

LIVING WITH “THE MAD”:
THE POLITICS OF PSYCHIATRIC CAREGIVING IN TURKEY



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2019

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Thesis submitted to the
Institute for Graduate Studies in Social Sciences
in partial fulfillment of the requirements for the degree of

Master of Arts
in
Sociology

by
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Boğaziçi University

2019

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DECLARATION OF ORIGINALITY

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ABSTRACT

Living with “the Mad”: The Politics of Psychiatric Caregiving in Turkey

This thesis is an exploration of the affective labor of women caregivers who reside with their mentally afflicted relative in contemporary Turkey. It examines the distinctive characteristics of psychiatric caregiving which primarily stem from the unpredictability of the mental afflictions and the intense period of hardships, the fear of stigma as well as the suffering these bring to the lives of the afflicted people and their caregivers. Today, there are thousands of women who are engaged with this type of caring and their labor is by and large rendered invisible due to AKP regime’s sacred familialism which defines caring as women’s social responsibility. This thesis ascertains that women caregivers are abandoned by the state and this is made more possible by the psychiatric knowledge that promotes the idea of supportive family. It shows how this abandonment is further maintained by the other family members who refuse to engage in with the troubles of the mentally afflicted person. By tracing the stories of two women and situating them in the context of contemporary Turkey; it sheds light on the fact that psychiatric caregiving is a labor process as much as it is an inevitable human need and a universal human capacity.

ÖZET

“Deli” ile Yaşamak: Türkiye’de Psikiyatrik Bakımın Politikası

Bu tez, günümüz Türkiye’inde ruhsal sorunları olan akrabalarıyla ikamet eden kadınların duygulanımsal emeği üzerine bir araştırmadır. Öncelikle ruhsal rahatsızlıkların tahmin edilemezliğinden, yol açtıkları yoğun sıkıntı dönemlerinden, damgalanma korkusundan ve bunlara maruz kalan insanların ve bakıcılarının hayatlarına getirdiği sıkıntılardan kaynaklanan, psikiyatrik bakımın kendine özgü özelliklerini incelemektedir. Bugün, bu tür bakım ile uğraşan binlerce kadın var ve onların emekleri, AKP rejiminin bakımı kadınların sosyal sorumluluğu olarak tanımlayan kutsal aileciliği nedeniyle büyük ölçüde görünmez hale gelmektedir. Bu tez, kadın bakıcıların devlet tarafından terk edildiğini ve destekleyici aile fikrini teşvik eden psikiyatrik bilgi ile bu durumun daha da mümkün kılındığını ortaya koymaktadır. Bakım verenlerin bu emek sürecinde yalnız bırakılmalarının, ruhsal sorunları olan kişilerin dertleriyle ilgilenmeyi reddeden diğer aile üyeleri tarafından nasıl daha da sürdürüldüğünü göstermektedir. İki kadının hikâyelerini izleyerek ve onları günümüz Türkiye’si bağlamına oturtarak, bakımın kaçınılmaz bir insan ihtiyacı ve evrensel bir insan kapasitesi olduğu kadar, bir emek süreci de olduğu gerçeğine ışık tutmaktadır.

ACKNOWLEDGEMENTS

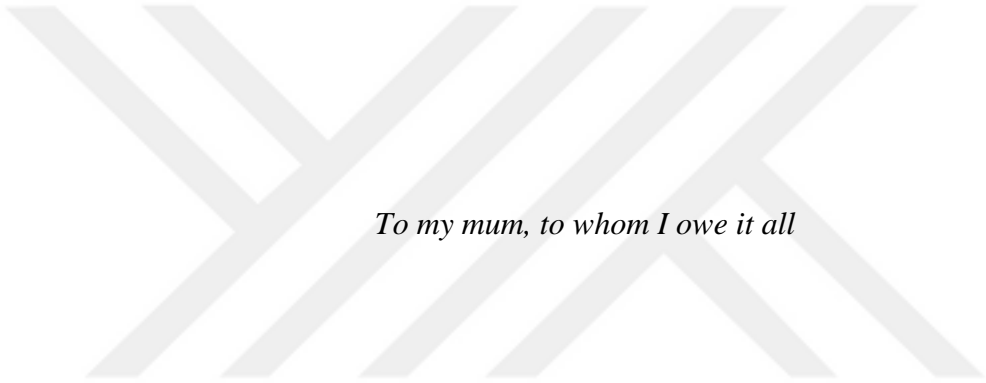
I would like to thank my advisor Ayfer Bartu Candan for her encouraging approach throughout my undergraduate and graduate education, and throughout the process of writing this thesis. If not for her warm support, this thesis would not exist. Many thanks to Felicity Aulino and Christopher Dole, for all their understanding and support when I needed it the most while I was overseas. Department of Sociology at Boğaziçi, with all the experiences I had there, had tremendously shaped my life. Many thanks to all the people I met there for teaching me critical thinking, in an environment of solidarity.

I am grateful to my friends and colleagues in RUSİHAK (Human Rights in Mental Health Initiative) for giving me the chance to meet with so many wonderful people and, for enabling me see behind the scenes of the mental health system across the country. I could not engage myself to the reality of mental affliction if it was not them. I'm especially grateful to Pınar, for her warm support and friendship throughout my time in RUSİHAK and after it.

I deeply appreciate the support of my beloved friends, Damla, Havle, Gül, Anıl, Can and, Çağatay for their endless patience, encouragement and love And, for reminding me what I tend to forget in times of sadness, anxiety and anger. They are the people making my life better in every possible way.

Without my family's generous support, I would not be who I am today. I'm so lucky to be the child of my dear mum and dad. I will forever be grateful to them for all their efforts and for all the valuable things they taught me.

DEDICATION



To my mum, to whom I owe it all

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ABBREVIATIONS

AKP	Justice and Development Party (<i>Adalet ve Kalkınma Partisi</i>)
ANAP	Motherland Party (<i>Anavatan Partisi</i>)
ASPB	Ministry of Family and Social Policies (<i>Aile ve Sosyal Politikalar Bakanlığı</i>)
CCT	Conditional Cash Transfer
CHP	Republican People's Party (<i>Cumhuriyet Halk Partisi</i>)
DSP	Democratic Left Party (<i>Demokratik Sol Parti</i>)
EU	European Union
MoH	Ministry of Health (<i>Sağlık Bakanlığı</i>)
RUSİHAK	Human Rights in Mental Health Initiative (<i>Ruh Sağlığında İnsan Hakları Girişimi Derneği</i>)
SHCEK	Social Services and Child Protection Institution (<i>Sosyal Hizmetler ve Çocuk Esirgeme Kurumu</i>)
TRSM	Community Mental Health Centers (<i>Toplum Ruh Sağlığı Merkezleri</i>)
WHO	World Health Organization
WWII	Second World War

CHAPTER 1

INTRODUCTION

In 2015, a woman named Aslı Sönmezler (32) strangled her mother Belgin Hızal (57) in Istanbul. Aslı's attorney demanded forensic psychiatrists' opinion which would prove her criminal insanity. ¹However, in 2017, the 20th high criminal court in Istanbul gave her life sentence for committing deliberate murder. In their report, the General Directorate of Forensic Medicine Institute of the Republic of Turkey (Türkiye Cumhuriyeti Adalet Bakanlığı) declared that Aslı Sönmezler has full criminal liability and therefore should be given life sentence for committing murder. In her defense, Aslı told that she does not have any regrets since she just “annihilated a jerk” and that she “followed the noise that told her to kill her mother to reach the light”.²

Aslı Sönmezler's case caused a fervent public debate regarding the punishment of her action. As it was written by a popular columnist after the declaration of the life sentence punishment, the question that generated the discussions was “whether Aslı who killed her mother should be punished or treated”.³ A strong opposition was made by the Federation of the Schizophrenia Associations (Şizofreni Dernekleri Federasyonu) in Turkey. In their public statement, the federation associates emphasized that Aslı is a schizophrenic person with impaired insight, meaning that she does not accept the fact that she is mentally afflicted. By referring to the 32nd article of the Turkish Criminal Law (Türk Ceza

¹ See Arıgan (2017); Kılıç (2017); Altın (2017) for newspaper reports on this issue.

² Ben, bir pisliği ortadan kaldırdım. Bir ses bana, aydınlığa ulaşmam için annemi öldürmem gerektiğini söyledi, ben de o sese uydum!”

³“Annesini öldüren Aslı cezalandırılmalı mı tedavi mi edilmeli?” (Arman, 2017).

Kanunu) which declares that mentally afflicted people cannot be found responsible for their criminal action; they requested Aslı's immediate release and a psychiatric treatment for her in Bakırköy Mental Institution. As they stated:

In this event, there is a mother who was killed. If she was alive, this mother - who made many efforts, got exhausted, made sacrifices and suffered while she was alive, so that her child can recover- would be the best person to know that all these things happened because of her child's affliction. Now the fact that her daughter is being punished, in a way means that she is being murdered again.⁴ (Federation of the Schizophrenia Associations in Turkey, 2017)

In his analysis on a similar case that attracted publicity in London in 1992, Nickolas Rose exemplifies the murder committed by Christopher Clunis who was a psychiatric patient discharged by a hospital admission (Rose, 1996). As the inquiry reveals, Mr. Clunis does not follow the treatment process as he stops taking the medications and misses the appointments after his discharge. Rose observes that, at the end of the investigation Mr Clunis was found innocent. In his analysis, Rose points at a new psychiatric order in which the treatment of the mentally afflicted people becomes more of a question of "risk management" as they are treated more in the community settings rather than in the closed mental institutions where they were constantly regulated. Within this context, Mr. Clunis is perceived as a mentally afflicted person who is not given a criminal liability despite the fact that he committed murder. Moreover, he is regarded "as much a victim of the mental health system as the young man he killed" (Rose, 1996, p. 2).

Comparing these two cases would reveal important insights as to the public discourses at play in Aslı's situation. In her trial, his father argued that Belgin Hızal

⁴ "Bu olguda, canına kıyılmış bir anne var. Hayatta olduğu sürece evladını sağlığına kavuşturmak için nice uğraşlar veren, yıpranan, bedeller ödeyen, acı çeken bu anne, bir biçimde hayatta kalmış olsaydı bütün bunların hastalıktan kaynaklandığını en iyi bilen kişi olacaktı. Şimdi kızının cezalandırılıyor olması, bir bakıma onun yeniden canına kıyılması anlamına geliyor." (Federation of the Schizophrenia Associations in Turkey, 2017).

sent him an email saying that Aslı is a schizophrenic and that she does not see her daughter for over a year. Other than this piece of information, there was no evidence about the psychiatric treatment Aslı received. There was no evidence about whether Aslı was diagnosed as schizophrenic or not either. Here, the fact that she is not recognized as a mentally afflicted person explains the public accusations towards Aslı. It also explains why, unlike in the case of Mr. Clunis, she is far from interpreted as an object of pity and a victim of mental health system. The psychiatric judgement in Aslı's case is still clinical and the authority is held by the forensic psychiatrists.

Such that, taking into account of forensic psychiatrists' judgement; the criminal court recognizes Aslı as a citizen with full criminal liability and sentences her for committing murder. Various newspapers support the sentence as they refer to Aslı as a murderer who deliberately killed her mother. Some others cover the press release of The Federation of the Schizophrenia Association which opposes the sentence and insists that Aslı is a schizophrenic person with impaired insight and therefore should not be considered as responsible for her behavior. The association appears as the only actor pointing at Aslı's affliction and demanding public recognition for that.

What are the roles at play in construction of the conflicting discourses concerning this case?

There is no doubt that Belgin's life has value and Aslı's action cannot be justified from any ethical standpoint valuing human life. Here, in starting this thesis with an elaboration on Aslı's case, I do not aim to discuss whether the verdict is justified or valid. I do not try to question criminal liability of Aslı and investigate her mental health condition either. I simply seek to problematize fundamental aspects of this case which are rendered invisible in the public debate in question. In their press release, The Federation of the Schizophrenia Association points at Belgin's efforts,

sacrifices and sufferings to emphasize that she would forgive Aslı as she knew about Aslı's mental affliction and its influence on her behaviors. Similarly, what attracts media attention is not Belgin's lifetime sacrifices but her death that is caused by her possibly schizophrenic daughter. Her death is the tragic moment that is found newsworthy. Therefore, the nature of their relationship and the problems Belgin has been facing are rarely urged upon in this debate. Yet it provokes important questions concerning the mentally afflicted people and their caregivers who are by and large the women family members, usually the mothers, in Turkey (Gülseren et al., 2010).

Today, over four hundred thousand disabled people are residing with their families in Turkey and a considerable amount of these people are mentally afflicted (Directorate General of Services for Persons with Disabilities and the Elderly, 2018, p. 11). How do these caregivers cope with their afflicted relative's troubles in the domestic sphere? What are the characteristic attributes of their labor as they care for their afflicted relative? What are the repercussions of that labor on their lives? In light of these questions, this thesis is an attempt to problematize the relation between mentally afflicted people and their family caregivers; it is primarily an investigation of care that becomes a lifelong activity, a form of labor which largely shapes the lives of the family caregivers who are usually women. By asking these questions, it engages with the larger question concerning the politics of care in Turkey. It focuses on women citizens' experience of what I call psychiatric caregiving and sheds lights on the gender inequalities they are subjected to in this context. In what follows, I explain my approach to this form of labor in the thesis and introduce my path in the following chapters. Before that, I will dwell on my approach to the application of psychiatric diagnoses and how I frame the question of mental affliction in my analysis.

Mentally afflicted people have been subjected to unfair and relentless treatment for many years in various places on the world. In fact, today the majority of the mentally afflicted people worldwide receive no treatment at all (Thornicroft et al., 2016). Incarceration has long been the dominant model of treatment which required incarcerating the mentally afflicted people in custodial mental institutions where they are strictly regulated by medical authorities. Since 1950s, patients' rights movements and political liberalization have been important factors in facilitating the process of deinstitutionalization which largely shifted the place of psychiatric care from custodial hospitals to community-based settings (Davis 2017:1). This political challenge and the policy shift it influenced have become the object of sociological and anthropological inquiry in the last decades.

Since the late 20th century, various feminist, postcolonial and post structural writers have contested and deconstructed the notion of subject in humanist theorizing. They argued that the subject is a product of gendered, racialized and colonial discourses rather than a fundamental reality for social scientific inquiry.⁵ One of the most influential people in this line of thinking, Michael Foucault investigated the historical complexities that construct science which largely shaped the functioning of modern institutions. In this regard, his study on psychiatric power exposes the role of the discipline in the construction of the concept of mental illness and its embodied forms (Foucault, 1997). In Foucauldian understanding, power relations are thought to be in mobile shape and consequently, the state itself is not done through coercive power held by a particular authority; rather governing is also done through the application of done through the application of various technologies which construct self-disciplined individuals. Therefore, government refers to a

⁵ See for example Biehl & Moran-Thomas (2009); Fanon (1963); Haraway, (1991); Said (2003).

particular conduct of conduct, which essentially implies that individual practices are influenced by various rationalities and techniques concerned with the government of the state. Following Foucault, I will broadly define state as the assembly of various governmentalities among which the discipline of psychiatry has a significant influence. In this regard, diagnostic categories applied by many psychiatrists, particularly the Diagnostic and Statistical Manual of Mental Disorders (DSM) released by the American Psychiatry Association; provide an influential instrument in producing standardizations for mentally afflicted people in many places today.

⁶The fifth edition of the manual, DSM-5, is released in May 2013 and it is largely seen as representing a shift towards a “standardized biological approach” in psychiatry as its practitioners employ a “descriptive rather than etiological diagnosis of symptoms” (Davis, 2017, p.2).

Within this framework, human life experiences are tried to be made stabilized objects of knowledge which are heavily invested in the pharmaceutical treatment. Since 1990s, editions of DSM have been contested by various scholars as they are found reductive and universalist in their conceptualization of the mental afflictions experienced by people from various backgrounds in different parts of the world.⁷ Their ethnographic investigations demonstrate that the procedures of diagnosing as well as the formation of diagnostic categories themselves are complex processes which cannot always meet the needs of the afflicted people. For example,

⁶ See Alix Spiegel (2004) for a brief account on the history of DSM.

⁷ There are a growing number of studies, particularly in the field of medical anthropology, which problematizes the utilization of standard diagnostic categories across cultures. See for example Elizabeth Davis for an ethnographic account on the psychiatric facilities in a border village in Greece (Davis, 2012). Similarly, in her study on the emerging psychiatric discourses in post- 1980s Iran, Orkideh Behrouzan demonstrates how the psychiatric dialect becomes a language of the everyday as the ways they express and interpret their feeling states are shifted (Behrouzan, 2016). Another example is Fassin and Rechtman’s far-reaching ethnographic work which offers a critical view on the historical construction and political uses of the concept of trauma (Fassin & Richard, 2019).

in his study on the psychiatric practices in Buenos Aires, Andrew Lakoff investigates this standardization of psychiatric experiences and points to the challenges posed by the political context in Argentina that does not give way to that standardization, or to what he calls “diagnostic liquidity”. As Lakoff argues, diagnostic liquidity is tried to be made possible through the “governmental regulation requiring that “pharmaceuticals be proven to have targeted effects in order to circulate in the biomedical system” (Lakoff, 2006, p. 10). His study shows how this standardization extends further into the field of research, as the researchers were under the pressure to demonstrate certain effects that the drugs treat and therefore they had to classify disorders in standardized ways. In a similar vein, in their study on the experience of schizophrenics and the application of DSM-3, Corin and Lauzon (1992) criticize the formulation of the diagnostic manual for focusing on the objective evaluation of signs and behaviours to the extent of bracketing off the meaning that afflicted people attach to their experience. Based on their research in a rehabilitation unit in Montreal, they point at different types of rehabilitative strategies that patients diagnosed as schizophrenics apply to integrate themselves to the community, which are framed as negative symptoms in the manual (Corrin & Lauzon, 1992, p. 267).

