limitations and suggestions in the future.

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APPENDIX B: INFORMED CONSENT FORM FOR ADULT OFFSPRING

2009
Psikoloji Bölümü
Department of Psychology

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TEDU UNIVERSITY
06420 ANKARA-TURKEY

Sayın Katılımcı,

Bu araştırma, TED Üniversitesi Psikoloji Bölümü, Gelişim Odaklı Klinik Çocuk ve Ergen Psikolojisi Yüksek Lisans programı öğrencisi İlayda Arkan tarafından Dr. Öğr. Üyesi Yağmur Ar-Karcı danışmanlığında yürütülmektedir. Araştırmanın amacı anne ya da babası **şizofreni tanısı almış çocukların psikolojik, sosyal ve ailesel bağlamdaki yaşantılarını anlamaktır.** Bu çalışmanın katılımcılarını anne ya da babası şizofreni tanısı almış 13-17 yaşları arasında olan ergenler, aile üyeleri ve ebeveyni şizofreni tanısı almış yetişkinler oluşturmaktadır.

Bu araştırmaya katılımınızı onayladığınız takdirde, projenin katılımcısı olacaksınız. Katılımcılar ile yaklaşık 1-1.5 saat sürecek görüşmeler yapılacak olup bu görüşmeler ses kayıt cihazı ile kayıt altına alınacaktır. Görüşmeler sırasında size, şizofreni tanısı almış ebeveyniniz ve bu hastalığın aileniz üzerindeki etkilerini anlamayı amaçlayan bazı açık uçlu sorular sorulacaktır. **Araştırmada size yöneltilen soruların DOĞRU ya da YANLIŞ cevapları yoktur**, bu nedenle soruları içtenlikle cevaplamanız araştırmanın sonuçları açısından önemlidir. Çalışma süresince ve sonrasında kimlik bilgileriniz proje dışındaki hiç kimseyle izniniz dışında paylaşılmayacaktır. Bu çalışma kapsamında elde edilecek olan bilimsel bilgiler sadece araştırmacılar tarafından yapılan bilimsel yayınlarda, sunumlarda ve eğitim amaçlı çevrimiçi bir ortamda paylaşılacaktır. Toplanan verilerden isminiz silinerek, bilgisayarda şifreli bir dosyada tutulacaktır. Görüşmeler sizin uygun gördüğünüz ve gizliliğin korunabileceği bir ortamda veya yine sizin tercihinize bağlı olarak çevrimiçi platformlarda gerçekleştirilecektir.

Bu çalışmaya katılım gönüllük esasına dayalıdır. Görüşmede tarafınıza yöneltilecek sorular kişisel rahatsızlık verecek nitelikte değildir. Ancak herhangi bir nedenden ötürü kendinizi rahatsız hissederseniz, görüşmeyi nedenini açıklamaksızın yarıda bırakmakta serbestsiniz. Böyle bir durumda vermiş olduğunuz bilgilerin araştırmacı tarafından kullanılması ancak sizin onayınızla mümkün olacaktır. Bu çalışmaya katıldığınız için şimdiden teşekkür ederim. Çalışma hakkında daha fazla bilgi almak ve yanıtlanmasını istediğiniz sorularınız için araştırmayı yürüten İlayda Arkan ve Yağmur Ar-Karcı ( ) ile iletişim kurabilirsiniz.

Bu çalışmaya tamamen gönüllü olarak katılıyorum ve istediğim zaman yarıda kesip ayrılabileceğimi biliyorum. Bu proje kapsamında görüşmelerin kayıt altına alınmasını ve verdiğim bilgilerin bilimsel amaçlı yayımlarda kullanılmasını kabul ediyorum.

Projeye katılmak istiyorum Evet / Hayır

Ad Soyad:

Katılımcının İmzası: .....

Tarih .....

Araştırmacının Adı, Soyadı ve İmzası
İlayda Arkan

Araştırmaya katılımınız ve haklarınızın korunmasına yönelik sorularınız varsa ya da herhangi bir şekilde risk altında olduğunuza veya strese maruz kalacağına inanıyorsanız TED Üniversitesi İnsan Araştırmaları Etik Kurulu'na telefon numarasından veya eposta adresinden ulaşabilirsiniz.