On the other hand, there are other issues concerning the use of psychiatric diagnoses which stem from the inadequate provision of healthcare services. Such that, although the majority of the people I refer to in my analysis were diagnosed as schizophrenic at least once in their lives, none of them were given a stable diagnosis throughout their treatment. As their narratives will reveal in the following chapters, the process of diagnosis is also highly problematic particularly as healthcare services are not sufficient enough with regards to the number of psychiatrists and healthcare workers working in the mental institutions. Taken into consideration the

problematics I point at here and, following the medical anthropologists who approach critically to the application of psychiatric diagnoses in across cultures; I refrained from referring to the mentally afflicted people by their diagnoses in my analysis. Rather, I pointed at the fact that they are” people with psychiatric diagnosis” who have some kind of a “mental affliction”. I neither discuss the nature of that affliction nor do I refer to its manifestations by conceptualizing them as “symptoms”. However, in this thesis, I do not offer an investigation of the psychiatric diagnosis categories or afflicted people’s experience of them, as my main focus is on the experiences of the women caregivers who reside with their mentally afflicted relative. Here, not discussing the question of mental affliction and psychiatric diagnosis further is also a humble yet conscious attempt to focus reader’s attention precisely to the experience of the caregivers whose labor is already largely rendered invisible in the current context.

Having clarified my approach to the psychiatric diagnoses and how I frame them in this analysis, I now return to the main questions of the thesis: What are the distinctive characteristics of psychiatric caregiving women caregivers engage in as they care for their afflicted relative? What are the repercussions of this labor on their lives? According to the 9463 Law on the Disabled, disabled people are defined as people who cannot participate to the society equally with other people; due to the various degrees of loses they have in their physical, cognitive, mental or sensual capacities (5378 Law on the Disabled People, 2013). Therefore, mentally afflicted people are generally referred under the category of “disabled” as mental afflictions are regarded as a disability.⁸ In the current literature, there are studies on the disabled

⁸ See also Turkey Disability Survey 2002 for samples demonstrating this classification (State Institute of Statistics Prime Ministry Republic of Turkey & Turkish Prime Ministry Presidency of Administration on Disabled People, 2004).

people and on Turkish state's healthcare provision policies concerning the disabled (Altuntaş & Topçuoğlu, 2014; Bezmez, 2012; Evren, 2012; Yılmaz, 2017). These studies reveal significant aspects concerning how the disabled people are assessed, categorized and are treated by the Turkish state and by the medical authorities in Turkey. Yet, the dynamics of home-based care, particularly the distinctive characteristics of caring for and about a mentally afflicted person, a person who is usually capable of catering for her material needs unlike the people with somatic "disabilities"; are predominantly left undebated. In this thesis, I call this particular caring experience as psychiatric caregiving. In this sense, this thesis is an attempt to shed light on the specific characteristics of psychiatric caregiving and to eventually disclose the "affective inequalities" women caregivers are subjected to as they reside with their mentally afflicted relative in contemporary Turkey. By the term affective inequality, I point at the asymmetrical distribution of the burden as well as the benefits of the affective relations such as "love, care and solidarity" in the domestic sphere (Lynch, 2007, 2009).

My argument is that families, particularly the women caregivers, are usually left alone in their struggle with the mentally afflicted person's troubles. Today, the organization of the psychiatric healthcare services and the normative framework concerning women's role in caregiving sustain this abandonment. In this regard, this thesis reveals that women caregivers are essentially abandoned by the state and, it demonstrates that this abandonment is made more possible by the psychiatric knowledge that promotes the idea of supportive family. It proves how caregivers are further abandoned as the other family members refuse to engage in with the troubles of the mentally afflicted person. In order to provide a profound investigation of state's role on this matter; I examine the current psychiatric healthcare policies of the

Justice and Development Party (Adalet ve Kalkınma Partisi—AKP) and, I argue that these policies demonstrate a particular gender politics of sacred familialism. I borrow this concept from Ferhunde Özbay who uses the term in a paper she presents in a project on alternative ways of imagining family in Turkey (Özbay, 2013). In a very recent study on the politics of care in Turkey, Başak Akkan applies the concept to explain the paradoxical association of religious conservatism and neoliberalism that informs the policy measures introduced by AKP in contemporary Turkey (Akkan 2017). In their conceptualization, sacred familialism refers to the gender politics of AKP which assigns women the role of devoted care providers and thus shifts the burden of care to them. While this attribution to women as devoted care providers has traditionally been an important aspect of the sociocultural structure in Turkey, new policy initiatives and changes are also at play in contemporary context (Kılıç, 2010). As I explain further below, these policies basically enable the state to address the neoliberal market demands as well. Concordantly, the transformation of the psychiatric facilities takes place in accordance with a conservative framework that takes advantage of women's labor while it reduces state's welfare responsibilities of care. Within this framework, the psychiatric knowledge appears as another factor sustaining women's role as care providers. Current treatment models applied in the psychiatric facilities, particularly the community mental health centers (Toplum Ruh Sağlığı Merkezleri—TRSM) I explain below, further demonstrates that families' role in care provision is taken for granted by the state. In my analysis of these models, I point at the political nature of the psychiatric knowledge which is manifested in the ideal family model promoted in theories on mental health treatment in the psychiatry literature.

In my analysis on women caregivers' labor, I mainly apply the theory of affective labor as it provides me the ground for accounting for the immaterial aspects of psychiatric caring in the domestic sphere. As my analysis reveals, psychiatric caregiving is a very complex labor process which is actually a form of life and communication and, it involves immaterial aspects which are not only emotions. In Antonio Negri and Michael Hardt's theorization, affective labor refers to relationships, affects, forms of cooperation and communication produced in the families. Therefore, it can address the distinctive characteristics of psychiatric caregiving which demonstrates that it is different than other forms of disability that require a consistent form of care. To investigate these aspects further and to shed light on the affective inequalities women caregivers are subjected to, I mainly focus on the stories of two women in my analysis. But my research on their lives as well the secondary data I analyze further below appear to be in consistency. I found that: most of the caregivers suffer from feelings of shame and guilt which appear to draw them into affective states in which diverse negative feelings are articulated; they are usually isolated from the social circle in their neighborhood; majority of the caregivers feel obscurity with regards to the cause and the course of the affliction and, this is usually substantiated with the lack of a stable diagnosis offering a particular explanation and a pattern; there is usually a chronic fear towards the afflicted person's unpredictable actions. These are what I define as distinctive characteristics of psychiatric caregiving and as I demonstrate, it has serious repercussions on the wellbeing of the caregivers in contemporary Turkey.

In order to further investigate this issue, I divided this thesis in three main chapters and formulated them as follows:

Chapter 2 is an investigation of Turkish state's healthcare policies with a focus on the transformation of the psychiatric facilities in the last decade. There are two sections in this chapter. First one covers the period from 1960 onwards till the beginning of the current regime under the Justice and Development Party (Adalet ve Kalkınma Partisi—AKP). I principally highlight policy changes and significant events, 1999 Marmara Earthquake and accession process of European Union (EU) in particular, which had an influence on the provision of psychiatric healthcare services during that period. The second section, divided into two subsections, provides an examination of the period under the regime of AKP, and a brief analysis on the deinstitutionalization policies in the world which facilitated the transition towards the community-based treatment model in various countries. In my analysis of AKP regime's healthcare policies in this period, I argue that these policies demonstrate a particular governmental rationality informed by a paradoxical association of neoliberalism and neoconservatism. I show how their intersection manifests itself in discursive as well as institutional level by AKP's sacred familialism which shifts the burden of care to women while enabling the state to address the neoliberal market demands (Akkan, 2017; Özbay, 2013). Here I take neoliberalism as a governmental rationality that is broadly based on the principles of the market economy. Following the studies of various scholars analyzing the social policy reforms in Turkey, I argue that the policy changes introduced under the AKP regime are generally adjusted to the demands of neoliberalism (Buğra, 2007; Keyder, 2005; Yeğenoğlu & Coşar, 2011; Yılmaz, 2017; Yılmaz (2), 2015). On the other hand, by the term neoconservative, I refer to a governmental rationality which essentially regards families as the core of the social order. In this regard, social policies introduced by AKP generally have a “pro-family social agenda” which by and large implies that

welfare responsibilities of the state are shifted to the families as the family institution is regarded as the solution to the problems like unemployment, domestic violence or divorce (Yılmaz (2), 2015). An important manifestation of the association of these governmental rationalities is the cash transfer system which grants benefits to the mentally afflicted people who reside with their families (Akkan, 2017; Altuntas & Topcuoglu, 2014).

As I elucidate in Chapter 2, number of the mentally afflicted people and caregivers benefitting from the beneficiaries has been increasing in the last decades, demonstrating citizens' negotiation with the normative framework concerning the care provision (Directorate General of Services for Persons with Disabilities and the Elderly, 2018, p. 11). On the other hand, a significant transformation occurs in the mental healthcare system with the establishment of the TRSMs. With the introduction of these centers, patients are no longer treated in closed mental institutions providing inpatient treatment and they are treated with rehabilitation programs that aim at their social integration. In my analysis, I show how the treatment model applied in these services integrates family members in the recovery plan, further demonstrating state's reliance on families for care provision.

Chapter 3 is an analysis of another factor that contributes to state's reliance on families for welfare provision and, paves the way for the caregivers, who are residing with their mentally afflicted relative, to be abandoned: the psychiatric knowledge. In this regard, I examine two factors shaping the contemporary landscape of mental health: the increase of the prevalence and the "efficiency" of the pharmaceuticals and the application of the recovery model of treatment in the last decades. I show how these factors facilitated the process of converting patients into consumers as the inpatients of the former custodial hospitals became "recovered

consumers” whose needs are attached to the psychopharmacological market. More important for the subject of this thesis is the repercussions of this transformation in the domestic sphere where not only the afflicted person but also the family caregivers are attributed a significant role in the recovery process. In my analysis on the family recovery model and the family assemblage theory, I point at the political nature of the ideal family promoted in these models and, I show how this political nature manifests itself in the Turkish context with the treatment model offered in the TRSMs. I also examine pharmaceuticals’ role in sustaining the relations at the domestic sphere and show how they became an “integral part of the organizational and the moral furniture of the contemporary households” (Biehl & Moran-Thomas, 2009, p. 273).

In Chapter 3, I analyze the studies on the concept of expressed emotion as well. The data examined in these studies provide significant insight on the experience of psychiatric caregiving in Turkey. Psychological studies I examine focus specifically on the caregivers of the mentally afflicted people, those who were diagnosed as schizophrenic in particular. The data examined in these studies provide significant insight on the experience of psychiatric caregiving in Turkey as most of them are based on surveys conducted with hundreds of women caregivers from different parts of the country (Arslantaş & Adana, 2012; Duman & Bademli, 2013; Durmaz & Okanlı, 2014; Ebrinç et al., 2001; Gülseren et al., 2010; Gümüş, 2008; Kızılırmak & Küçük, 2016; Özlü et al., 2010; Tel & Pınar, 2013; Tel, Saraç, Günaydın, Mesik & Doğan, 2010). They reveal that majority of the caregivers go through intense periods of hardships which are usually caused by the problems such as the unpredictability of the afflicted person’s moods, fear of stigma towards the people outside the family and the culmination of negative feelings like hopelessness,

anxiety, stress etc. (Gülseren et al., 2010; Tel, Saraç, Günaydın, Mesik & Doğan, 2010; Kızılırmak & Küçük, 2016). In this regard, this literature actually provides me a secondary data and enables me to grasp the enormity of psychiatry caregiving in Turkey. It also strengthens the argument of this thesis as it demonstrates that the caregivers in question are usually women, who are mostly either mothers or sisters in the families (Awad & Voruganti, 2008; Lowyck et al., 2004; Nasr & Kausar, 2009). Therefore, in my analysis, I borrow from psychiatric literature on these aspects as well. But as I show forth in Chapter 3, my overall critical approach to these psychiatric conceptualizations is consistent as I also show how these studies leave the political nature of the familial relations undebated, while they risk masking the inequalities women caregivers are subjected to and the significance of their labor. In this regard, Chapter 4 is an attempt to problematize and reveal these aspects.

In Chapter 4, I situate psychiatric caregiving in the feminist literature on caring labor and analyse the narratives of the caregivers whom I met during my research for the thesis. There are two subsections in this chapter. In the first one, I provide a brief summary of the feminist debates on the concept of caring labor, which was initially considered as a form of domestic labor by various Marxist and socialist feminists (Himmelweit, 1983; Vogel, 2013). As I show forth below, the debates on domestic labor primarily aimed at revealing the material aspects of women's oppression in the domestic sphere. Taking my cue from that debate, I explain my approach to psychiatric caregiving and analyse it as a form of affective labor. Following the conceptualization of Antonio Negri and Michael Hardt, I basically define affective labor as a form of interaction and human contact which not only requires material tasks but also produces relationships, forms of cooperation and communication as well as affects in the communities (Hardt & Negri, 2004).

In this sense, the theory of affective labor provides me the ground for accounting for the immaterial aspects of psychiatric caring in the domestic sphere which are largely rendered invisible in the normative framework concerning women's role as caregivers.

In the second subsection of the Chapter 4, I analyse my data and present the methodology I applied. My main focus is on the narratives of two women, Gülay and Zeynep, whom I met regularly to learn about their lives with the mentally afflicted family member. As their lives were my major focus of attention and as my concern was to gain an in-depth understanding of their experience; I primarily implemented case study analysis. Therefore, I also provide an account of the debates on the methodology of case studies and clarify my reasons to apply this particular methodology in the thesis. On the other hand, I conducted several other interviews which appear throughout the Chapter 4. In 2017-2018, I was a volunteer as well as a project assistant in Human Rights in Mental Health Initiative (RUSİHAK, Ruh Sağlığında İnsan Hakları Girişimi Derneği), the only NGO that has an agenda on the rights of people with psychiatric diagnosis in Turkey.⁹ As I explain in detail in Chapter 2, my experience in the Deinstitutionalization Project by RUSİHAK enabled me to gain a better perspective about the conditions of TRSMs today and I reflect that insight to my analysis of the narratives of the people in question.

This thesis is an attempt to investigate the distinctive characteristics of psychiatric caregiving in contemporary Turkey and, to reveal the affective inequalities women caregivers are subjected to in their everyday lives, by analyzing the following issues; 1) the transformation of psychiatric facilities in Turkey in the last decades and its repercussions on the provision of psychiatric care (Chapter 2); 2)

⁹ See RUSİHAK's website for a detailed account on RUSİHAK's history and vision (<https://www.rusihak.org/>).

the psychiatric knowledge that conceals the political nature of the care relations while strengthening state's welfare policies that attribute women the role of caregivers (Chapter 3); 3) the affective labor women are engaged in as they cope with their mentally afflicted relative's troubles in the domestic sphere (Chapter 4). By framing the experiences of the caregivers as a form of affective labor, I aim to shed light on diverse forms of inequalities women are subjected to as they are left alone with their mentally afflicted relative, whose needs can be distinctive for reasons such as the unpredictability of their moods and behaviors, the vagueness concerning the cause as well as the course concerning their affliction, and the stigma on mental illness in the society etc. I intend to engage with the larger question concerning the neoconservative and neoliberal governmental rationalities informing the healthcare policies in Turkey, its experience by women citizens who are subjected to gender inequalities emerging at the intersection of the rationalities in question.

CHAPTER 2
FROM CUSTODIAL PSYCHIATRIC HOSPITALS
TO COMMUNITY MENTAL HEALTH CENTERS:
THE TRANSFORMATION OF PSYCHIATRIC FACILITIES IN TURKEY

2.1 Introduction

In this chapter, I examine the provision of healthcare services in Turkey with a focus on the transformation of psychiatric services in the last decade. Taking my cue from the social scientists analyzing the social policy reforms in Turkey, I provide an analysis of the neoliberalisation of the healthcare services.¹⁰ In what follows, I do not try to present a linear history of Turkey on its way to become a neoliberal state, although neoliberalisation largely shaped the transformation of healthcare services as well. Instead, I provide a detailed account of the changes in psychiatric healthcare system in different historical periods, with a focus on how this particular field is governed. Particularly, I dwell on the implicit basis of the state-society relations which provides me the ground for an analysis of the policy debates in the area of family. Within the context of neoliberal policies, states diminish their role in welfare provision and increasingly shift most of its caring responsibilities to families in the domestic spheres where most of the unproductive population receives care (Özbay, 2013, p. 107). Under the current regime of AKP, the politics of care largely sustains women's role as the primary caregivers of the children as well as the elderly and disabled people in Turkey (Acar & Altunok, 2013; Akkan, 2017; Altuntaş & Topçuoğlu, 2014; Kılıç, 2010; Özbay, 2013). This politics of care is manifested in

¹⁰ See for example Buğra (2007); Keyder (2005); Kohlwes (2014); Yeğenoğlu & Coşar (2011); Yılmaz (2017).

AKP's "sacred familialism", which strengthens the conventional emphasis on the women's role in the family while paradoxically addressing the neoliberal market demands (Akkan, 2017; Özbay 2013). As I aim to demonstrate in this thesis, the ideological and the moral stance that underlies this approach towards women's role became prominent in recent years while fostering the gender inequality in today's neoconservative Turkey (Acar & Altunok, 2013).¹¹

By applying the term neoconservative in this thesis, I refer to a particular kind of governmental rationality which considers the family as the core of the social order. In this rationality, the problems like unemployment, domestic violence or divorce are explained by the weakening of the family institution in modern societies (Acar & Altunok, 2013, p. 5). Consequently, strengthening the role of the family institution is conceived as a solution for these problems as well as other social risks (Yılmaz (2) 2015). In his article on the family-centered social policy agenda in Turkey, Yılmaz (2015) analyzes the pro-family social policy agenda of AKP and argues that in the current regime, the goal is not simply to strengthen the family. Rather, as he argues, it is "to transform it once again as a means of armoring the conservative political hegemony and discipline the Turkish society according to neo- conservative principles" (Yılmaz, 2015, p. 383). Following his argument, I frame the transformation of psychiatric health care services as a demonstration of neoconservative governmental rationality. Yet this rationality not only serves to strengthen the family on the basis of caregiving relations, but also transforms it according to the neoliberal demands. As I explain below, this is manifested the cash-

¹¹ In their article on the gender inequality in contemporary Turkey, Acar and Altunok (2013) point at the neoliberal and neoconservative governmental rationalities which are simultaneously at play under the regime of AKP. They argue that the intersection of these rationalities strengthen the gender inequality as they leave disadvantaged groups open to the detrimental effects of dominant power relations in Turkey

for-care transfers introduced by AKP, which are granted to the mentally afflicted people residing with their families. In this arrangement, the benefits are not given to women as a compensation for their labor since care is not seen as a form of work (Altuntaş & Topçuoğlu, 2014; Kılıç, 2010). Yet these transfers sustain women's role in care provision whereas essentially they are pushed into vulnerability as their labor in the domestic sphere, including that of caring, is essentially ignored. Within this framework, the existing gender inequalities in the labor market are further maintained and simultaneously women are made dependent on their working husbands or fathers (Ulusoy, 2013, p. 119).

My take on the neoliberal context in Turkey and its impact on the relations at the domestic sphere necessitate a more nuanced explanation. In this sense, the theoretical framework that I draw in this chapter predominantly stems from Michel Foucault's conceptualization of governmentality. Governmentality can simply be defined as an analytical tool used in examinations of governmental rationalities and political technologies in contemporary societies (Foucault, 1991). Taking Foucault seriously, I define government broadly as a conduct or, more particularly as a conduct of conduct which points to a wide space between individual practices and the rationalities as well as the techniques concerned with the government of the state. By the term neoliberalism, I refer to the attempts to project the principles of the market economy onto a general art applied by a government. In this regard, I take AKP's healthcare reforms as efforts to create a system in which all the citizens answer the demands of neoliberalism. My aim is to focus reader's attention to the implications of the reforms on the mental healthcare services for the lives of women caregivers in the families, as their role in the provision of care for the mentally afflicted people has largely been sustained.

In light of this conceptual framework, I divide this chapter in two sections which highlight the transformations in the healthcare system. The first one covers the era between WWII and the 1980s in which I dwell on the transformation in healthcare system with a comparison of the worldwide policy trends in that period. The second section is divided into two parts; firstly, I present a brief analysis of the policies on decarceration in the world which provided the basis of community-based treatment in various countries years after. Secondly I include an analysis of the neoliberalisation of the healthcare services in early 2000s when AKP came to power in Turkey. I dwell on the period when the first TRSM was opened under the regime of AKP in 2008.

2.2 Contextual analysis

People suffering from symptomatic disturbances are given a psychiatric diagnosis under very poor conditions in Turkey. The treatment they receive is equally poor once they are diagnosed. These are the words of a specialist nurse working in women's clinic in Bakırköy Ruh ve Sinir Hastalıkları Hastanesi (Bakırköy Psychiatric Hospital):

In our clinic, average length of stay is two months. People who are not diagnosed before coming to this clinic get a diagnosis short after their stay here. But a patient should be clinically examined for at least 6 months before she is given a diagnosis. At least this is what it says in the psychiatric literature. (C. Altunsoy, personal communication, 2017)¹²

However, when I ask Cemre about the cause of the problem, there was no critique or a reference concerning the practice of diagnosing in the hospitals. On the other hand, virtually all the health professionals in the hospital, including her, have

¹² “Kliniğimizde ortalama yatış süresi iki ay. Kliniğe gelmeden önce bir teşhisi olmayan insanlar burada yatışlarından kısa bir süre sonra teşhis alıyorlar. Ama aslında bir hastanın teşhis almadan önce en az 6 ay klinik olarak incelenmesi gerekiyor. En azından psikiyatri literatüründe böyle geçer bu.”

primarily complained about the lack of rooms, specialists and personals in the hospital. They directly attribute these inefficiencies to the malpractices in the services.¹³ These mental health services are generally public and majority of them are closed institutions where patients stay for long terms. Current average length of stay in these institutions is very long which brings into question the quality of treatment provided. As was also documented by the civil watching commission of RUSİHAK (Human Rights in Mental Health Initiative), today's main mental health institutions are referred to as DEPO (storage) hospitals by the health professionals (RUSİHAK, 2014). This is due to the fact that numerous inpatients are living as if in a storage compartment where they have to share the same beds, clothes and even toothbrushes with each other. Here I define the psychiatric hospitals as zones of social abandonment where people are severely disregarded.¹⁴

In what follows, I explain the transformation in psychiatric care that took place in the early 2000s which clearly had an impact on the workings of the psychiatric services in Turkey. This transformation is demonstrated the most in the establishment of community mental health centers. Before explaining this shift, it is necessary to present a brief history of the modernization of psychiatric services in the context of Turkey.

¹³ My statements here stem from the observations I made and short interviews I conducted in a few days in the clinic. As I do not have any recordings for the interviews which were more like conversations, I provide paraphrased accounts of our conversations.

¹⁴ In his study on Vita, Brazil, Joao Biehl investigates the lack of governmental and medical attention towards the jobless, the impoverished, the homeless and the mentally challenged people in the city. He defines it as "the end-station on the road of poverty; [...] where living beings go when they are no longer considered people" (Biehl, 2015, p. 2). In his analysis, he designates Vita and places alike as "zones of social abandonment" (p. 2). Especially after having heard the term storage several times, I find it proper to use Biehl's phrase to define the conditions in the closed mental institutions in Turkey.

2.2.1 From protective welfare state to the limited attempts in the healthcare reform

The end of WWII marks an important period in the transformation of the provision of healthcare services in Turkey. This period appears to be effected by the international patterns and developmentalist economy policies in the national context. Pre 1960s in general is regarded as a period when Turkey takes the form of a “protective welfare state”. In this model, social rights are given solely to citizens who are attached to labor market and thus constitute only a very limited portion of the society.¹⁵

In 1960s, Turkey starts to expand its public capacity for the provision of healthcare services in line with the developments in countries of Western Europe. A 15-year government project, namely the Socialization of Health Services Program, was introduced in 1961. The project aims to establish a kind of healthcare provision system that is vertically organized and that serves all the citizens, from those in the smallest villages to those in larger ones. As was argued by Yılmaz (2017) in his book on the healthcare reform in Turkey, this policy paradigm promotes a “tax-based universal national healthcare system” that has a solid approach of public health (Yılmaz, 2017, p. 54). This transformation in the organization of the modes of government and the political rationalities can be taken as a reaction to “populist, clientelistic and authoritative” policies of The Democratic Party (Demokrat Parti — DP) (Kohlwes, 2014, p. 37).¹⁶ According to the authorities of Republican People’s

¹⁵ See Rudra (2007) and Yılmaz (2017) for analysis on Turkey as a protective welfare state.

¹⁶ I borrow this argument from Stefan Kohlwes’ thesis on the transformation in the health care system in Turkey. His study is an interpretation of different historical episodes of Turkish health policies since the late Ottoman Empire. It pays special attention to the changing political conceptions of health as well as to the strategies and techniques that governments relies on to effect the conduct of receivers and providers of health services (Kohlwes, 2014).

Party (Cumhuriyet Halk Partisi — CHP) and to the coup leaders, DP caused the decline of state development for the sake of personal interests. This unstable period had repercussions on the health insurance system which continued until the military takes over in 1980. The attempts to widen coverage of health expenditures, which the Law on the Socialization of Health Care demonstrates the most, fail substantially (Kohlwes, 2014, p. 37).

However, when urbanization accelerates in 1980s and 1990s, the healthcare services cannot meet the increasing demand of the public. When the cost of the services cannot be afforded by the government, people get rejected by the hospital administrators. In this context, the neoliberal restructuring of the Turkish Republic starts to take place under the rule of Motherland Party (Anavatan Partisi — ANAP). Thus the country becomes among the first “periphery” countries applying the rationality of neoliberalism whereas neoliberalism already gains strength in USA and UK (Kohlwes, 2014, p. 37). Consequently, competition and privatization are promoted as solution to the problems of the state which is caught in indebtedness and inefficiency. Overall, this transformation paves the way for the diminishing of the state’s role as the provider of services; while paradoxically families’ inadequacy in fulfilling their “de facto role of welfare provision” becomes visible in this period (Kılıç, 2010, p. 166).

Within this framework, the implementation of Green Card policy in 1993 marks an important step toward the provision of the healthcare services for all the citizens in Turkey, while manifesting that families’ inadequacy in providing welfare is formally admitted. As was argued by Ayşe Buğra, Green Card model is an important “procedural formalization” in the history of public policy which grants the poor the right to access the services of healthcare in Turkey (Buğra, 2008, p. 214).

The healthcare provision in this period consists of a social insurance-based healthcare system and its “governance, financing and provision” are led by the state (Yılmaz, 2017, p. 4). Yet this system does not provide a universal coverage that ensures provision of healthcare services for each and every citizen as it provides healthcare only for the poor citizens without insurance, “on the basis of a means-test” (Kılıç, 2010, p. 166). In this sense, implementation of a significant healthcare reform does not enter the political scene until 2003 in Turkey.

In 1983 elections that takes places after the military coup, the Democratic Left Party (Demokratik Sol Parti—DSP) comes first and constitutes a coalition government with ANAP and the Nationalist Action Party (Milliyetçi Hareket Partisi—MHP). This coalition government does not succeed in dealing with the consequences of 1999 Earthquake, an important “natural” disaster that struck many towns in northwestern Turkey on August 17, 1999. On the other hand, its economic policies leads up to the Republic’s largest economic crisis in 2001, in spite of its progress in the accession process of European Union (EU). As I explain below, in this instable period between 1999 and 2001, the coalition government does not succeed in dealing with the ramifications of several events which had severe consequences on citizens’ lives. Respectively, these events are “the major earthquake on August 17, 1999; the political crisis of February 2001 and the following economic crisis of March 2001” (Evren, 2012, p. 17). Under these circumstances, the coalition government starts losing power and fails to gain seats in the parliament. Therefore, before AKP came to power in 2002, the problems concerning healthcare provision already becomes visible both to the political actors and to the public.¹⁷ As a reaction

¹⁷ For example, a study on health expenditures cited in Yılmaz’s book shows that for healthcare services, the citizens in Turkey made a considerable amount of out-of-pocket expenditures. They constituted approximately 29 per cent of total expenditures for healthcare services in 2000 (Yılmaz, 2017, p. 70).

to these, the AKP promises a transformation in the healthcare system. In what follows, I will highlight several events that took place in the period between the late 90s and the early 2000s that had crucial ramifications for the transformation of psychiatric services in Turkey during AKP period:

In the history of Republic, 1999 Marmara Earthquake stands as one of the most catastrophic events causing the death of thousands of people. It is also regarded as a demonstration of the coalition party's lack in responding to a national crisis. This disaster has a considerable, although limited, impact on the transformation of psychiatric services in Turkey as well: in 23 November 1999, Urgent Reconstruction of the Marmara Earthquake Project (Marmara Depremi Acil Yeniden Yapılandırma Projesi — MEER) is signed by the government and World Bank after the earthquake.¹⁸In the report, there is a subsection on the improvement of the national mental health services that offers a project covering the period between 2001 and 2004. A considerable budget of 5.15 billion dollars is reserved for the project (Ulaş, 2008). Yet a more comprehensive and long term planning is made years later in 2006, after the release of a report about human rights abuses in Turkey by Mental Disability Rights International (2005). A more solid program enters the political scene in 2006 when National Mental Health Action Plan is published with the cooperation of World Health Organization (WHO). I will dwell on the implications of this plan in the second section of this chapter.

On the other hand, the first Disabled Council in 1999 is organized on the demands by UN with the purpose of serving disabled citizens by forming

¹⁸ In his study on the post disaster Turkey after the 1999 earthquake, Dole (2015) explores the struggle of the residents of the Saddam's Homes against the provincial government. Saddam Homes are gifted to the earthquake survivors by the then president of the Iraq government, Saddam Hussein in 1999. Dole argues that the houses emerge out of an interesting convergence of the bureaucratic regimes of charity and property with psychiatric expertise.

governmental bodies. In his thesis on the framework of disability assessment and classification in Turkey, Evren (2012) analyzes prominent disability policies from late 1990s until 2010 and defines them as parts of an ongoing performance of the Turkish state. He argues that “the unable state of the late 90s’ gave way to a new characterization of the Turkish state in post-2002, marked by its ability to appear as progressive and aggregated” (p. 14). He argues that the organization of the disabled council symbolizes state’s attempt to perform in advanced states’ level. Following Evren, I also define the mental health projects between 1990s and 2000s as “advancement” oriented performances of the Turkish state.¹⁹ Within this context, it can be argued that these projects reflect the state’s anxiety to keep up with the modern Europe. Here, these ambitious attempts of the Turkish state to reach the level of the so called developed West can also be defined as a modernization allegory; performed by the Turkish republic as the political successor of the Ottoman Empire, which had long constituted the modern West as its other (Davis, 2012, p. 26).²⁰

In what follows, I shed light on the period when neoliberalism became the governmental reason under the AKP regime.

¹⁹ Evren (2012) defines performance as “a mode of action where the presentation of an object is prior to the object, and determines the effects that the object produces” (p. 16). When I refer to performance, I also point to the modes in which the performances are presented to audiences, both in national and international context. Turkish government’s definition of disability reflects a performance of the state that was performed in the post-2002 (the period marked by AKP’s coming to power) Turkey.

²⁰ Here, I borrow the phrase modernization allegory from Elizabeth Davis who applies the term in her ethnographic analysis of the psychiatric facilities in a border village in Greece. She investigates the psychiatric reform movements which, as she argues, demonstrate Greek authorities’ enduring admiration to be a welfare state. In this regard, she refers to these policy reforms in Greece as “a paradigm and an allegory of modernization” (Davis, 2012, p. 26).

2.2.2 The 2000s: Mental health policies in the neoliberal era

In this section, I trace the developments in the healthcare system with a focus on the transformation of psychiatric facilities in Turkey. Firstly, I present the debates on decarceration in the world context whereas in the second part I briefly analyse the neoliberal context when AKP came to power. The transformation of psychiatric services in Turkey is demonstrated more clearly in the establishment of the community mental health centers. I focus on the implications of the establishment of these centers and on their role in sustaining the normative framework concerning family caregivers' role in Turkey.

2.2.2.1 On decarceration: Transition towards community-based treatment model in the world

Analyzing the establishment of community mental health centers requires an understanding of the global dynamics. There are different explanations as to the reasons triggering their establishment in different countries, yet there seems to be a general pattern in terms of aiming a transition towards a more humanitarian psychiatry in countries where it has occurred (LaFond & Durham, 1992). Yet, from a political-economic perspective, this transformation is also explained as an attempt of the state to relieve its burden on welfare provision (Scull, 1977). On the other hand, there are also studies which show that this transformation was uncoordinated and underfunded which was not beneficial especially for the service users, especially in the US (Cockerham, 2003; Mechanic, 2008; Torrey, 1997).

It has been argued by many social scientists that the failure of Keynesian policies in balancing the need for the extraction of surplus value and the retaining the political support caused fiscal crises, primarily in western industrialized countries.

This crisis resulted in policy shifts in many areas. However, as for the policies concerning the mentally afflicted people, there had already been changes in the legislation concerning the mentally afflicted people in different countries, primarily on the basis of “allowing for early treatment and voluntary admission” (Goodwin, 1997, p. 8). Perhaps more significantly, many mental health institutions also started to be closed following this period. These closings opened the way for the community-based model of treatments which basically prioritize that the afflicted people are treated within the community, in services where they do not have to stay 24 hours a day. Below, I present a brief analysis of the global context in the late 20th century when these policies towards deinstitutionalization entered the political scene across the globe. I will start with a brief analysis of the context in the United States:

In 1960s, a broad based movement questioning “the legitimacy of standard psychiatric theory and practice”, namely the anti-psychiatry movement takes place in the United States (Whitley, 2012, p. 1040). Not only the mentally afflicted people themselves, but also their relatives as well as critical psychiatrists participate in this movement. Among the psychiatrists there were David Laing, David Cooper, Franco Basaglia and Thomas Szasz who became the leading figures of the movement and produce academic writings constructing its theoretical base.²¹ With a self-reflexive perspective, they question the dominant psychiatric practices in analyzing the complex psycho-social behavior and basically depict their mistake in their way of expressing and organizing the psychiatric knowledge. Having received the support of

²¹ See for example Szasz (2010). Also, there are more recent oppositions to psychiatric treatments in the United States. For example, in his analysis on the increase in the severe mental health illness in the United States, Whitaker (2010) points at the curious relation between that increase and the rise of the use of medications in the United States. Later, his work inspired the non-profit organization called MindFreedom International, which campaigns for human rights in mental health across the globe (<https://mindfreedom.org/>).

many people in the political atmosphere of the 1960s, the movement becomes successful and influences the policies towards deinstitutionalization considerably. Yet, understanding the factors underpinning deinstitutionalization necessitates a more interdisciplinary and comprehensive approach. In what follows, I compare dominant explanations of deinstitutionalization:

In his book on decarceration policies in United States and England, Scull (1977) defines decarceration as a state policy that refuses the admission of mentally afflicted people to the psychiatric facilities by discharging many “ex-patients” and encouraging them to be in the community. From a macro sociological perspective, Scull suggests that the triggering forces behind decarceration are the emergence of different perspectives concerning working class’s participation, accelerating reliance on welfare as a crucial constituent of controlling the labor force and the emergence of the fiscal crisis in that period (Scull as cited in Speigman, 1979, p. 68). He argues that the fiscal crisis is engendered by advanced capitalism’s need to socialize the costs of production and that consequently deinstitutionalization policies are mainly motivated by the attempts to modify a market system that has been “inherently self-destructive” (p. 68).²²In this regard, he points at the care and social security crisis in United States and in Europe in 1970s, which is triggered by the increase in life expectancy and the frequency of diseases. Within this framework, Scull explains the roots of the transition to the community based services by governments’ reliance on the provision of the care at the domestic sphere which characterizes their approach to

²² Scull (1977) also points to the failure of decarceration policies that is demonstrated in increasing public opposition. As he explains, many citizens feared for their safety as the patients were discharged from the hospitals without any supporting policy that could stimulate their integration. Besides, this inefficiency led to the springing of private hospitals while the poor were dumped into decaying urban centers. Here Scull argues for the existence of “a pro-decarceration lobby” that these private institutions’ owners constitute (Scull, 1977).

the social care services. This paradigm stimulates the intergenerational and traditional family care and in this sense it resonates with the neoliberal and neoconservative regime of AKP. As I elaborate on below, AKP's "sacred familialism" facilitates the shifting of Turkish state's welfare responsibilities, particularly that of care, to families in contemporary Turkey.

However, Speiglman (1979) argues that Scull's overemphasis on economy blurs our vision and makes us blind to the contributions of the antipsychiatry movement. He defines antipsychiatry movement as a political struggle of the patients, their relatives as well as psychiatrists against a debilitating and repressive reality and states that deinstitutionalization is not entirely "a ruling class device to ease the fiscal crisis" (p. 69).²³ Additionally, there are criticisms within the political economy perspective. In his comparative study on mental health policies, Goodwin (1997) opposes the argument that deinstitutionalization was a governmental reaction to the fiscal problems. He analyzes the relationship between fiscal deficits and deinstitutionalization by comparing the number of beds to the percentage average borrowing, and argues that the welfare expenditure cuts and therefore deinstitutionalization are not related to the governments' reactions to the fiscal problems (Goodwin, 1997, p. 54). In light of these different accounts on deinstitutionalization, it can be argued that there is heterogeneity in governments' reactions to fiscal crisis. Yet Scull's analysis stands as an important account on the role of economy in influencing social policies.