APPENDIX C: PARENT CONSENT FORM

Sayın Veli,

Bu çalışma TED Üniversitesi, Gelişim Odaklı Klinik Çocuk ve Ergen Psikolojisi Yüksek Lisans Programı'nda öğrenci olan İlayda Arkan tarafından, Yağmur Ar-Karcı danışmanlığında yürütülen bir tez çalışmasıdır.

Yapılacak olan bu çalışmanın amacı kronik ebeveyn psikopatolojisinin çocuğun psikososyal gelişim öyküsündeki yerini detaylı bir biçimde irdelemek ve anlamaktır. Bu araştırmaya katılımını onayladığınız taktirde, çocuğunuzla yarı-yapılandırılmış bir görüşme gerçekleştirilecektir. Görüşme yaklaşık bir- bir buçuk saat sürecek olup, yapılan görüşme ses kayıt cihazı ile kayıt altına alınacaktır. Görüşmeler sırasında çocuğunuza ebeveyninin hastalığının aileniz üzerindeki etkilerini anlamayı hedefleyen birtakım açık uçlu sorular sorulacaktır. Bu görüşmeler sadece eğitim amaçlı kullanılacak olup, ses kaydı ve görüşmelerin yazılı hali bilgisayar ortamında şifre ile saklanacaktır. Çalışmaya katılım sağlamak istediğiniz takdirde, görüşmeler sizin ve çocuğunuzun uygun gördüğü sakin ve gizliliğin korunmasının mümkün olduğu bir ortamda veya yine tercihinize bağlı olarak çevrimiçi platformlarda gerçekleştirilecektir. Ayrıca, saklanılan verilerde çocuğunuz ya da size ait kimlik belirtici hiçbir bilgi yer almayacaktır. **Araştırma sırasında çocuğunuza yöneltilecek soruların DOĞRU ya da YANLIŞ cevapları yoktur.** Bu nedenle çalışmaya katılan çocuklardan sorulan sorulara içtenlikle yanıt vermesi istenecektir. Çalışmaya katılım gönüllülük esasına dayalıdır. Görüşme sırasında aktarılacak sorular çocuğunuza rahatsızlık verecek nitelikte olmamakla birlikte, herhangi bir nedenden ötürü çocuğunuz ya da siz rahatsızlık hissederseniz, nedenini açıklamaksızın çalışmadan ayrılma hakkına sahipsiniz.

Çocuğunuz ile görüşmeyi gerçekleştirebilmemiz için gerekli olan önemli bir kriter çocuğunuzun ebeveyninin hastalığı ile ilgili bilgiye sahip olmasıdır. **Bu noktada, çocuğunuzun en azından ebeveyninin tedavi gerektiren bir psikolojik problemi olduğunu bilmesi gerekmektedir**.

Bu çalışma kapsamında elde edilecek olan bilimsel bilgiler, sadece araştırmacılar tarafından yapılan bilimsel yayınlarda, sunumlarda ve eğitim amaçlı kullanılacaktır. Çalışma süresince sizin ve çocuğunuzun kimlik bilgisi araştırma ekibi dışındaki hiç kimseyle izniniz dışında paylaşılmayacaktır. Süreç içerisinde çocuğunuzun ve sizin paylaştığınız bilgiler de kesinlikle gizli tutulacak ve sadece araştırmacılar tarafından değerlendirilecektir. Çalışma sırasında çocuğunuzun ve sizin vermiş olduğunuz bilgilerin araştırmacı tarafından kullanılması ancak çocuğunuzun ve sizin onayınızla mümkün olacaktır. Bu çalışmaya katıldığınız için şimdiden teşekkür ederim. Çalışma hakkında daha fazla bilgi almak ve yanıtlanmasını istediğiniz sorularınız için aşağıda yer alan iletişim kanalları aracılığıyla bana ulaşabilirsiniz.

Yukarıda açıklamasını okuduğum çalışmaya, velisi olduğum _____'nin katılımına izin veriyorum. Araştırmacılar tarafından çalışma hakkında yeterince bilgilendirildim. Bu çalışmaya çocuğumun katılmasına, görüşme boyunca ses kaydı alınmasına izin veriyorum. Çocuğumun, istediği zaman bu çalışmadan ayrılabileceğini ve araştırma süresince elde edilen bilimsel bilgilerin bilimsel makaleler ve akademik sunumlar dışında kesinlikle kullanılmayacağını biliyorum. Ayrıca, çocuğumun eşimin hastalığı ile ilgili bilgi sahibi olduğunu onaylıyorum.

Velinin Adı, soyadı: _____

İmzası: _____ Tarih:

Teşekkürler,

İlayda Arkan.

İletişim:

E-posta:

Çocuğunuzun katılımı ya da haklarının korunmasına yönelik sorularınız varsa ya da çocuğunuzun herhangi bir şekilde risk altında olabileceğine, strese maruz kalacağına inanıyorsanız TED Üniversitesi İnsan Araştırmaları Etik Kurulu'na telefon numarasından veya eposta adresinden ulaşabilirsiniz.

APPENDIX D: INFORMED CONSENT FORM FOR THE MINOR OFFSPRING

Sevgili Genç,

İsmim İlayda Arkan. Tez danışmanım Yağmur Ar-Karcı ile birlikte ebeveynleri psikolojik olarak problemler yaşayan çocukların yaşadıklarını anlamaya çalıştığımız bir araştırma yürütüyoruz. Bugün, bu araştırma hakkında seni bilgilendirmek ve onayını almak için beraberiz.

Bize Nasıl Yardımcı Olabilirsin?

Bu çalışma kapsamında senin gibi gençlerin neler yaşadığını daha iyi anlayabilmek için yaklaşık 1-1.5 saat süren görüşmeler gerçekleştiriyoruz. Bu görüşmelerde sana kendinle, ailenle ve ebeveyninin psikolojik durumu ile ilgili bazı sorular soracağız. Bu soruların DOĞRU YA DA YANLIŞ cevapları yok. Senden istediğimiz bu görüşmelere katılarak, sorduğumuz sorulara kendini düşünerek yanıt vermen. Anlattıklarını kaçırmamak ve iyi analiz edebilmek için bu görüşmeler sırasında ses kaydı almayı istiyoruz. Ses kaydını sen bu forma sözel ve yazılı olarak onay verdikten sonra başlatacağız.

Bu Görüşmeler Sonucunda Neyi Hedefliyoruz?

Bu görüşmelerden elde edilen bilgilerle, seninle benzer bir aile yaşantısı olan çocukların yaşadıklarını ve ihtiyaçlarını daha iyi anlamayı ve bunu bilimsel olarak paylaşmayı istiyoruz.

Benim Kim Olduğumu Başkalarının Bilme Şansı var mı?

Hayır, senin bize sağladığın bilgileri analiz ederken adın-soyadın ya da kimliğinle ilgili tüm bilgileri siliyor ve bir başkasıyla paylaşmıyor olacağız. Sen, ailen ve biz araştırmacılar haricinde bu bilgilerin sana ait olduğunu hiç kimse bilmeyecek.

Görüşmeyi Yarıda Bırakabilir miyim?

Sorularımızı seni rahatsız etmeyecek şekilde hazırlamaya özen gösterdik. Ama yine de, herhangi bir sebepten, görüşmeye devam etmek istemezsen bunu bana söyleyebilirsin ve bu durumda görüşmemizi sonlandırırız. Eğer görüşmeyi tamamlamak istemezsen, senin onayın olmadan senin verdiğin bilgileri kullanamayacağımı da hatırlatmak isterim.

Soru Sorma Hakkım Var mı?

Tabii ki, araştırma öncesinde, sırasında ve sonrasında merak ettiğin ya da anlamadığın şeyleri bana sorabilirsin. Sorularına elimden geldiğince yanıt vermeye çalışacağım.

Bu Çalışmayı Katılmayı Reddedebilir miyim?

Senin bize vereceğin bilgileri araştırmamız için çok kıymetli bulmakla beraber, bu görüşmelere katılmayı reddedebilirsin. Senin onayın olmadan görüşmeleri gerçekleştirmemiz mümkün değil.

Şimdi lütfen sana verdiğimiz bilgileri değerlendirerek bizi görüşmeye katılım kararın hakkında bilgilendir.