On the other hand, some scholars emphasize the impact of the introduction of anti-psychotic medications on the policy shift towards deinstitutionalization. For

²³See Madianos (2002) and Morzycka-Markowska et al. (2015) for studies on antipsychiatry movement and deinstitutionalization in Greece and Italy, respectively.

example, Jenkins (2015) argues that Thorazine and its derivatives produced remarkable results in sedating patients and had facilitated the decrease in the numbers of patients admitted to the hospitals, especially in the United States. Yet she also notes that introduction of antipsychotic medications is not considered as the sole reason behind the emptying of the asylums here. In fact, there were many people who were not even responsive to medication treatment.

Lastly, in his study on the recent mental health reforms in the UK, Australia, Italy and Brazil; Hazelton (2014) evaluates these countries' deinstitutionalization practices and argues that they provide "employment, education, housing and income support" services in similar ways, despite the differences in their deinstitutionalization practices (p. 237). He emphasizes that the collaboration between non-governmental and governmental organizations in providing the fundamental services for the outpatients is necessary. In this regard, his analysis reveals that the inadequacies of deinstitutionalization are linked to inefficient social support and aftercare services including crisis intervention, psychosocial rehabilitation, income support and housing (Hazelton, 2014).

All in all, these different analyses on deinstitutionalization policies demonstrate the complex reasoning behind their implementation. Yet the attempt to use that policy as a means of returning people to their everyday living arrangements seems to fail in many countries. While it was assumed that people will be better off when located in the community, there are solid evidences proving that community care is not necessarily always better than what ex-patients have been receiving in the institutions. In fact, as Goodwin argues, "it may be worse" (Goodwin, 1997, p. 119). For most of the cases, one of the fundamental problems is the distribution of resources for mental health and it results in the inefficient funding of community

based services.²⁴ Having mapped the emergence of the community based treatment model and implications of its implementation in different countries here, I now continue with an examination of the Turkish context.

2.2.2.2 Context of Turkey: Transformation in the healthcare system and the establishment of the community mental health centers (toplum ruh sağlığı merkezleri) AKP rises to power at a time when the healthcare provision problems are already visible to citizens. It comes with an agenda about a healthcare reform which aims to change many arrangements in the area of medical services, including those of mental health. Yılmaz (2017) argues that despite the fact that the reforms in the emerging market economies mostly took place in a similar path, the global policy paradigm did not sustain a parallel route for marketization in every country, including Turkey. In fact, the grounds on which the policies were implemented were mostly dependent on different global and domestic political factors. In this regard, AKP introduced The Turkish healthcare reform with the goal of “generating public legitimacy in its first-term rule and during an economic boom period that lasted until the mid-2010s” (p. 108). Yet, the party followed the dominant pro-market healthcare transformations in countries where the market economies were emerging and introduced the Turkish healthcare reform accordingly.

Here it is important to note the sociopolitical context that largely shaped the nature of transformation in the healthcare system as well. As Buğra (2012) argues,

²⁴ There is a significant absence of evaluative studies assessing whether outpatients are better off when placed in the community. See Geoffrey Nelson and his team-mates’ ethnographic study that analyses outpatients’ integration to community in consumer-run organizations. The study basically verifies the assumption that consumer service users are better integrated in the community in the long run while the amount of hospitalization in general decreases through “stable housing and employment programs” (Nelson et al 2006).

AKP regime becomes more authoritarian as well as conservative after the EU integration process which lost influence. After this period, the party's religious conservatism comes forth, which is manifested the most in its discursive rhetoric of sacred familialism. As Özbay (2013) argues, this sacred familialism cannot be regarded as a return to past influenced by an Islamist perspective and is involved extensive family norms (p. 110). Although these characteristics are still present, sacred familialism is the product of globalization and demonstrates a neoliberal ideology. In this regard, it also differs from the Mediterranean familialist welfare regimes, with which Turkey was largely associated (Buğra, 2008; Buğra & Keyder, 2006; Dedeoğlu & Elveren, 2012; Saraceno, 2002). In these regimes, state-society affairs have a more informal, personal quality which reminds the logic of relations in the family. This informal quality directly informs what individuals could ask from political authorities. Consequently, it has inevitable repercussions on the working of healthcare services as welfare responsibilities, including the provision of care for the children, the elderly and the disabled, is taken in a normative framework. In this normative framework burden of care is heavily shifted to the families, particularly to the women who are attributed the caregiver role. However, in the "less familialist systems" gender equality is formally supported as "women are encouraged to work" (Kılıç, 2010, p. 169). In this regard, as I discuss below, the sacred familialism of AKP differs from the former Mediterranean familialist welfare regimes as it addresses neoliberal market demands while applying a neoconservative rationality.

On the other hand, this sacred familialism does not only manifest itself in the discursive level as there have been related institutional transformations as well. These transformations are manifested the most in the establishment of the Ministry of Family and Social Policies (Aile ve Sosyal Politikalar Bakanlığı — ASPB) in

2011 (Akkan, 2017, p. 8). Before the establishment of ASPB, the Social Services and Child Protection Institution (Sosyal Hizmetler ve Çocuk Esirgeme Kurumu — SHCEK) was in charge of the provision of services to the children, the elderly and the disabled. The previous Directorate for Family and Social Research and the Directorate of the Status of Women and Women’s Issues was subsumed into this Ministry and its mission is basically defined as supporting and protecting the family institution (Akkan, 2017).

An important step regarding the disabled people is taken by the ASPB with the publication of “The Care Services Strategies and Action Plan” in 2011. This plan emphasizes the healthcare needs of the disabled people who cannot fulfil their personal needs on their own and points at the importance of care services (Ministry of Family and Social Policies, 2011). What is particularly important for the topic of this thesis is the clear preference for the home-based care in this plan (Ministry of Family and Social Policies, 2011). This preference for home-based care is manifested in the introduction of cash –for- care transfers. To be eligible to benefit from this system, a person must have a diagnosis that proves at least 50 percent of disability. Also, the mentally afflicted people are required to live in the same household with their families so that they can receive the beneficiaries (Akkan, 2017; Altuntas & Topcuoglu, 2014).²⁵ Today, approximately 500,000 people receive cash- for care transfers whose numbers were only around 30,000 in 2007; demonstrating citizens’ increasing negotiation with the normative framework concerning their role in care provision. (Directorate General of Services for Persons with Disabilities and the

²⁵ However, I should also mention the simultaneous marketization of care provision which followed this cash transfer scheme. As Akkan (2017) analyses in her article, the number of the private facilities have also expanded “from 10 in 2007 to 174 in 2017”. Nevertheless, she observes that the Ministry’s priority remains to be supporting “care providers within the family and families who provide care for a disabled member” (p. 11).

Elderly, 2018). It is also significant to note here that another eligibility criteria is the welfare dependency evaluation (muhtaçlık değerlendirmesi); which examines the income, wealth and expenditure of all the members in the household (Ministry of Family, Labor and Social Services, 2019). While this emphasis on the household reflects the continuing familialism of the state; the fact that cash benefits are granted only to the low income people reveals that the care needs of the higher income people are essentially neglected. Yet the dependency on care is an inevitable condition and therefore the lack of care is a risk faced by every human being. I will elaborate more on this aspect further below.

This scheme clearly manifests the shift in the burden of care from the shoulders of the state to the women in the families whose labor is largely taken for granted (Kılıç, 2010, p. 173). While the commodification of the unconditional labor renders visible the women's labor in the home sphere, it is paradoxically not regarded as a form of work since the cash is not granted as a wage for the labor of the caregivers who are consequently exempt from social security for their labor as well (Altuntaş & Topçuoğlu, 2014, p. 315). Rather, these transfers are provided as beneficiaries which largely resonates with AKP's neoconservatism. Within this framework, women are pushed into vulnerability as their labor in the domestic sphere is essentially ignored and in the current social security context, they are made dependent on their working fathers or husbands (Ulusoy, 2013, p. 119).

Here, I would like to open a parenthesis and elaborate on some other policies introduced by the AKP which manifest the paradoxical intersection of neoliberalism and neoconservatism informing its governmental rationality.²⁶ “Home-based

²⁶ Another manifestation of this is the Conditional Cash Transfer (CCT) program which grants benefits to mothers who belong to the “poorest 6% of the population”, and it basically aims at improving the children's use of education and basic health services (Kılıç, 2010, p. 173). While the

occupations, including both subcontracted and micro-credit jobs” pave the way for a work-family reconciliation that allows women to perform their duties in the domestic sphere while maintaining the gendered division of labor (Kılıç, 2010, p. 177). This work-family reconciliation policy is further manifested in the “Family Package” that was launched by AKP in 2015.²⁷ This program brought new labor market regulations which also introduced part-time jobs with flexible working hours, for women with children as well (Akkan, 2017, p. 9). Although these arrangements indicate a shift towards a relatively more gender neutral framework, it essentially makes women more dependent on the market as they are not integrated to it.

Moreover, the existing gender bias in the labor market is furthered as women are concealed more to the domestic sphere with the home-based occupations (Kılıç, 2010, p. 177). Today, among the other OECD countries, Turkey comes the last with regards to women’s participation in labor force as only 27.8% of its women population are employed. In 2012, 61.3% of women who do not work explained their unemployment with the domestic responsibilities (as cited in Ulusoy, 2013, p. 114). Relatedly, İlkkaracan (2010) shows that a significant obstruction regarding women’s employment is the caring responsibilities attributed to them.

The reforms in the mental healthcare system require further attention here. A comprehensive and long term plan concerning the provision of mental health services was not prepared after the release of Mental Disability Rights International’s (MDRI) report about human rights abuses in Turkey. Following this report, the National Mental Health Action Plan was promulgated with the collaboration of World Health

program benefits many women and children, the fact that it is paid only to the mothers fosters the gendered division of labor in the domestic sphere (Kılıç, 2010). See also Ecevit (2012).

²⁷ See İlkkaracan Ajas (2012) for a study on the variety of “work-family balance environments” on seven OECD member countries.

Organization (WHO) in 2006. The plan consisted of eight modules which concern the organization of mental health services, the child and adolescence mental health policies, finance of mental health services, the treatment and rehabilitation services, improvement of the quality of these services, the legal arrangements in the area of mental health, the education, research and human resources in that area (Ulaş, 2008, p. 11).²⁸ However, despite the stir the report had caused, the attempts to fulfil its objective are still in the gristle. Nonetheless, within the general framework of the healthcare reforms at the beginning of the 2000s and following the release of the National Mental Health Action Plan in 2006, the Ministry of Health declared its decision to establish TRSMs across the country while touting its benefits for mental health treatment in April 2009. In fact, the first community mental health center was opened in Bolu, in 2008 as a pilot project. Back then, there were 223 more centers that was planned to be established in nine cities where there are mental hospitals. Provision of these services to all the rest of the cities was also included in the longterm plan.²⁹ However, TRSMs were started to be established in 2011, after the release of the second National Mental Health Plan in 2011 (Ministry of Health, 2011a). Today, there are 175 TRSMs in Turkey, which are generally located in big cities. The centers are tied to the Public Hospitals Administration of Turkey (Türkiye Kamu Hastaneleri Kurumu) and work under the state hospital in the region they are appointed to, which is generally the closest one to their location (Ministry of Health, 2019). People diagnosed with psychotic disorders such as schizophrenia or with chronic mental illnesses such as mood disorders are generally referred to “patients with serious mental illness” in the Prescript on the Community Mental Health

²⁸ The original text of the National Mental Health Action Plan 2006 is not available online. Here I borrow from Halis Ulaş’s brief account on the transformation of psychiatric services (Ulaş, 2008).

²⁹ See Alataş (2009) for an account on this.

Centers (Toplum Ruh Sağlığı Merkezleri Hakkında Yönerge) (Ministry of Health, 2014, p. 1). They are accepted to the centers on condition that they are sent by the closed mental institution or the outpatient clinic where they were treated before. Similarly, Family Health Centers (Aile Hekimlikleri) and Community Health Centers (Toplum Sağlığı Merkezleri) are obliged to report to the Public Health Directorate (Halk Sağlığı Müdürlüğü) where the records of the patients are kept and sent to the TRSM the patient will be accepted to. The patients or their family members can personally apply to centers as well. Yet they are only accepted with the permission of the psychiatrist or the specialist working in the center (Ministry of Health, 2014, p.5)

The TRSMs are generally designed to rehabilitate the mentally afflicted people, who are referred to as patients in the centers, and to provide these patients with psychosocial support programs. These programs include group therapies, rehabilitation activities as well as occupational treatments provided with painting, music and computer classes or with activities like wood painting (Ministry of Health, 2014, p. 3). Unlike the former institution based treatment model which principally focuses on curing the symptoms of the patients while isolating them, community based treatment model applied in TRSMs works on a more comprehensive treatment and follow-up plan that aims at facilitating patients' social integration. In this regard, they work in cooperation with several other institutions such as the Provincial Directorate of Family and Social Policies (Aile ve Sosyal Politikalar İl Müdürlüğü) and the Municipal Directorate of Social Affairs (Belediye Sosyal İşler Müdürlüğü) as well as with the abovementioned establishments (Ministry of Health, 2014, p. 6). An important component of this social integration agenda is demonstrated in the emphasis on families' involvement in the treatment and rehabilitation plan. Indeed, the general mission of the TRSMs is stated as follows:

The service model in Turkey is focused on the service users and the family; and it aims at improving the capacity to support the patient and their family members who have mental problems. The main constituents of this model are as follows: to provide efficient treatments for improving personal function; family support, psychoeducation; coordination of psychosocial support services.³⁰(Ministry of Health, 2011b, p. 6)

As it can be seen from this statement, in the back-stage of community-based treatment model, it is assumed that family caregivers will be supporting the outpatients for the duration of their treatment. This is also reflected in the formation of the travel teams (gezici ekipler) that visit the family members when the patients skip their visits to TRSM. Also, while the personnel in the center including those in the travel teams, primarily work for guaranteeing patients' regular treatment in the TRSM; they are also responsible for informing the family members about the treatment and follow-up plan as well as for basically ensuring that family members fulfil their role in that plan (Ministry of Health, 2014, pp. 4-6).³¹

It can be argued that in this community-based treatment model, the mentally afflicted people are not seen as capable of living apart from their families and this is demonstrated the most in the design of the TRSMs as auxiliary modes of care. In this thesis, I focus on the implications of this on the lives of family caregivers and point out that they are predominantly women in most of the countries, including Turkey. It should be noted that there is not an extensive literature on the gender dimension of psychiatric caregiving. Yet, as I show in the second chapter, there are several studies in the psychiatry and psychology literature that investigates this aspect.³²

³⁰ "Türkiye'nin hizmet modeli, hizmet alan ve aile odaklı bir model olup, hastayı ve ailelerin ruh sağlığı sorunları bulunan aile bireylerini destekleme kapasitesini güçlendirmeyi amaçlamaktadır. Bu modelin kilit bileşenleri aşağıdaki gibidir: Bireysel işlevi iyileştirmeye dönük etkin tedaviler sunulması; aile desteği, psikoeğitim; psikososyal destek hizmetlerinin koordinasyonu. (Toplum Ruh Sağlığı Merkezleri için Çalışma Rehberi, 2011, p. 6)"

³¹ See for example the TRSM Education Form (Toplum Ruh Sağlığı Merkezi Eğitim Formu), an official signature form that ensures that both the patient and the family members participate in the education session on a particular aspect regarding patients' treatment and follow-up plan (Ministry of Health, 2016).

³² See for example Awad and Voruganti (2008); Lowyck et al. (2004); Nasr and Kausar (2009).

On the other hand, it can be argued here that the mental health reform in Turkey is more of a “paradigm and an allegory of modernization” for a government which at the time was aspiring to construct itself as a humanitarian welfare state (Davis, 2012). The 2000s in general can be seen as a period when the paradigm of human rights came to the fore. In this period, the people with disabilities were started to be seen as “subjects” having exclusive rights; not as objects of medical treatment, charity or social protection (Evren, 2012, p. 29). Such that, in 2006, fifty-eight years after the Universal Declaration of Human Rights by the United Nations, a new convention was added in order “to change attitudes and approaches to persons with disabilities” (as cited in Evren, 2012, p. 29). The Convention on the Rights of Persons with Disabilities was signed by the Turkish government in 2008 and it was underscored in all pertinent governmental documents that it is among the first states signing the protocol; an ideological performance aimed at demonstrating “simultaneity of Turkey with the advanced world” (p. 33).

In other respects, discrepancies emerged in the implementation of the mental health reform plan. It became clear that the Turkish government was not as passionate as its European counterparts in pursuing an exhaustive deinstitutionalization policy and transition to community treatment. To further illuminate this stance, not a single psychiatric hospital was closed after the promulgation of National Health Plan in 2006. Before explaining the current conditions in the TRSMs, I would like to open a parenthesis and explain how I generated insight on the workings of the TRSMs through my engagement with RUSİHAK.

As I mentioned in the introduction, it is the only NGO that is concerned with the rights of mentally afflicted people in Turkey. Established in 2006, they run

different projects on issues such as fighting against stigma, reporting the life conditions of inpatients in mental health institutions and on creating alliances with similar human rights initiatives in certain European countries and in USA. Their current project aims at creating a perspective of deinstitutionalization among disabled people organizations and service providers in Turkey. The project team paid visits to five different cities in the country including İstanbul, İzmir, İzmit, Adana and Ankara. I have been a volunteer at this project and in fact became the assistant coordinator for a period of time. The project team organized symposiums on deinstitutionalization in these cities and then made follow-up visits to the services in order to gain a better understanding of the functioning of the community mental health, care and rehabilitation services and the service providers' perceptions about it. During my assistantship I visited several services and these visits enabled me to meet people from diverse backgrounds, including the afflicted people themselves, their relatives, health care workers, psychiatrists, volunteers of the friends' alliances for schizophrenic people and patient activists etc. These affiliations enabled me to generate insight into the conditions in the existing community mental health centers. In this regard, it can be observed that these centers continue to be inefficient in recognizing the outpatients' needs distinctive to those of inpatients, such as their need to be transported to the TRSM, and from there to their home, on a regular basis. TRSMs also fail to compensate the needs of the inpatients who still receive treatment in the closed mental institutions, especially as their number is still insufficient. These centers operate as units dependent on the families of the outpatients particularly as they are expected to reside with their families. This demonstrates Turkish state's ongoing reliance on families for welfare provision while revealing an important aspect of the burden of care women caregivers are left with in the domestic sphere.