Bu araştırma konusunda bilgilendirildim. Evet _____ Hayır _____
Görüşmelere katılmak istiyorum. Evet _____ Hayır _____
Görüşmeler sırasında ses kaydımın alınmasına izin veriyorum. Evet _____ Hayır _____

APPENDIX E: INFORMED CONSENT FORM FOR THE UNAFFECTED PARENTS

2009
Psikoloji Bölümü
Department of Psychology

TED ÜNİVERSİTESİ
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Sayın Katılımcı,

Bu araştırma, TED Üniversitesi Psikoloji Bölümü, Gelişim Odaklı Klinik Çocuk ve Ergen Psikolojisi Yüksek Lisans programı öğrencisi İlayda Arkan tarafından Dr. Öğr. Üyesi Yağmur Ar-Karcı danışmanlığında yürütülmektedir. Araştırmanın amacı **ebeveyni şizofreni tanısı almış çocukların psikolojik, sosyal ve ailesel bağlamdaki yaşantılarının derinlemesine incelenmesidir.** Bu çalışmanın katılımcılarını anne ya da babası şizofreni tanısı almış 13-17 yaşları arasında olan ergenler, aile üyeleri ve ebeveyni şizofreni tanısı almış yetişkinler oluşturmaktadır.

Bu araştırmaya katılımınızı onayladığınız takdirde, projenin katılımcısı olacaksınız. Katılımcılar ile yaklaşık 1-1.5 saat aralığında sürecek görüşmeler yapılacak olup bu görüşmeler ses kayıt cihazı ile kayıt altına alınacaktır. Görüşmeler sırasında size, şizofreni tanısı almış bir ebeveyne sahip olmanın çocuğunuzun psikososyal gelişimi üzerindeki etkilerini anlamayı hedefleyen birtakım sorular sorulacaktır. **Araştırmada size yöneltilen soruların DOĞRU ya da YANLIŞ cevapları yoktur**, bu nedenle soruları içtenlikle cevaplamanız araştırmanın sonuçları açısından önemlidir. Çalışma süresince ve sonrasında kimlik bilgileriniz proje dışındaki hiç kimseyle izniniz dışında paylaşılmayacaktır. Bu çalışma kapsamında elde edilecek olan bilimsel bilgiler sadece araştırmacılar tarafından yapılan bilimsel yayınlarda, sunumlarda ve eğitim amaçlı çevrimiçi bir ortamda paylaşılacaktır. Toplanan verilerden isminiz silinerek, bilgisayarda şifreli bir dosyada tutulacaktır. Görüşmeler sizin ve ailenizin uygun gördüğü ve gizliliğin korunabileceği bir ortamda veya yine sizin tercihinize bağlı olarak çevrimiçi platformlarda gerçekleştirilecektir.

Bu çalışmaya katılım gönüllük esasına dayalıdır. Görüşmede tarafınıza yöneltilecek sorular kişisel rahatsızlık verecek nitelikte değildir. Ancak herhangi bir nedenden ötürü kendinizi rahatsız hissederseniz, görüşmeyi nedenini açıklamaksızın yarıda bırakmakta serbestsiniz. Böyle bir durumda vermiş olduğunuz bilgilerin araştırmacı tarafından kullanılması ancak sizin onayınızla mümkün olacaktır. Bu çalışmaya katıldığınız için şimdiden teşekkür ederim. Çalışma hakkında daha fazla bilgi almak ve yanıtlanmasını istediğiniz sorularınız için araştırmayı yürüten İlayda Arkan ve Yağmur Ar-Karcı ile iletişim kurabilirsiniz.

Bu çalışmaya tamamen gönüllü olarak katılıyorum ve istediğim zaman yarıda kesip ayrılabilceğimi biliyorum. Bu proje kapsamında görüşmelerin kayıt altına alınmasını ve verdiğim bilgilerin bilimsel amaçlı yayımlarda kullanılmasını kabul ediyorum.

Projeye katılmak istiyorum Evet / Hayır

Ad Soyad:

Katılımcının İmzası: .....

Tarih .....

Araştırmacının Adı, Soyadı ve İmzası
İlayda Arkan

Araştırmaya katılımınız ve haklarınızın korunmasına yönelik sorularınız varsa ya da herhangi bir şekilde risk altında olduğunuza veya strese maruz kalacağına inanıyorsanız TED Üniversitesi İnsan Araştırmaları Etik Kurulu'na telefon numarasından veya eposta adresinden ulaşabilirsiniz.

APPENDIX F: SEMI-STRUCTURED INTERVIEW QUESTIONS FOR ADULT OFFSPRING

1. Sizi tanımak isterim. Bana biraz kendinizden bahseder misiniz?
2. Anne ve babanız nasıl kişilerdir? Biraz anlatır mısınız? Anne/babanızla olan ilişkiniz nasıldır? Anne/babanızla vaktinizi nasıl değerlendirirsiniz? Nelerden konuşursunuz, neler yaparsınız?
3. Daha önce de size kısaca bahsettiğim gibi bugün anne/babanızın (hangi ebeveyn hastaysa ona işaret edilecek) hastalığıyla ilgili sizden biraz bilgi almak istiyorum.
    a. Anne/babanızın durumunu ilk nasıl öğrendiniz?
    b. Öğrendiğinizde neler hissettiniz/düşündünüz?
    c. Nasıl bir tedavi süreci oldu, tedaviye erişiminiz kolay oldu mu? Hastalıkla ilgili bilgilere, destek grupları… Bu hastalığa sahip kişiler ve ailelerinin tedavi/sosyal destek/… erişimi…
    d. Anne/babanızın şu anki durumu sizce nasıl?
4. Sizce anne/babanızın hastalığı sizi ne şekilde etkiledi/etkiliyor? Peki bu hastalıkla ilgili aklınıza gelen sizin için önemli bir anıyı paylaşabilir misiniz?
    a. Bu durumla ilgili neler hissediyorsunuz? / Neler düşünüyorsunuz?
    b. Annen/babanızın bu hastalıkla ilgili problemleri arttığında neler yapıyorsunuz? / Bu dönemde ne gibi sorumluluklarınız oluyor? / Anne/babanıza nasıl davranıyorsunuz? Sizi ve ailenizi nasıl etkiledi?
    c. Anne/babanızın yaşadığı hastalıkla birlikte onunla ilişkilerinizde bir değişim oldu mu? Şu anda ilişkinizi nasıl tanımlarsınız?
    d. Anne/babanızın hastanede kalması gerektiği zamanlar oldu mu? Olduysa; o zamanlarda neler hissederdiniz? Neler yapardınız (bekler miydiniz)? Onu düşünür müydünüz (evetse ne şekilde)?
    e. Anne/babanızın hastalığıyla ilgili sizi endişelendiren/korkutan şeyler olmuş muydu? Şu an için sizi anne/babanızın hastalığıyla ilgili sizi endişelendiren/korkutan şeyler var mı?
    f. Sizce bu hastalığın en zorlayıcı yanı/yanları neler? Bu zorluklarla baş etmede size yardımcı olan şeyler nedir? Geçmişi düşündüğünüzde en zorlayıcı yanları nelerdi? Bunlarla nasıl başa çıkmaya çalışırdınız?
    g. Geçmişi düşündüğünüzde hatırladığınız en önemli anlar nelerdir? Anne/babanızın Şizofreni hasta bir ebeveynle yaşamanın sizin için nasıl bir şey olduğunu gösteren bir olayı anlatabilir misiniz?

h. Biri sizden şizofreni tanısı almış bir ebeveynle büyümenin nasıl bir deneyim olduğunu bir cümleyle tarif etmenizi istese ne söylersiniz?

i. Peki bir yetişkin olarak anne/babanızın bu hastalığı bugününüzü nasıl etkiliyor/etkiledi? Kişiliğinizi nasıl etkiledi?

j. Ebeveyniniz şizofreni hastası olmasaydı hayatınız daha farklı olur muydu? (Evet ise) Neler olurdu bu farklılıklar? (Olumsuz gelirse) olumlu şeyler de olabiliyor sizin bu şekilde ele aldığınız şeyler söz konusu mu?