2.3 Conclusion

In this chapter, I provide an analysis of the transformation of the psychiatric healthcare services in Turkey and I point at the dynamics at the international and national context that pave the way for this transformation. Following the policies towards deinstitutionalization, community treatment model becomes prominent in most parts of the world. Unlike in the custodial mental hospitals where inpatients are largely isolated from the society, in this model the patients are treated in community settings with a humanitarian perspective that aims at their social integration through the application of rehabilitative treatment. Yet as I demonstrate, there are different explanations as to the reasons triggering this transformation in different parts of the world. For example, from a political economic perspective, deinstitutionalization policies in United States are seen as a reaction to fiscal crisis and they are framed as state's attempts to socialize the costs of care. This perspective is criticized for economic reductionism which undermines the impact of antipsychiatry movement in stimulating the transformation in question. As for the context in Turkey, there does not appear to be a general trend towards a complete deinstitutionalization in state policies. However, establishment of the community mental health centers are part of the mental health reform introduced by the AKP regime. The initial stages of this reform process takes place after the promulgation of the National Mental Health Action Plan. In my examination, I point at how this plan followed the report by Mental Disability Rights International report on the human rights abuses in the mental health institutions in Turkey. Within the framework of EU integration process, these initial stages appear as an allegory of modernization demonstrating Turkish state's aspiration to construct itself as a humanitarian welfare state. This transformation reaches its final phase through the establishment of community

mental health centers across the country, after EU integration process lost its influence. In this thesis, I focus mainly on the implications of this newly introduced model on the lives of women caregivers who reside with their mentally afflicted relative. I show how caregiving responsibilities are attributed to women as part of a general social policy framework in which the welfare responsibilities are shifted to families under the regime of AKP.

I analyzed the healthcare policies as part of a particular governmental rationality that lies at the paradoxical intersection of neoliberalism and neoconservatism. This intersection manifests itself in discursive as well as institutional level by sacred familialism that shifts the burden of care to women while enabling the state to address the neoliberal market demands. Cash for care scheme introduced by the ASPB demonstrate state's increasing reliance on women as care providers while sustaining women's vulnerable position in the labor market. While the cash transferred to the caregivers are granted to them as benefits, not as salaries for their work; they are also exempt from social security unless dependent on their husbands or fathers. The work- family reconciliation policies further sustain gendered division of labor as women are expected to continue "their duties", while not being fully integrated to the labor market. Within this framework, these regulations eventually create more gender inequalities.

In this thesis, I mainly point at the fact that care is a labor process that should be examined from the perspective of the caregivers as well. Therefore, I do not discuss it as a civil right of the disabled people. In this regard, I should mention that by criticizing the familial dependency that is implied in mental health policy, I do not indicate any lack in recognizing disabled people's capacity to be independent. Similarly, I do not advocate for their rights to hire personal attendants. In fact, there

is a controversy concerning the role of personal attendants within the disabled community which needs to be considered within this framework. In her study on personal attendants, Rivas (2003) nicely summarizes the discussion in question:

Informing this debate is the disabled community's history with 'care' that imprisoned them in institutions, made them the victims of 'caregiving' professionals, or left them at the mercy of abusive or controlling familial relationships. Consumers who reject the word care see it as implying too much passivity on the part of the care receiver. Others embrace an idea of caregiving in which receivers recognize their dependence on their personal attendants and understand that personal attendants can also fulfill emotional needs. (p. 80)

Hiring personal attendants for provision of psychiatric care is not a common practice in Turkey and therefore I do not include their service as a factor to be examined in this thesis. Nonetheless, I would like to open a parenthesis here and emphasize that the labor of personal attendants delivers a distinctive cultural good that provides an illusion of independence" to the care receivers (Rivas, 2003). In this relationship, care receivers define themselves as capable of being independent economically, politically as well as morally. Yet, here the dichotomy between dependency and independency fails to reflect the empirical reality as dependency is an inevitable human condition. What is described as independence is substantially a result of invisible or unacknowledged dependencies on other factors and "on social understandings of what constitutes dependence and independence" (Feder & Kittay, 2003). Besides, buying a personal attendants' service –when framed with an independency trope- conceals their labor while legitimizing the inequality concerning the distribution of rights and resources (Feder & Kittay, 2003; Rivas, 2003). In Chapter 4, I elaborate further on this debate on care which approaches it as a universal human need and defines dependency as an inevitable condition. In what follows, I shed light on the psychiatric knowledge that plays a significant role in sustaining women's role as caregivers of the mentally afflicted.

CHAPTER 3

IMAGINING THE “IDEAL FAMILY” AND THE BURDEN OF CARE THROUGH THE LENS OF PSYCHIATRY: A THEORETICAL EXAMINATION OF THE PSYCHIATRIC LITERATURE ON CAREGIVING

3.1 Introduction

Previous chapter examines Turkish state’s politics of care that is shaped by sacred familialism which strengthens the conventional emphasis on women’s role in the family, while paradoxically addressing the neoliberal market demands.

Correspondingly, it is also demonstrated in the studies in psychiatric literature that families are the primary resource of caregiving for psychiatric patients. This chapter reveals distinctive characteristics of psychiatric caregiving among other caregiving practices. It shows that psychiatric caregiving has significant repercussions on the lives of the caregivers who go through intense periods of hardships when residing with their mentally afflicted relative. On top of that, the families are often left alone “in their battle against the disease”.³³ Here, I have two reasons to argue that families are “left alone” and I will explain them as the products of a particular neoliberal governmentality which establishes afflicted people and their relatives as consumers. On the one hand, this governmentality is demonstrated in the increase of the prevalence and the “efficiency” of the pharmaceuticals in the last decades. On the other, it can also be linked to the increase in the use of the recovery model of treatment. As I will argue, the use of this model is manifested the most in the establishment of TRSMs I examine in Chapter 2.

³³ See for example Gülseren et al. (2010); Tel, Saraç, Günaydın, Mesik and Doğan (2010); Kızıllırmak and Küçük (2016).

It is worth examining two factors that are crucial in understanding the contemporary mental health landscape: the role of psychotropic drugs and the recovery approach in psychiatry. The psychotropic drugs have a considerable, although virtually invisible, influence on how we perceive disease and the treatment today. Particularly after the 1950s, they become an increasingly important part of mental health treatment. Psychotropic drugs primarily define the nature of afflictions as a configuration of symptoms similar to the ones which they themselves treat. Therefore, they not only trigger a “psychopharmacological revolution” through transforming countless psychological problematics into “a vast multibillion-dollar market”; but also alter the social, cultural as well as clinical landscape (Braslow, 2013, p. 795). This is demonstrated the most in the changing perceptions about mentally ill health and the process of converting patients into consumers. In this process, patients are perceived having diseases treatable by the commodities which are named after the symptoms treated by them while the “recovered consumer” appearing in this context becomes attached to the psychopharmacological market. For example, in his review of the studies on the recovery-based policies, Braslow (2013) shows how the introduction of a psychiatric drug named Thorazine changes meanings of psychiatric illnesses as the clinicians start to perceive illnesses as a “complex mix of their patients’ biological predispositions, past experiences, and failed relationships” (p. 796). Within this framework, many “ex-patients” become expected to be self-empowered and be independent, while they establish themselves as consumers. Thus, the biologically and psychologically embedded psychiatric patients of the 1950s are turned into the recovering consumers, whose needs are enabled to be satisfied by the consumer capitalism in the 1990s.

Similarly, in his anthropological study on the psychiatric practices in Buenos Aires in 1990s; Lakoff (2006) points to the challenges posed by the political context in Argentina that does not give way to the standardization of psychiatric experiences within the neoliberal context. This standardization, or what he calls diagnostic liquidity, is tried to be made possible through a governmental regulation that requires “pharmaceuticals be proven to have targeted effects in order to circulate in the biomedical system” (p. 10). His analysis also reveals how human experiences are further tried to be converted into objects of knowledge since researchers were under the pressure to classify disorders in standardized ways so that the medications can demonstrate certain effects.

What is important for the subject of this thesis is these psychiatric medications’ role in sustaining the relationships at the domestic sphere. As the cases I examine in Chapter 4 also illustrate, they basically sedate the afflicted person who is now regarded responsible for her or his own recovery; whereas the family caregivers are expected to ensure the regular use of the medications. Within this framework, the usage of psychiatric medications becomes an integral part of the organizational and the moral furniture of the contemporary households.

Another significant factor to be examined is the recovery approach which gains prevalence in the 1990s as a treatment philosophy, following this psychopharmaceutical revolution and the deinstitutionalization policies analyzed in Chapter 2. Since then, it forms the virtually unquestioned basis of the organization of the public mental health services. The advocates of this approach defines it as an undoubtedly revolutionary as well as a more moral and humane model than previous ones; arguing that the model takes its roots from the antipsychiatry movements of the 1960s. Yet, the ideological values of this model should be examined before reaching

to the conclusion that it was revolutionary. As a treatment philosophy that begins to appear in the wake of neoliberalism, the recovery approach openly promotes a self-empowered individual who is independent and responsible. The needs of this individual, as a consumer, is expected to be satisfied with just another capitalist product, regardless of the complexity of the psychosocial world she is embedded in and is perhaps suffering from. At this point, it is crucial to be aware of the “desired ends” of this treatment model as well as the beliefs and the values of neoliberalism that infuses it (Lakoff, 2006, p. 803). On the other hand, the recovery approach is regarded as a hope- inspiring and revolutionary model for the former inpatients who were treated in the custodial hospitals before. In this regard, Chapter 2 points at the desired ends of this model in the context of Turkey, where the establishment of the TRSMs demonstrates state’s policy to shift its caring responsibilities to families. Their establishment also reflects a recovery vision by implication since TRSMs mainly aim at outpatients’ social integration through the use of psychosocial rehabilitation and treatment plans (Ministry of Health, 2014, p. 1)

In this chapter, I provide an examination of psychiatric literature on psychiatric caregiving. The studies I examine and the psychiatric knowledge produced with them are reflected in the regulatory state mechanisms organizing the workings of the public psychiatric services today. Here, I refer to the psychiatric knowledge in a Foucauldian sense and argue that this knowledge makes intelligible the human conduct while constituting particular forms of expertise suitable for knowing and acting according to it. Here I aim to demonstrate that the dimensions of psychiatric caregiving are understood and explained in psychiatric categories and these categories make caregivers’ experiences assessable and eventually governable. As was explained by Nikolas Rose:

Those who profess specialist knowledge and esoteric skills have come to acquire a crucial role in helping to shape the problems that must be governed, in giving techniques for the conduct of their authority in relation to those who are their subjects, and in making up the relays that link programmes of government to the multitude of dispersed sites where conduct is to be judged, assessed, evaluated, understood and acted upon. Psychiatry has, since the 19th century at least, been intrinsically bound to problematics of government (Rose, 1996, p. 4).

In this vein, I approach the literature below with a critical gaze that depicts the political nature Rose points at and I basically argue that this political nature gets mystified in conceptualizations of familial care. In what follows, I examine the psychiatric literature on familial care and divide them in two groups.³⁴ In the first group, I dwell on two important notions: the recovery approach and the concept of family assemblage. I highlight the ways the family members are taken as inherent actors of the treatment process. I argue that the fact that family caregivers' labor is taken for granted in these studies results in a kind of connivance whitewashing the burden that they are troubled with. In the second group, I examine another psychiatric concept, namely the concept of expressed emotion. I point at the studies which, compared to the first group of studies, appears to recognize more the burden of the caregiving. The studies on this concept, together with the concept of burden and the grounded theory I also examine below, analyze precisely the family environments and the interaction patterns between members. In general, they emphasize the culmination of "negative feelings" in family members living with the afflicted people, as well as the repercussions of this culmination on the caregivers' own "mental health". Yet, as I demonstrate, although the concept of expressed

³⁴ The studies I examine are mostly from journals including *Achieves of Psychiatric Nursing*, *Annual Review of Psychology*, *Current Approaches in Psychiatry*, *International Journal of Mental Health*, *Journal of Abnormal Psychology*, *Journal of Intellectual Disability Research*, *The American Journal of Psychiatry*, *Western Journal of Nursing Research*, *Anatolian Journal of Psychiatry* and *Turkish Journal of Psychiatry*.

emotion aims to shed light on the heavy burden that most family members are troubled with, it nevertheless focuses primarily on the impact of family members' feelings on the afflicted person. Thus it ultimately fails to capture the affective labor the caregivers are engaged with and importance of this for caregivers' lives.

Much of the studies I examine are based on surveys conducted in a relatively short time and the scales used can very well be open to discussion. However, I do not discuss the methodologies applied neither do I provide a detailed analysis of all the studies I refer to. Rather, I refer to them in categories based on the dimension of caring they examine. My main goal is to shed light on the implications of these studies on the understanding of psychiatric caregiving and the risk of mystifying the oppressive mechanisms shaping caregiving labor in quotidian experiences. In many contexts, families are made to live with their afflicted relative and I analyze the mechanisms enabling and accepting family caregiving as the primary resource of support to the afflicted person. Yet, despite the implications of the studies in question, I have to note that they make the majority of the literature on the practice of psychiatric caregiving. To illustrate, I refer many times to the data used in studies on expressed emotion below, as they are virtually the only source enabling me to grasp the enormity of the psychiatric caregiving in contemporary Turkey.

Yet, I do not mean that the afflicted people used to reside less with their families before this transformation of the psychiatric facilities. Also, this chapter is not an attempt to compare and contrast previous familial psychiatric care provisions. Rather, I point to the change in the organization of care and argue that the current health policies are directed at making the afflicted people live with their families. The use of pharmaceuticals and the treatment and rehabilitation program applied in TRSMs sustain these familial dependency relations.

3.2 The recovery approach and the concept of family assemblage

After the anti-psychiatry movements that took place among the Civil Rights movements in the 1960s and 1970s, recovery approach becomes prominent in most parts of the world.³⁵ This allegedly alternative psychiatric approach emphasizes treatment in the community and is defined by its advocates as “as both revolutionary and unquestionably more humane and moral than those that previously have shaped mental health services” (Braslow, 2013, p. 783). As the advocates argue, the approach promises a satisfying and meaningful life despite of the on-going restrictions of the so called “mentally ill health” (Roberson et al., 2017, p. 410).³⁶ However, this recovery paradigm is also criticized by many because of its emphasis on individualism. It is argued that this Individualism ignores the interpersonal aspect of the process of recovery. The point that I want to emphasize here is the concept of “family recovery” that entered the psychiatric debates at this point.³⁷

While the roots of the recovery approach were mainly criticized for its emphasis on individualism, family recovery approach points to families’ role in the recovery process. It emphasizes the complex relation emerging from different experiences in family life. As these experiences involve commitment and deep care, they are supposed to provide a salient context for recovery. For example, its

³⁵ In his review, Braslow (2013) demonstrates how in English speaking countries the recovery approach was adopted simultaneously in 1990s. All these countries try to solve their fiscal problems through orienting themselves to managed care. He argues that “the past 50 years of mental health policy could be seen as a progressive effort to shift the care of severe mental illness from a collective social responsibility to a private, individual responsibility” (p. 800). He tries show how “the individual recovered consumer, ultimately responsible for his or her own recovery, is cut from the same ideological cloth as the neoliberal’s welfare recipient” (p. 800).

³⁶ The biggest and the most systematic attempt to date to synthesize the literature on recovery resulted in the CHIME model. This very influential model based on five recovery processes which are “connectedness, hope, identity, meaningfulness and empowerment” (Price-Robertson et al., 2017, p. 409). Also see Leamy et al. (2011) for an analysis of this model.

³⁷ Today, there is a growing literature on this concept. See for example Braslow (2013); Nicholson (2014); and Nicholson et al. (2014).

advocates argue that afflicted people's role in their families as parents provide them "a safety zone of stability" while destabilizing "the foundations of their defiant sense of identity" (Roberson et al., 2017, pp. 419-420).³⁸ Pointing at the limiting individualism of the recovery approach, Darryl Maybery and his colleagues observe the following:

Across this literature, reference was commonly made to 'people accessing mental health services', 'person', 'individual', and 'people with lived experience', but it rarely (if ever) employed terms such as 'children', 'parent', or 'parenting and recovery'. Terms commonly appearing were 'carers' and 'family' and there were predominantly employed in relation to community participation, social inclusion, personal connectedness, and identity. Reference to family was usually described in terms of the family and the well parent providing care and support to the person (generally their child) living with a mental health condition. Parents living with mental illnesses and caring for others were rarely acknowledged (Maybery et al., 2015, p. 314).

As it is apparent in the quotation above, the family recovery approach takes family life as central to the process of recovery, rather than defining it as a circumstantial or contextual component. Yet, this focus on the familial identities is also criticized for hardly capturing the lived experiences of the people in the families. These lived experiences are actually affected by the social, discursive, affective and material organization of people's lives. Pointing at this deficiency in family recovery approach, the concept of family assemblage comes to be offered in current studies on recovery.³⁹ By focusing on the more-than-human aspects of the family life, this concept offers an explanation of the ways mental illnesses are manifested, understood and managed.

Moving beyond the anthropocentric explanations of the recovery process, advocates of the family assemblage approach urges upon the importance of varied

³⁸ Although scarce, there is a literature on the role of parenting in the recovery process. See for example, Nicholson (2014); Nicholson et al. (2014); and Maybery et al. (2015).

³⁹ See Duff (2016); Huff and Cotte (2016); Price and Epp (2015); Price-Robertson et al. (2017).

resources in the work of recovery; nonhuman forces, spaces as well as bodies which are incorporated with human bodies. From this perspective, recovering or becoming well does not only apply to the afflicted person, rather, all the constituent parts of this assemblage live that experience⁴⁰. Here, the concept of assemblage that provides the basis of this approach is initially a conception of Deleuze and Guattari (1988).