6. Anne/babanızın durumunu o zamanlarda kimler bilirdi? Onların tepkileri nasıldı? / Bu konuyla ilgili duygularınızı paylaştığınız kişiler var mıydı? Bu konuyla ilgili hislerinizi paylaşmak istediğinizde kendinizi nasıl hissederdiniz? Anne/babanıza (hasta olan kişiyi ifade ederek) sormak istediğiniz, söylemek istediğiniz şeyler olur muydu? (Evet ise) Bunlar nelerdi? Anne/babanızın hastalığıyla ilgili sıkıntılarınız olduğunda size destek olan kişiler oldu mu? (Evet ise) Kimler ve ne yaparak destek oldular?

7. Anne/babanızın durumunu şimdi kimler biliyor? Onların tutumlarını nasıl değerlendiriyorsunuz?

8. Toplumun bu hastalığa yönelik tutumlarını nasıl değerlendiriyorsunuz? Bunlar sizi nasıl etkiliyor?

9. Son olarak sormak ya da eklemek istediğiniz bir şey var mı?

APPENDIX G: SEMI-STRUCTURED INTERVIEW QUESTIONS FOR MINOR OFFSPRING

1. Bana biraz kendinden bahseder misin? Nasıl birisin, neler yapmaktan hoşlanırsın? Yapmaktan en keyif aldığın şeyler neler? Bana tipik bir gününü anlatır mısın?
2. Anne ve baban nasıl kişilerdir? Biraz anlatır mısın? Anne/babanla olan ilişkin nasıldır? Annenle/babanla vaktini nasıl değerlendirirsin? Ailenle nasıl vakit geçiriyorsunuz? Nelerden konuşursunuz, neler yaparsınız? / Ailede kim kiminle daha çok vakit geçirir? Neler yaparsınız?
3. Aile içinde senin yerine getirmen gereken en önemli sorumlulukların neler?
4. Daha önce de sana kısaca bahsettiğim gibi bugün anne/babanın (hangi ebeveyn hastaysa ona işaret edilecek) hastalığıyla ilgili senden biraz bilgi almak istiyorum.
    a. Annenin/babanın durumunu ilk nasıl öğrendin? Anne/babanın nasıl bir hastalığı var?
    b. Öğrendiğinde neler hissettin/düşündün? Bu durum seni nasıl etkiledi?
    c. Anne/babanın şu anki durumu nasıl sence?
5. Sence annenin/babanın hastalığı seni ne şekilde etkiledi/etkiliyor? Bu durumla ilgili neler hissediyorsun? / Neler düşünüyorsun?
    d. Annen/babanın bu hastalıkla ilgili problemleri arttığında neler yapıyorsun? / Bu dönemde evde ne gibi sorumlulukların oluyor? / Anne/babana nasıl davranıyorsun?
    e. Sence annen/baban hasta olmasaydı hayatın daha farklı olur muydu? (Evet ise) Neler olurdu bu farklılıklar?
    f. Sence bu hastalığın en zorlayıcı yanı/yanları neler? Bu zorluklarla baş etmede sana yardımcı olan şeyler nedir?
    g. Annenin/babanın hastalığıyla ilgili seni endişelendiren/korkutan şeyler oldu mu?
    h. Anne/babanın yaşadığı hastalıkla birlikte onunla ilişkilerinizde bir değişim oldu mu?
6. (Çocuğun bilgisi dahilinde ise) Annenin/babanın hastanede kalması gerektiği zamanlar oldu mu? Olduysa; o zamanlarda neler hissederdin? Neler yapardın (bekler miydin)? Onu düşünür müydün (evetse ne şekilde)?
7. Anne/babanın durumunu kimler biliyor? Onların tepkileri nasıl? / Bu konuyla ilgili duygularını paylaştığın kişiler var mı? Annenin/babanın hastalığıyla ilgili sıkıntılarınız olduğunda size destek olan kişiler oldu mu? (Evet ise) Kimler ve ne yaparak destek oldular?
8. Peki sence anne/babanın durumu seni ne şekilde etkiliyor? Bunların içerisinde olumlu olanlar var mı? (Evet ise) Nedir bu olumlu etkiler?