Their assemblage theory basically takes assemblage as composed of non-material and material components which enables it to affect and be affected by different entities in the quotidian experience. This “relational capacity” implies a different analytical perspective that is critical of the emphasis on personal and subjective feeling states and which points at the power of encounters between bodies. In this regard, affect connotes a capacity to act within the boundaries of a particular scope of activity and the emotions only appear following an affective transition. In other words, affects are defined as “pre-cognitive” and “pre-subjective” which are either reducing or increasing particular emotions in a given assemblage (Duff, 2016; Price-Robertson et al., 2017). In this connection, the focus of the concept of family assemblage is on the assemblages which foster positive emotional experiences stimulating the process of recovery at their best. Therefore, recovery is taken as the outcome of a relational, affective process; rather than as states of subjective feelings as promoted in the recovery approach. In their study on the concept of family assemblage, Price-Robertson (2017) and his colleagues suggest the notion of “distributed management” to define the practices the afflicted person and the other members in the family engage in order to help that person to “maintain control over,

⁴⁰ In his book on the concept of family assemblage, Duff (2016) defines recovery as a construed process of “manipulating the signs, affects, events and territories of “one’s ‘becoming well’” (p. 93). He conceptualizes recovery as a process “by which the recovering body becomes sensitive to an array of affects and relations”, affects and relations making “bodies become well” (p. 93).

his(her) thoughts and moods” (Price-Robertson et al., 2017, p. 423). In their study, they examine the case study of two fathers, whose attempt to fulfill their role of a caring father helps the recovery of the mentally afflicted person. As it is demonstrated in the statements of the fathers, this attempt becomes the central purpose in their life. Following quotation is from the words of a father (34) who is diagnosed with anxiety and depression:

So in terms of being responsible and organizing and a being role-model... it's just basically become that that's everything. If I didn't have the kids, I wouldn't have a point to be sober, I wouldn't have a point to be putting effort into, not being happy, but just not being miserable, you know. (Price-Robertson et al., 2017, p. 423)

In their analysis of the quotation above, the researchers point to the ways that this person fulfills the role of an “engaged father” and to the strategies his wife and kids apply in order to support his process of recovery. For example, they point at how his wife works fulltime, although she would prefer not to, and simultaneously does much of the housework; in order to enable her husband to spend more time with the children. So while other members’ support is accounted as a contributing factor to father’s well-being, family home’s salubrious environment is celebrated as another positive and environmental factor. They argue that this environment, “with its stabilizing duties, obligations and routines” which, as “different components of his family assemblage”, ultimately structure and define the father’s personal efforts by their interactions (Price-Robertson et al., 2017, p. 424). In this regard, the concept of distributed management is used to emphasize the importance of the larger composition of factors on the management of the so called mentally ill health. The family assemblage approach seems to be answering the limiting individualism and reductionism of the recovery approach by accounting for the more-than-human aspects of the relations in the family. However, I argue that this approach carries the

heritage of recovery approach. It leaves undebated, if not totally ignored, the experiences of other members in the family whose sufferings might actually be escalated by the troubles of the mentally afflicted person in the first place. In this regard, I want to point at the normative familial conventions that are embedded in this “assemblage”. These conventions might well be sources of stultification or oppression. Here I follow the example of Edward and Gillies (2012) and take the concept of family as connoting a political nature itself, where power is exercised through processes associated with “social divisions and institutionalizations of gender and generation” (p. 65).

In their review, Edwards and Gillies (2012) examine the current intellectual move away from the concept of family. They argue that this direction risks “becoming trapped in the pivot around a reflexive, responsabilised individual self, disconnecting from other meanings and significances captured through the term ‘family’” (p. 67).⁴¹ They argue that this direction paves the way for obscuring the social inequalities which emerge through familialisation. I continue using the concept of family, and agree with the argument that there is a political nature to families themselves. The relations of togetherness, commitment, obligation and care are the kind of characteristics of families. Yet they can be implicit sources of inequalities in the division of labor, subordination and oppression through domestic abuse and violence (Edward & Gillies, 2012). Therefore, I argue that the political nature of the families and the oppressive mechanisms operating through familial relations should be considered before promoting the idea of family assemblage as a recovery model. As I show above, recovery model basically emphasizes the idea of distributed

⁴¹ See also Gilding (2010) for an analysis of this move away from using the concept of family in sociology.

management and points at the family members who seem to be willing in shouldering their afflicted relative's troubles. Yet in doing this, there is the risk of silencing –if not totally ignoring- majority of families' troubles in living with the mentally afflicted person.

This political nature is also manifested in the discourse on ideal family promoted in the psychiatric literature I examine here. I argue that in emphasizing the role of family members as significant actors in the recovery process of the mentally afflicted people; the family recovery approach and family assemblage theory I examine here attributes family members a supportive role and define an ideal family. The encouragement towards this ideal family is demonstrated in the treatment models applied in the community based centers which aim at outpatients' social integration through the support of the family members. It is important to note here that the imaginations of the ideal family are shaped according to the political ideologies of the government (Özbay, 2013, p. 109). As I examine in Chapter 2, in the TRSMs established under the regime of AKP in the last decade, the treatment and rehabilitation plans are designed to integrate family members into the recovery process as well. This is demonstrated in the education plans ensuring that family members are informed about particular aspects concerning the mental affliction or, in the functioning of the travel teams (*gezici ekipler*) which contact with the family members when the mentally afflicted person do not continue to the program in TRSM. Also, as TRSMs do not provide accommodation for the service users, it is also taken for granted that the outpatients will be residing with their families every day, at end of their visit to the center. In light of these considerations, it can be argued that the integration of families in the treatment model gives an idea about the ideal family promoted in TRSMs. As part of a mental healthcare system designed

and provided by the state, TRSMs address AKP regime's sacred familialism in contemporary Turkey. In this regard, they exemplify the political nature of the psychiatric knowledge which is, as Rose observes, "intrinsically bound to problematics of government" (Rose, 1996, p. 4).

On the other hand, my examination of the current psychiatric literature revealed other aspects of psychiatric caregiving. I will continue this chapter with examination of another concept used in psychology studies, namely the concept of expressed emotion.

3.3 The concept of expressed emotion: recognition of the burden?

There is a growing literature in psychiatry and psychology on the burden associated with psychiatric caregiving. Introduced by George Brown in 1960s, the concept of expressed emotion refers to a group of particular behaviors, attitudes and emotions expressed by the family caregivers of a diagnosed person, usually with schizophrenia (Jenkins & Karno, 1992). However, in this literature the primary focus is still on the impact of the attitudes of caregivers on the prognosis of "the disease". This fact is also demonstrated in the psychotherapies and the psychoeducational programs proposed for caregivers, which were mainly structured for involving them in the treatment plan (Gülseren et al., 2010; Pitschel-Walz et al., 2001).

A related term used in these studies is the "burden of care" which is particularly applied for investigating the relationship between the "burden of care, and patient/illness-related variables (e.g. gender and symptom patterns) and caregiving variables (e.g. coping styles, psychological problems, presence of a supportive network, and beliefs about the etiology of schizophrenia)" (Gülseren et

al., 2010, p. 2).⁴² In their review of the research on the quality of lives of caregivers in schizophrenia, Caqueo-Urizar (2009) and her colleagues demonstrate the relation of negative correlation between the burden of care and the caregiver quality of life; which is explained by the factors such as negative prognosis and inadequate social support (Caqueo-Urizar et al., 2009). Particularly the “economic burden” is found to be negatively affecting the quality of life of caregivers in countries where the cost of the treatment is high whereas the quality of the healthcare centers is poor. In this regard, the burden associated with caregiving is mostly examined through two different notions, namely the objective and the subjective burden. While the former is usually associated with the time spent for care, finances and the health status of the caregivers; the latter deals with caregivers’ own perception of the burden of care.⁴³ Here, I would like to point out at the implications of this differentiation for the understanding of the sufferings associated with psychiatric caregiving. The concept of subjective burden examines caregivers’ coping strategies as related with feelings of courage, hope or their stress-coping abilities etc. This analysis can risk mystifying the impact of the economic and social conditions on their everyday lives whereas these conditions are roughly defined as objective. As was also implied by the concept of family assemblage, conditions defined as outside of the control of individuals, for example the economic cost of the affliction or the time needed to spend for caring, could well be examined as non-material components of the quotidian experiences which cause individuals “to affect and be affected by different entities” (Duff, 2016; Price-Robertson et al., 2017). This relational aspect of the quotidian experiences gets

⁴² There are plenty of studies on the concept of burden. See for example Durmaz and Okanlı (2014); Jenkins and Schumacher (1999); Jones and Jones (1995); Maurin and Boyd (1990); Reinhard (1994); Rose et al. (2002).

⁴³ See for example, Awad and Voruganti (2008); Flycky et al., (2015).

obscured when the effect of burden is divided in zones of subjectivity and objectivity.

Another conceptualization that exemplifies the kind of mystification I pointed at above is the grounded theory. Proposed by Rose (2002) and her colleagues, the concept aims to provide an analysis of families' responses to mental illnesses over time. They argue that family members' ultimate responses to mental illness is "pursuing normalcy" which is usually done through "confronting the ambiguity of mental illness, seeking to control impact of the illness, and seeing possibilities for the future" (Rose et al., 2002, p. 516). In fact, there is a literature on the concept of normalizing which basically defines the attempts of caregivers, usually with a child who is chronically ill; to behave as if life is normal. This attempt is examined as a coping strategy.⁴⁴ In this regard, the grounded theory is offered to conceptualize the strategy of pursuing normalcy "as goal-oriented" (p. 516). With this theory, Rose and her colleagues point at families' efforts to "help the patient be normal" while actually revising their "notion of what it means to be normal" (p. 531). Their analysis clearly acknowledges the difficult and complex process that family members go through in their acceptance of the mental illness and the challenges they face over time in sustaining their motivation to accommodate the illness. Nevertheless, the analysis conceptualizes the pursuit of normalcy as a coping strategy. They claim that this strategy requires further research in order to "identify ways that health professionals can assist families in their struggles to achieve a sense of normalcy for themselves and the family member who has a serious mental illness" (p. 533). I would argue that a similar risk of mystification appears again as achieving the sense of normalcy is represented as an efficient coping strategy. The troubles of the family members are

⁴⁴ See for example, Anderson (1981); Knafl and Deatrick (1986); Strauss and Glaser (1975).

recognized yet the fact that they are positioned as the primary source of support to the afflicted person is not elaborated on. Families which “cope well” are analyzed as good examples and set models which are presented as requiring further attention.

Yet, there are important contributions of this literature to the understanding of psychiatric caregiving. In these studies, caregivers’ effort to cope with their afflicted relative’s sufferings is found to be highly stressful. This burden is reflected the most in their concerns about the future and in the unpredictability of the so called patient’s progress (Chafetz & Barnes, 1989). Similarly, the initial diagnosis of the disorder is found to be particularly stressful for the family members, which results in “reactions of shock, confusion and fear” (Rose et al., 2002, p. 518). Another factor that is found to be hampering the process of coping for families is their fear of the stigma. This fear causes them to be very selective when seeking support from other people particularly as they anticipate a lack of understanding and negative reactions (Polat et al., 2000; Rose et al., 2002). Lastly, an equally important aspect these studies reveal is that the majority of the caregivers in question are women, who are mostly either mothers or sisters in the families (Awad & Voruganti, 2008; Gülseren et al., 2010; Lowyck et al., 2004; Nasr & Kausar, 2009).

On the other hand, there are relatively less studies on these concepts for the Turkish context. However, these studies make up the majority of the existing social science literature on the psychiatric caregiving in Turkey and they demonstrate that families are the primary resource of caregiving for psychiatric patients although they are often left alone in coping with their afflicted relative’s troubles (Gülseren et al., 2010; Tel, Saraç, Günaydın, Mesik & Doğan, 2010; Kızılırmak & Küçük, 2016).⁴⁵ It

⁴⁵ See for example Arslantaş and Adana (2012); Duman and Bademli (2013); Durmaz and Okanlı (2014); Gümüş (2008); Ebrinç et al. (2001); Özlü et al. (2010); Tel and Pınar (2013).

is also observed that the majority of the afflicted people are living out their entire life with their families. This process is long enough for having an impact on “the well-being and stress level” of caregivers as to cause them to have “relatively higher levels of depression and anxiety” compared to that of the general population (Gülseren et al., 2010; Kızılırmak & Küçük, 2016; Martens & Addington, 2001; Saunders, 2003). Another point raised in these studies is made through an examination of the gender dimension. Women caregivers are found to be suffering more from the so called subjective burden. Following analysis is illustrative of this point:

(...) we observed that most of the patients were cared for by female caregivers (mostly mothers). Female caregivers reported higher-level burden of care than the male caregivers, probably because of the fact that they were mostly housewives and had limited resources for functioning in different social contexts or assuming different social roles.⁴⁶ (Gülseren et al., 2010)

In the study I quote above, Gülseren (2010) and her colleagues point at caregivers’ feelings of being excluded from the social world and these feelings’ relation to the limited resources they possess. Although examined through the perspective of a different discipline, a discipline that argues for objective and subjective conditions, the recognition of women caregivers’ burden and their limited resources provide a crucial element for this thesis. As mentioned earlier, the concept of expressed emotion and the studies on the burden of care are virtually the only analysis on the psychiatric caregiving in the literature. They enable me to contextualize better the women caregivers’ narratives I examine in Chapter 4.

⁴⁶ In another study, no correlation between caregivers’ gender and the burden of care was found. See Aydın et al. (2009).

3.4 Conclusion

Among other caregiving practices, there are distinctive characteristics of psychiatric caregiving which are explored in this thesis. The studies in this chapter shed light on virtually all of these studies, it is acknowledged that being the primary source of care is unpreventable for the majority of family members. Despite this, family members' involvement in the treatment process is regarded as a positive factor for the mental health of the afflicted person. The first group of studies which have their basis in the recovery approach openly take families as integral to the recovery process. Such that, some studies point at the stabilizing role of the “duties, obligations and routines” of parents, which, as it is argued, motivates the afflicted person. On the other hand, second group of studies focus on the burden of caregiving. This burden is described as dependent on several factors which are roughly demarcated as subjective and objective in some of the studies.

In my interpretations of these studies, my aim is to draw attention to the ways that the political nature of the familial relations is risked being masked. For the first group of studies, I show the significant challenges that the concept of family assemblage poses to the former recovery models. Yet I remark how the concept nevertheless ignores the complex and mostly conventional dynamics in family relations which might well be oppressive and, I emphasize that this oppression does not always necessarily have to be towards the afflicted person. Moreover, the family recovery approach and the family assemblage theory promote an ideal family in which family members are assigned a supportive role. In this regard, they manifest the political nature of the psychiatric knowledge which is linked with the problematics of the government. In the context of Turkey, this is manifested in the establishment of TRSMs which are based on a recovery model and integrate families

in the treatment process. Therefore, they address AKP's sacred familialism which relies on families' role in care provision. In addition to this, the critical examination of the recovery approach reveals that in pursuing recovery, both the afflicted people and the family members negotiate with a neoliberal rationality. This rationality requires them to be responsible for their own and each other's well-being. I explain the ways they are turned into consumers when they are expected to consume products which are, in this case, the psychiatric medications. As in the case of other products, these medications are advertised to be in their best interests.

On the other side, the findings suggested in the studies on expressed emotion and on burden provide important insights into the life worlds of caregivers. As these studies demonstrate, majority of the caregivers go through intense periods of hardships. These periods are caused by the problems such as the unpredictability of the afflicted person's moods, fear of stigma towards the people outside the family and the culmination of negative feelings like hopelessness, anxiety, stress etc. Yet, while revealing these considerable aspects, the studies in question appear to lack in recognizing the normative framework fostering relations like obligations and commitment. As I also depict in the following chapter, these relations inevitably have a political nature. This political nature potentially makes caregiving experience more burdensome for family members, especially for women, while this fact is rendered invisible in these studies.

In Chapter 4, I continue with an examination of the same experience. Yet, as I also explain below, I use a considerably different methodology and conceptualization than the ones offered by psychiatry literature that I analyse here. By pointing at the affective inequalities particularly the women caregivers are subjected to, I aim to reveal what these studies risk masking.

CHAPTER 4

LIVING WITH “THE MAD”: ON THE AFFECTIVE LABOR OF WOMEN IN THE CASES OF MENTALLY AFFLICTED PEOPLE

4.1 Introduction: A feminist debate on care

Previous chapters demonstrate how in the policy debates on deinstitutionalization and community care, the women family caregivers are assigned the role of care provision by the medical and the state authorities in the discursive level. These attributions are further sustained at the institutional level as a shift from large psychiatric institutions to the treatment in the communities, which are broadly seen as carrying a healing virtue, started to take place. As the first chapter demonstrates, this policy shift had resonances in the context of Turkey as well. This chapter aims to shed light on the implications of the mental healthcare policies on the lives of women caregivers whose labor is largely sustained within the framework of AKP’s sacred familialism in Turkey. For this aim, I divided this chapter in three sections. In the introduction, I examine the feminist literature on care and briefly present the theoretical debates on the concepts of domestic, emotional, caring and affective labor respectively. Then I explain my approach to psychiatric caregiving with a focus on the theory of affective labor. In the second part, I provide an analysis that is built on the narratives of the caregivers whom I met during my research for this thesis. The large parts of these narratives belong to two women whose lives were my major focus of attention and therefore I mainly apply case study analysis. For this reason, the second part also contains an account of the debates on the methodology of case studies and I elucidate my reasons to apply this particular methodology for the thesis. Then I end this chapter with a conclusion section in which I summarize my findings.

4.1.1 Domestic labor

It is impossible to provide a review on the feminist debates on care without paying attention to the studies on domestic and household labor. The studies of Marxist and socialist feminists on domestic labor reveal women's oppression in the households and its material aspects with a focus on their role in production and reproduction.⁴⁷ These debates in 1960s and 1970s basically provided a foundation “for understanding women's differential positioning as mothers, family members, and workers and thereby for a materialist analysis of women's subordination” in the patriarchal capital system (Vogel, 2000, p. 2). On the other hand, caring labor is by and large is defined as a form of domestic labor in neoliberal and radical economists' analyses on households in 1960s and 1970s.⁴⁸ These studies demonstrate the fact that the relational aspects of caring are not manifested in physical activities despite these aspects' significance for domestic life. It is argued that this makes them less likely to be regarded as a form of work and hence “least comparable with traditional paid work” (Himmelweit, 2000, p. xxvii). Yet, as most of this domestic labor literature employed a “functionalist explanatory framework” and failed to provide a satisfactory account on human agency, the concept of domestic labor lost its appeal for many socialist feminists in the last decades (Vogel, 2000, p. 3).