APPENDIX H: SEMI-STRUCTURED INTERVIEW QUESTIONS FOR UNAFFECTED PARENTS

1. Eşinizin tanı alma sürecinden bahsedebilir misiniz lütfen?
    a. İlk belirtiler nelerdi? O dönemde eşiniz neler yaşadı?
    b. Nasıl fark ettiniz? Profesyonel desteğe ilk başvurma süreci nasıldı?
    c. İlk fark ettiğinizde neler yaşadınız? (örn, aile/eş/çocuk alanları detaylandırılacak) Ne hissettiniz, neler düşündünüz?
    d. Eşiniz şu an hastalığı nedeniyle bir tedavi görüyor mu? (Evet ise) Nasıl bir tedavi görüyor? (Hastane yatışları sorgulanacak)
    e. Eşinizin şu anki durumunu nasıl tarif ederseniz? Eşiniz hastalığıyla ilgili neler düşünüyor/hissediyor?

2. Çocuğunuz eşinizin hastalığını ne zaman ve nasıl öğrendi? Nasıl bir tepki gösterdi?
    a. Çocuğunuz eşinizin hastalığıyla ilgili sorular sorar mı, ne gibi sorular sorar, nasıl yanıtlarsınız?
    b. Çocuğunuz eşinizin hastalığıyla ilgili sizinle ya da başkalarıyla paylaşımlarda bulunuyor mu? (Evet ise) Ne gibi paylaşımları var?
    c. Siz kendisiyle bu konu hakkında konuştunuz mu? (Evet ise) Neler paylaştınız?
    d. (Hastane yatışları var ise) Eşinizin hastanede yattığı dönemde evinizde çocuğunuzun bakımıyla ilgili nasıl bir düzenleme oluyor?
    e. Çocuğunuz ebeveyninin evde olmayışıyla ilgili ne biliyor? Kendisiyle sizden başka ilgilenen biri/birileri oldu mu? (Kimler) Bu dönemde çocuğunuzun davranışlarında bir değişim gözlemliyor musunuz? Bu durumla nasıl baş ediyorsunuz?

3. Eşinizin hastalığıyla birlikte aile olarak hayatınızda çeşitli değişimler oldu mu? (Evet ise) Eş olarak sizin için farklılaşan şeyler neler oldu? /Çocuğunuz için farklılaşan şeyler neler oldu?

    a. Eşiniz hastalandıktan sonra çocuğunuzla olan ilişkisinde değişimler oldu mu? Neler gözlemlediniz? (Evet ise olumsuz ve olumlu olası değişimler detaylandırılacak).
    b. Eşiniz bu değişimlerin farkında mı? Bu değişimlerle ilgili ne düşünüyor/hissediyor?
    c. Eşiniz hastalandıktan sonra sizin ebeveynlik deneyimleriniz nasıl şekillendi?
    d. Ailenizin şu anki durumunu göz önüne alırsanız, ailenizin ne gibi sıkıntıları, zorlukları, sorunları var? Bu zorluklarla başa çıkmada size yardımcı olan şeyler var mı? /Daha zorlaştıran şeyler var mı?

4. Sizce şizofreni tanısı almış bir ebeveyne sahip olması çocuğunuzu nasıl etkiledi? (Duygusal, düşünsel, sosyal ilişkiler, kişilik gelişimi ve okul başarısı alanları detaylandırılacak)
    a. Sizce eşinizin hastalığı söz konusu olmasaydı çocuğunuzda/ailenizde neler farklı olurdu?
    b. Çocuğunuzun eşinizin hastalığıyla bağlantılı olarak problem yaşadığını hissettiğinizde kimlerden destek alırsınız? Bu kişilerin çocuğunuzla ilişkisi nedir?
    c. İleride çocuğunuzun da bu hastalığa yakalanmasına yönelik korkularınız/kaygılarınız var mı? Varsa bunlarla başa çıkmak için başvurduğunuz yöntemleriniz nelerdir?

5. Sizce şizofreni tanısı almış bir ebeveyne sahip olması çocuğunuzu nasıl etkiledi? (Duygusal, düşünsel, sosyal ilişkiler, kişilik gelişimi ve okul başarısı alanları detaylandırılacak)

6. Eşinizin hastalığını aileniz dışında bilen kişiler var mı? Onların tutumlarını nasıl değerlendiriyorsunuz? Onların bu tutumlarının çocuğunuz üzerinde bir etkisi olduğunu düşünüyor musunuz?

7. Son olarak sormak ya da eklemek istediğiniz bir şey var mı?