⁴⁷ For a survey of the literature on domestic labor see Vogel (2013). See also Hansen and Philipson (1990); Himmelweit (1983); Sargent (1981) for overviews on this debate.

⁴⁸ In her introduction to the book *Inside the Household: From Labour to Care*, Himmelweit (2000) provides an illuminating overview of the crucial role played by feminist scholars in 1960s and 1970s in questioning the liberal as well as Marxist assumptions on household and domestic labor. See Himmelweit (2000).

4.1.2 Emotional labor

On the other hand, relational and emotional aspects of labor are debated by various other scholars. In this regard, another important concept that informs many feminist discussions on care is emotional labor. The concept basically refers to workers' management of their feelings in the work settings.⁴⁹ In her theorization, Hochschild (2012) defines the concept of emotional labor as the management of feelings to create a bodily and facial display that is publicly observable. She emphasizes the public display side of this labor in order to demonstrate the labor aspect of the feeling managements in question and argues that the effectivity of the display is being measured according to its consequences for the customers. Here, by drawing attention to the implicit ways of laboring, the concept of emotional labor enhances the meaning of caring labor I elaborate on below (Himmelweit, 2000, p. xxvii). As a form of activity, caring labor also requires management of one's feelings and hence can be conceptualized as a form of emotional labor that is usually invisible.

However, as was argued by the critiques of Hochschild, the concept fails to capture the complexity of care particularly as it demarcates between public and private spheres.⁵⁰ In this distinction, the feelings of estrangement are only attributed to the public sphere where Hochschild does not see a possibility for more altruistic feelings.

In other respects, Kathi Weeks criticizes Hochschild for presenting an outdated analysis with the concept of emotional labor in the sense that the concept is based on the notions of essential self and authentic feelings (Weeks, 2007, 2011).

⁴⁹ In another conceptualization of caring labor, James (1992) formulates caring as the sum of the organization, physical labor and the emotional labor. She argues that while in paid caregiving the organization parts and psychical care are evident; the emotional labor aspect remains mostly informal. Although I do not aim to explore the concept of paid care, I should note here that this conceptualization risks incarcerating emotional labor to the "public domain" while ignoring its affective aspects.

⁵⁰ See for example McClure and Murphy (2007); Wouters (1989).

According to her, Hochschild's "strategy of placing references to the 'real', 'true' and 'authentic' self in quotes paradoxically serves to problematize" the essentialism on which the analysis depends (Weeks, 2007, p. 244).⁵¹ Yet Weeks argues that this strategy is not sufficient in acknowledging that these concepts are social constructs. However, here the feminist challenge to the commodification of emotional labor, particularly the forms of affective labor that I will explain below, does not have to be a matter of claiming the authenticity against social. In a rather contemporary critique, Johanna Oksala argues that it could be an "attempt to mediate, shape, and manage our affects through freer and less exploitative social relations" (Oksala, 2016, p. 296). This perspective informs a political project that is not necessarily based on the idea of a true love or true self, while it can challenge the contemporary normative discourses idealizing the family. I will return to this criticism on essentialism in the part on affective labor.

4.1.3 Caring labor

Studies on caring labor appear to become one of the most studied areas in the current feminist literature. As was observed by Richard Freeman:

Care entails emotional commitment, and is also physical and material, effected by human bodies in collaboration with tools, instruments and machines. It has a communicative or symbolic function, significant and meaningful only to the extent that it is intelligible to others. It is, by the same token, an articulation of values, normative, a pursuit of good, and as a corollary, the inevitable neglect of others. It is future oriented: it has the sense of nurture, of growing and cultivating that which might be brought into being. (...) as a practice, it is an irreducible unit of social life, existing and persisting when other kinds of usually more formal and explicit institutional and organizational arrangements break down (Freeman, 2017, p. 195).

⁵¹ Similarly, Weeks criticizes traditional Marxist critiques of alienation for being "hindered by a tendency toward nostalgia for an earlier time, a romanticization of craft production" which ultimately shapes their perspective on an alternative to capitalism (Weeks, 2011, p. 87).

As it is captured in this detailed account, care has a significant value for human lives. However, despite this significance caring has mostly been undervalued in economics.⁵² Such that, the interdependency of human beings is ignored, whereas the concepts of autonomy and dependency are rigidly demarcated. The distinction between the private and public spheres is taken as representing the social reality of quotidian experience while caring is mostly underestimated and confined to the private sphere. Yet, in the everyday lives, the relationships established through unpaid and paid care seem less able to be demarcated as the dichotomies of “‘public and private’, ‘paid and unpaid’ ‘market and nonmarket’ would suggest” (Himmelweit, 1999, p. 36). As human beings are not pure economic beings deprived of moral incentives, their choices and actions are not always guided by incentives of competition defined in neo-liberal capitalism. There are nonmonetary motivations of people and therefore complete commodification of every kind of work they are engaged in, including that of caring work, is impossible. To explain this aspect, Himmelweit (1999) borrows the concept of “incomplete commodification”. Initially offered by Margaret Radin (1996), the concept underscores the idea that nonmarket and market understandings of a particular situation can coexist (Radin, 1996; Himmelweit, 1999). In her conceptualization, Radin draws a distinction between work and labor and argues that work has a noncommodified aspect all along, whereas labor can be conceptualized as being virtually always commodified.

⁵²Fraser (2016) analyses this systematic undervaluing of care in capitalist societies which paves the way for a “crisis of care” concerning the social reproduction. She describes this crisis by pointing at a contradiction: “on the one hand, social reproduction is a condition of possibility for sustained capital accumulation; on the other, capitalism’s orientation to unlimited accumulation tends to destabilize the very processes of social reproduction on which it relies. This social-reproductive contradiction of capitalism lies at the root of the so-called crisis of care” (Fraser, 2016).

Himmelweit (1999) contributes to this debate with a conceptualization that defines caring as having two components, which are “caring for” and “caring about” another person. While the former implies “the activity of catering directly to another person's needs, both physical and emotional”, the latter is defined as “the desire for the other's well-being that motivates the activity” (Himmelweit, 1999, p. 29). According to this analytical division, caring does not only imply physical tasks concerning biological needs, but it could also involve motivations to help other people to sustain or develop “their basic capabilities for sensation, emotion, movement, speech, reason, imagination, affiliation” (Engster, 2005, pp. 51-52). This approach to caring implies that due to a particularly sustained relationship between a caree and a carer, caring can always has an aspect that concerns the motivations for caring about a person and that cannot be commodified. Yet, as Himmelweit (1999) also remarks, “paid or unpaid carers may not always succeed in developing such relationships” (p. 37). She argues that in the cases that they do not, “maintaining appropriate emotional engagement may be as hard and as wearing as in the more transitory forms of emotional labor” (p. 37). Also, while this analytical distinction between caring for and caring about sheds light on the complexity of caring and its immaterial aspects, it might not always be manifested in the practical level.⁵³ This is another reason why I prefer to apply the concept affective labor in my analysis. As I explain below, the concept not only refers to the emotions; but also to the

⁵³ For a critique on this analytical distinction, see Leira and Saraceno (2016). In their analysis, they argue that the lived experiences of the well-educated, middle class women who had demands for not only domestic labor but also for emotional labor in several countries in 1970s provides an important point for this analytical division. They argue that these women's lived experiences demonstrate that caring about and caring for are not easily distinguished at the practical level than they can be at the analytical level. They argue that this is due to the family or kin relations of care in which “there were normatively and emotionally strong expectations that both dimensions should be present” (p. 14).

relationships, forms of cooperation and communication as well as affects produced in the families and communities. By problematizing these immaterial aspects, the concept further reveals the exploitation women are predominantly subjected to.

On the other hand, it is important to notice here the underlying analytical distinction between caring for people who can manage well on their own and who are literally dependent on the care they receive. As was argued by Leira and Saraceno (2016), today, only the paid care work for dependent people is accepted as a matter of policy intervention. This neglect leaves undebated the complex aspects of caring which are for the people who are not seen as dependent. It is “possibly because of this explicit or implicit reference to the actual or possible sphere of intervention by the welfare state, much care analysis focuses on the dependent status of those needing care” (Leira & Saraceno, 2016, p. 15). As I show in Chapter 2, this is demonstrated in care policies introduced by ASPB in Turkey as well. Opposite to this tendency to focus on the dependent status of people in need of care, in the last decades, care feminists from across many disciplines have invited scholars to acknowledge that caring is an inevitable aspect of human reality. In this sense, they called for an approach that recognizes human beings’ dependency, interdependency as well as emotionality while redefining the concept of citizenship respective to these terms.⁵⁴ In her critique on the notion of autonomous citizens, Fineman (2002) defines caring labor as inevitable and universal; and argues that in contrast to the prevailing myth on autonomous citizens, dependency is an indispensable characteristic of any society.⁵⁵ In a similar vein, Nelson (2015) emphasizes that human beings are “neither

⁵⁴ See for example Feder and Kittay (2003); Fineman (2002, 2004); Lynch (2009); Nelson (2015); Rivas (2003).

⁵⁵ In her book *The Autonomy Myth*, Fineman (2004) examines the popular ideology and the political rhetoric in the United States which, as she argues, became fixated on the myth of autonomous citizens to the extent of ignoring the inevitability of dependency.

mythical separative nor mythical soluble but individuals- in- relation” (p. 4). Nelson calls for an approach that recognizes our need to be cared for and cared about as a necessary human condition. Another contribution to this debate is made by Kathleen Lynch in her work on affective inequality. As she observes:

The binary divisions, between private and public, between independence and dependence, are now seen to be both unhelpful and false. Although human beings are, at times, autonomous, rational self-interested actors, they are more than that. They are deeply relational beings, part of a complex matrix of social and emotional relations that often give meaning and purpose to life, even though they can also constrain life’s options. (Lynch, 2009, p. 411)

However, in recognizing caring as an inevitable aspect of human reality, there appears a risk of conceptualizing it without attention to the varieties of - and the asymmetric relations in- caring. In order to explain these inequalities, Lynch offers the concept of “affective inequality”, which refers to the human deprivation that occurs when people cannot use their capacity to establish supportive affective relations (Lynch, 2009). As Lynch argues, “love, care and solidarity” are affective relations requiring work and the inequalities emerge when not only benefits but also the burdens of these types of work are distributed unequally (Lynch, 2007, 2009). She argues that overcoming this inequality requires the recognition of people’s need to care and love in order to develop and grow, if not only to survive.

In this sense, the labor aspects involved in caring gets obscured when care is seen as inherent in femininity and when unpaid work and care are interpreted as authentic expressions of love. Here, the metaphor of “labor of love” refers to the labor aspects in this kind of intimate caring.⁵⁶ This labor takes place in certain relationalities and thus cannot be replaced by any kind of paid work as long as the identities of the caregiver and care receiver, and hence the relationship between them is not changed.

⁵⁶ See for example Finch and Groves (1983); Leira (1992).

However, this relationality does not imply that care-giving work is always done with altruistic motivations. In fact, as it is argued by many other feminist scholars, in family-oriented care, care-giving work does not always bring compulsory altruism.⁵⁷ It might actually occur on the basis of feelings of duty, without incentives for caring about.

4.1.4 Affective labor

The theory on affective labor continues to influence a considerable part of the social scientific debates on care today. It can be argued that the theory basically analyses the change in the quality of labor in the contemporary age in which, according to Negri and Hardt (2004), there has been a passage toward what they call an informational economy. In this theorization, not only information, knowledge and communication but also affect appears to play a fundamental role in the production process. Taking it as a component of immaterial labor, Hardt defines affective labor as follows:

This labor is immaterial, even if it is corporeal and affective, in the sense that its products are intangible: a feeling of ease, well-being, satisfaction, excitement, passion—even a sense of connected-ness or community.⁵⁸ (Hardt, 1999, p. 96)

Here, it is important to acknowledge the “affective turn” dominating much of the social scientific debates in the last decades.⁵⁹ Basically, the affect theory provides

⁵⁷ See for example Land and Rose (1985).

⁵⁸ Introduced in the works of Antonio Negri, André Gorz and Marício Lazzarato, the concept of immaterial labor can be taken as a specific interpretation of Marxist concepts of “labor”, “class” and “value”. It refers to an intellectual production that requires a particular labor process involving the use of information and knowledge. Here I deliberately do not examine the concept in more detail as that analysis would inevitably exceed the scope of this thesis. Rather, I emphasize its influence on feminist debates as a conceptual tool that can be used to explain implicit forms of labor women are engaged in.

⁵⁹ See Clough and Halley (2007) for an influential edition of essays on affect. In the introduction, Patricia Clough defines affective turn as an expression of a new configuration of technology and bodies which instigates a shift in critical theory thinking. She argues that this turn brings a transdisciplinary approach to method and theory that “necessarily invites experimentation in capturing the changing co-functioning of the political, the economic, and the cultural, rendering it affectively as change in the deployment of affective capacity” (Clough, 2007, p. 2).

a new perspective in analyzing the changes in dominant forms of production and labor. It recognizes both the mind's power to think and the body's power to act and thus it provides a theoretical space to challenge the modern duality of mind and body. Therefore, the affect theory argues that analytically people are both able to be affected as recipients of external ideas and as organisms that are sensitive to other bodies; while simultaneously they have the power to affect these sources (Hardt, 2007). Here the concept of affective labor recognizes the interaction and human contact forms which are important aspects of the labor performed mostly by women.⁶⁰ In their conceptualization, Hardt and Negri (2004) define domestic labor as "a paradigmatic example of affective labor" (p. 110) as it not only requires material tasks but also produces relationships, forms of cooperation and communication as well as affects in the families and communities. In this regard, in his work on affective labor Hardt (1999) argues that certain feminist investigations on caring labor have already "grasped affective labor" in what has been conventionally defined as "women's work" (p. 89).

In my analysis, I take on the above mentioned conceptualization of affective labor and define caring labor as a form of affective labor that is "entirely immersed in the corporeal, the somatic", in which there is also a creation of affects (p. 96). I mainly define the labor of psychiatric caregiving as a form of affective labor especially since, as a form of human relation; psychiatric caregiving has immaterial

⁶⁰ However, although affective labor is undoubtedly gendered it is also crucial to acknowledge the fact that it is not performed solely by women. As Weeks (2007) argues, "the practice of affective labor and presumably the potential political subjects that can be constituted on its basis cuts across the older binary divisions of both space and gender. Women and men are indeed still often engaged in different laboring practices, but these differences cannot be mapped onto a binary schema secured by recourse to a model of separate spheres" (pp. 238-239) In this thesis I emphasize that caregivers analyzed are primarily and mostly women in the given context but my analysis is nevertheless informed by the fact that "the binary of men's and women's work has become increasingly unstable" as well (Oksala, 2016, p. 285). See Oksala (2016) for an account on affective labor and its connection with feminist politics.

aspects which are also manifested in the cases I examine. These immaterial aspects are largely rendered invisible by the romantic, essentialist approaches to caring which define it as an expression of true, authentic love. Following the feminist critiques on this essentialism which emphasize the social aspect of these feelings, I point at the dominant normative discourse idealizing the family as well as the healthcare policies sustaining the gender inequalities in Turkey and, shed light on the burdensome aspects of psychiatric caregiving which, as would Weeks argue, cannot be explained as an authentic expression of caregivers' love (Weeks, 2007, 2011). I aim to highlight the forms of exploitations and inequalities, particularly "the affective inequalities"; which are generated in the affective domains of the lives of the caregivers (Lynch, 2007).

In focusing on the experiences of the caregivers in question; I do not argue that there is a pure dependency relation between them and their mentally afflicted relative. I refrain from analyzing care as an exchange relation between different autonomous selves as it can be broadly defined in neoclassical economic sense. Contrary to the neoclassical economic thinking, this analysis of care recognizes people's capacity to care for and about each other in a variety of ways. In this vein, focusing solely on the so called dependent status of those needing care, since virtually all "the actual or possible sphere of intervention by the welfare state" is already only focused on the people with that status; stands as a considerably risk (Leira & Saraceno, 2016, p. 15). Here it is important to acknowledge the invitation of the care feminists to recognize caring as an inevitable aspect of human reality and, to focus our attention to the interdependency of human beings as well. However, as I mention above, in emphasizing the human beings' interdependency and the universal inevitability of caring, there is a risk of demystifying the asymmetrical distribution of

care. In light of these considerations, in my analysis on the experiences of the caregivers below, I explore and emphasize the burdensome aspects of caring labor which is essentially a form of affective labor, and point at the exploitation the caregivers are subjected to when the labor of psychiatric caregiving is not done equally between members in a family and hence in the society.

On the other hand, it is important to emphasize here the class dimensions of caring. As I also mention in Chapter 2, there is an increase in the number of private care services which is simultaneous with the rise of the beneficiaries of the cash transfer system. Yet, despite this marketization, the Ministry prioritizes supporting the provision of care within the family (Akkan, 2017; Altuntaş & Topçuoğlu, 2014). In this regard, my analysis is on the lower class households where marketized forms of care cannot be afforded. However, in the cases I analyze below, the mentally afflicted family members receive monthly disability allowances, publicly known as 2022 Allowance (2022 Aylığı) which is an amount considerably less than the minimum wage (Ministry of Family, Labor and Social Services, 2019).⁶¹ Although these allowances are given directly to the mentally afflicted people themselves, the fact that the amount they receive barely can afford them a so called independent life, appears as another factor why they mostly reside with their families. Besides, similar to the cash-for-care scheme, they are subjected to a welfare dependency evaluation (muhtaçlık değerlendirmesi) that evaluates the income, wealth and expenditure levels of all the family members for the disability allowance. As I explain in Chapter 2, cash-for care is another viable option for the mentally afflicted people and it requires that the person must provide a health certificate that proves at least 50 percent of

⁶¹ According to the report published by the Directorate General of Services for Persons with Disabilities and the Elderly (2016), people with %70 and more disability receive 1.748 Turkish Liras, whereas people with %40 to %69 disability receive 1.399 Turkish liras (Directorate General of Services for Persons with Disabilities and the Elderly, 2016, p. 9)

disability (Ministry of Family, Labor and Social Services, 2019).⁶² In the cases I examine, the mentally afflicted people were found 40 percent disabled, which made them only eligible for disability allowances. Nevertheless, as both the cash transfers and disability allowances are given to the people who are found eligible based on the welfare dependency evaluation, this thesis lacks a comprehensive perspective that also acknowledges more “privileged” women’s experience of caring.⁶³

In light of these interrogations, I mainly asked the following question in my examination of the narratives: when “left” with their mentally afflicted relative, how do they perform affective labor? Looking from a critical perspective, this question requires a problematization of the family institution as well. Here, taking Foucault seriously, I consider family as a straightforward example of bio-power and the domestic sphere as a particular space where the state exerts its power to make live its citizens and thus its population in a certain way (Foucault, 2008). In the case of Turkey, families are imagined as a resource of care provision that the state can rely on. As I explained in Chapter 3, this expectancy is made ever more possible today with the wide and regular use of tranquilizers and the establishment of community services providing daily care. In the governmental rationality that I refer to here, families are not ruled by coercion but rather are governed by the technologies of power which are maintained with knowledge making, including that of psychiatry (Foucault, 1988).⁶⁴ At this point, the households emerge as significant plateaus where

⁶² See Chapter 1 for an examination on the eligibility criteria regarding cash-for cash transfers.

⁶³ In a relatively old study on the class dimension of caring, Arber and Ginn (1992) explore the class differences in provision of what they call “informal care” in United States. Using the data from 1985 General Household Survey, they examine the location and prevalence of informal care- giving and argue that “working class bears the greatest burden in the provision of care” (p. 619).

⁶⁴ See also Dean (1994) for another study on the Foucauldian governmentality that is concerned with the rationality behind political programs and policies. Elaborating on the concept of governmentality, Dean extends the meaning of the concept while defining it as a space across the domains of politics and ethics, a space where the “practices of government” and the “practices of the self” are weaved together “without a reduction of one to the other” (p. 174).

these individualities are tried to be sustained in accordance with the neoliberal rationality in Turkey. As I explain in Chapter 2, the households gain more importance within a neoconservative context in which they are also subjected to a “pro-family social policy agenda” promoted by AKP (Yılmaz (2), 2015).

It is necessary to underlie here that, in my analysis of caregivers’ narratives I refrained from presenting the caregivers as the victims of state regulations which are informed by a neoliberal and a neoconservative rationality. I present an analysis of the gendered aspect of the care relations which designate women certain responsibilities and I examine the state's role in regulating and reproducing these gender relations. Yet I do not aim to conceptualize state as a static entity, just as I do not approach gender relations as stationary. Rather, I consider gender relations and state regulations as “articulations of dynamic, multiple and historically-determined power relations” which can be transformed or resisted by oppositional forces (Acar & Altunok, 2013, p. 2). In this regard, I pay special attention to the power revealed in caregivers’ narratives and I argue that this power is manifested by their use of different strategies in their everyday lives.

4.2 An analysis on the experiences of the caregivers

The analyses in this part are based on my interviews with women family caregivers who have been living almost their entire lives with their afflicted relative. I focus primarily on the stories of two wonderful women who agreed to meet me on regular basis to tell me about their life histories. Yet following analysis is not solely based on these interviews. As I explained in Chapter 2, thanks to my contacts in RUSİHAK, my assistantship in the Deinstitutionalization Project and to my visits to Bakırköy Psychiatric Hospital, I met with people from different walks of life, including the

afflicted people, health care workers, psychiatrists, volunteers of the friends' alliances for schizophrenic people and patient activists etc. Hence I also met many family caregivers and was able to conduct interviews with some of them. In this chapter, I do not provide an analysis of all of these interviews. But some of the narratives will also show up throughout the text.

In his study centered on the life story of a young inpatient, named Catarina, Biehl (2015) points to the limits of care when the people around the mentally afflicted individuals, could excuse themselves from those individuals. They blame the afflicted people for their own suffering and disqualify them “from care and human connection” in a “space of disregard at the nexus of market rationality, science, and intimacy” (Biehl, 2012, 2015). Catarina lives out her days in Vita, a psychiatric hospital with dire conditions in Brazil. As I mention in Chapter 2, Biehl applies the term zones of social abandonment to describe Vita where people are exempt from medical care and family life. I had a fair amount of chance to gain insight into the general conditions of the psychiatric hospitals in Turkey. My visits to the Bakırköy Psychiatric Hospital (although I had a limited access), the insights I gained in the Deinstitutionalization Project as well as my examination of the documentary DEPO that describes the conditions in several hospitals in detail can demonstrate that. Based on these insights, I can argue that the general conditions of psychiatric hospitals in Turkey are close to being the empirical evidences of the zones of social abandonments which Biehl describes. Yet, in terms of the family disregard that Biehl points at in his analysis, there can hardly be found a similarity. Family members' general approach does not contribute to the overall social abandonment since majority of the mentally afflicted people actually reside with their families in Turkey. Living together does not imply that afflicted people are not

exempt from care, but it does not indicate an absence of human connection either. Following analysis sheds light on that connection, meaning the quotidian relations at the domestic sphere and the impact that the sufferings of the afflicted person have on these relations. In accordance with this, the head nurse of the women’s clinic of the Bakırköy Psychiatric Hospital shared with me the following anecdote when I ask her about the family members of the afflicted people:

Majority of the family members usually allow the patient to be back home. But I cannot say that they call the clinic to ask about the patient, most of them do not even come to visit. As for the patients who have frequent relapses, family members do not see this hospital as a place for recovery. They drop their relatives and never ask about them until their discharge. It gets really crowded here before the Bairam holidays [laughs], they tell you they cannot take their lunatic with themselves to their hometown. But they do come back or agree to reside with the patient when the hospital itself transports the patient back home.⁶⁵ (M. Bulut, personal communication, 2017)

The head nurse’s account supports the argument that a total exclusion from family life is rarely the case for the mentally afflicted people in Turkey. Such that, when they cannot “take their psychotic relative to the hometown in Bairam”, family caregivers utilize the psychiatric hospitals as temporary solutions. But they accept the patient back home eventually. This is also demonstrated in the increasing numbers of people who apply for cash-for-care beneficiaries thus negotiating with the familialist framework guaranteeing their support. As I point out in Chapter 2, while around 30,000 people were receiving cash-for care transfers in 2007, today there are approximately 500,000 people who receive these benefits (Directorate General of Services for Persons with Disabilities and the Elderly, 2016).

⁶⁵ “Ailelerin çoğu hastayı eve geri kabul ediyor. Ama hastaneyi arayıp hastayı sorarlar diyemem, çoğu ziyarete bile gelmez. Çok yatışı olan hastaların aileleri hastaneyi bir iyileştirme yeri gibi görmüyor zaten, hastayı buraya bırakıp, çıkışına kadar gelmiyorlar. Burası bayram tatillerinden önce çok kalabalık olur (gülüşmeler), deliyi birlikte memlekete götürmeyiz derler. Ama hastane hastayı eve geri gönderdiğinde gelir ya da hastayla yaşamayı kabul ederler”

On the other hand, although neglect is not the prevailing manner in these households, family members experience living with their afflicted relative in inevitably complex ways. Following narrative is told by Cansu whose older sister was given different psychiatric diagnoses before:

Caring for her rarely required a physical labor. She was always able to look after herself. Hers is not a disease one could easily define. It is one that you cannot ask from your neighbor to help you in caring. In fact, you are ashamed of asking for help as you want to deny any association of the disease with your own intelligence or even with your honor. You are afraid of the scenarios she might write and blame you for denigrating her. Therefore, you want to be one step further in her paranoidias, to foresee them and be as neutral as possible towards her to prevent her paranoidias. You are lucky if you can manage that. So you do not tell people that your sister is something, not normal. You are not sure how to define it either; you do not have a recipe. You do not know whether there will be a full recovery or not. Doctors say stuff, none of them you see more than once as state keeps appointing a new one at each time. You grow up being estranged from yourself. Because you realize that there actually is someone in your life who you dream the death of and you cannot help with your hate. You just hate and wish that she had cancer or something instead. Something definable, something does not hurt your heart. Something causing less dispute at home. Something you do not have to be afraid of telling people after all. ⁶⁶(C. Akıncı, personal communication, 2018)

Cansu's account demonstrates significant problems which kept occurring in many of the conversations I had with the caregivers. They are also frequently referred to in the psychiatric literature I examined in chapter II. As it can be seen in Cansu's statements as well, many family members find themselves in an ambiguous

⁶⁶ Ona bakmak çok nadiren fiziksel emek isterdi zaten, o kendine bakabilirdi hep. Onunki öyle birden tanımlayabileceğiniz bir şey değil, komşundan bakması için yardım istemeyeceğin türde bir şey. Hatta yardım istemeye bile utanıyorsun, senin kendi zekânla, hatta onurunla bağıni reddetmek istediğin için. Onun yazabileceği senaryolardan ve onu kötüledin diye düşünüp seni suçlamasından korkuyorsun. O yüzden onun paranoyalarından bir adım önde olmak istiyorsun hep, önceden kestirmek ve olabildiğince nötr olmaya çalışıyorsun onun paranoyalarını önlemek için. Yapabiliyorsan şanslısın. İnsanlara benim ablam şöyle, normal değil diyemiyorsun yani. Kendin de nasıl tanımlayacağımı bilmiyorsun zaten, bir reçete olmuyor elinde. Tamamen iyileşme olacak mı olmayacak mı bilmiyorsun. Doktorlar bir şeyler söylüyor, devlet her seferinde yeni birini verdiği için hiçbirini tekrar görmüyorsun zaten. Kendine yabancı olarak büyüyorsun, çünkü fark ediyorsun ki hayatında ölmesini gerçekten hayal ettiğin biri var ve nefretine hakim olamıyorsun. Nefret ediyorsun, ediyorsun ve diyorsun ki keşke kanser ya da başka bir şeyi olsaydı. Tanımlayabileceğin, kalbini acıtmayan bir şey. Evde daha az kavgaya yol açan bir şey. İnsanlara söylemeye çekinmeyeceğin bir şey işte.”

and therefore burdensome situation that largely stems from the intractability of mental illnesses. The afflictions in question are also very complex which is demonstrated in the unpredictability of the “paranoia”. As it can also be seen in Cansu’s story, family members appear to apply different strategies to prevent these paranoias. Below is the account of another woman, Nazan, whose older sister is also given a psychiatric diagnosis:

In our case, it was not like another disease such as like heart or stomach disease, or even depression. There was a problem, but she did not accept the diagnosis and was not aware of her problem. We had this difficulty for a very long time. It is after five or six years that the treatment process could start when she herself could say ‘I have a disease; I should see a doctor’. Mother or the father, whoever you are, you cannot accept it very easily. You tend to see it like ‘she is behaving capriciously’ etc. But the real difficulty occurs when one cannot accept her own disease.⁶⁷(N. Metin, personal communication, 2018)

The cases I examine exemplify the process after which both the afflicted person and the family members acknowledge a certain diagnosis. Yet Nazan’s account points at another fundamental problem they encounter: the process of accepting the diagnosis itself. To shed light on the difficulty of this confrontation, I will refer to the concept of grounded theory I analyze in the second chapter. As I explain, there is a debate in psychiatry literature on the troublesome process that family members go through in accepting the affliction and the challenges they face over time in accommodating it. They examine family relatives’ tendency to “pursuing normalcy” which is defined as a coping strategy applied by them when they confront the affliction (Rose et al., 2002, p. 516). Similarly, Nazan and her family goes through the same challenging, complex process when they are

⁶⁷ “Herhangi bir başka hastalık gibi, işte kalbim, midem neyse, ya da depresyon hatta gibi olmadı bizde. Bir sorun vardı ama o teşhisi kabul etmiyordu ve rahatsızlığının farkında değildi. Biz baya uzun bir süre o zorluğu çektik. Bir 5-6 sene sonra, ‘bende bir hastalık var benim doktora gitmem lazım’ diye kendisi söyleyince ancak tedavi süreci başlayabildi. (...) Anne ya da baba her kimseniz, çok çabuk kabullenemiyorsunuz. ‘Kapris yapıyor bu’ gibi şeylere dönüyor. Ama asıl zorluk kişinin kendi hastalığını kabul edememesi.”

confronted with the diagnosis for the first time. Here I can argue that this difficulty is one of the topics that appeared repeatedly in the various interviews I conducted.

Following is another narrative told by a 54 year old woman, Elif. She is the mother of a 32 year old afflicted person who was diagnosed as manic depressive:

I'm using antidepressants for six or seven years now. Because, I should definitely do it to be able to help my child as a mother. It is his doctor who prescribed me this anyway. I'm also going to gym. I'm making fun of the situations because I do not want him to see me sulky, worried or anxious. Because I do not want him to feel the same way. ⁶⁸(E. Arabacıoğlu, personal communication, 2018)

Elif attempts to manage her feelings in certain ways, to not to be “sulky, worried or anxious” so that her child does not feel the same. She defines it as her responsibility, as her child’s mother, to be motivated to feel better so that she can help him. I was not able to ask Elif about the psychiatrist’s advises specifically, but it is not hard to imagine Elif’s motivation to feel better as something that was also encouraged in clinical settings. Elif does not only have to feel better for herself; she should also be able to do it for her children. This account reveals the affective labor which is an aspect specific to this care relation and it is largely explicit in Elif’s attempt to manage her feelings. She does not only take care of the material tasks in the domestic sphere which also includes her constant control over her son’s use of medication. But she also performs the emotional task of staying positive. Her hope here is to have a positive impact on the feelings of her son by feeling and expressing positive emotions. This hope resonates with the use of the concept of expressed emotion which refers to the impact of the expressed emotions on the condition of the

⁶⁸ “Ben yaklaşık 6 7 senedir antidepresan kullanıyorum. Çünkü bir anne olarak çocuğuma yardımcı olabilmek için bunu mutlaka yapmam lazım. Kendi doktoru verdi zaten bana bunu. Spora da gidiyorum. İşi gırgıra vuruyorum çünkü beni somurtkan, düşünceli, kaygılı görmesin istiyorum. Çünkü aynı duygulara o kapılsın istemiyorum.”

afflicted person. As I demonstrate in the second chapter, studies on expressed emotion centers primarily upon the impact of family members' feelings on the afflicted person. Therefore, it does not take into account of the affective labor the caregivers are engaged with and its impact on their lives. I suggest that the form of relation that is manifested in Elif's statement produces "forms of cooperation and communication as well as affects" in their family, while Elif contributes to this relation with her affective labor (Hardt & Negri, 2004, p. 110). Leaving this aspect here for further elaboration below, I will move on to the last narrative that I want to include here. Head of the Eurasia Friends Alliance for Schizophrenic People, Mustafa Alper, who is also the father of a 20 year old mentally afflicted woman, observed the following:

In the households where this disease fell on, the soul of classical family disappears. Almost ninety percent of the families get dissolved. In general, the fathers do not prefer to stay; they abandon, families dissolve. (...) If there are 20 to 25 friends' alliances for schizophrenic people in Turkey, only in one of them the head is a father. In the others it is the mother. Here we have 53 members, in the families of most of them the father has left. ⁶⁹(M. Alper, personal communication, 2018)

Mustafa's account reveals an aspect that is of primary importance to this thesis: majority of the caregivers are consisting of mothers. On the other hand, fathers tend to abandon the afflicted people, causing the dissolution of the families. Yet his account reveals another aspect of the women caregivers' engagement with their afflicted relative's troubles: their strategy of becoming part of the alliances which aim to support them as well. Today these alliances have hundreds of members, creating a network for the afflicted people and their relatives in nonclinical

⁶⁹"Bu hastalığın düştüğü ailelerde klasik aile ruhu kalmıyor. Ailelerin neredeyse yüzde doksani parçalanıyor. Genellikle de babalar tercih etmiyor; baba terk ediyor, aile parçalanıyor. (...) Türkiye'de 20, 25 tane şizofreni derneği varsa bunların sadece bir tanesinde bir baba başkan; diğerleri anne. Burada 53 üyemiz var, çoğunun ailesinde baba terk etmiş."

settings.⁷⁰ As Mustafa mentions, there are over 25 friends' alliances in Turkey and so far they represent the only group of civil society organization which was established by the relatives of the mentally afflicted people. More specifically, they are the family caregivers of "schizophrenic people".

I conducted interviews with several other people thanks to my contacts in RUSİHAK. Their answers converged into certain findings in line with the accounts above: a constant feeling of obscurity as to the course and the cause of the disease (substantiated with the lack of a persistent diagnosis which might offer a certain explanation and a pattern); a chronic fear towards the diagnosed person's unpredictable actions; feelings of shame and a consequent loneliness in one's social circle (especially towards the neighbors, distant relatives who might be suspicious of afflicted person's unseemly behaviors) and resulting from these, articulation of negative feelings like ambivalence and fear in virtually all of the family members.⁷¹ Yet I have to note here that these are not represented as bold generalization of caregivers' experiences. Rather, I include them here as to highlight important aspects of psychiatric caregiving and its distinctive characteristics as a particular caring experience with respect to differences in every case.

Within this context, it appears that disregard is rarely the case for the majority of the families in Turkey, regardless of the complexity of and the intimacy in their relations. Residing with their afflicted relative has inescapable repercussions on the lives of family members, usually women caregivers. Yet they apply different strategies to cope with their troubles while continuing to negotiate with AKP's

⁷⁰ For example, Friends of Schizophrenia Association in İstanbul has 432 members today (Friends of Schizophrenia Association, 2015).

⁷¹ See Chapter 3 for an examination of the concept of expressed emotion, in which articulation of these feelings is elaborated on in detail.

sacred familialism through which state's welfare responsibilities are shifted to them. First, I will provide a methodological discussion on case studies, and then will continue with caregivers' narratives respectively told by Gülay and Zeynep.

4.2.1 Case studies: A methodological discussion

There has long been a philosophical division in research approaches applied in social sciences: those supporting qualitative approaches and those aligned with quantitative paradigms; the latter generally supports positivism (Harrison et al., 2017. p. 3).

Qualitative methods include ethnography, narrative research, phenomenology and grounded theory (Denzin & Lincoln, 2011). In early twentieth century, particularly the ethnographic research was a popular methodology applied in social sciences as people's lives were examined through a long-term, systematic investigation conducted in the usual setting of their experiences (Merriam, 2009). Contemporary case study research is considered as a form of qualitative methodology and between 1920s and 1950s, it was one of the main research methodologies applied in Chicago School of Sociology (Stewart as cited in Harrison et al., 2017). Yet the validity of qualitative methodologies was contested as positivism became the dominant paradigm in science in late 1940s and 1950s. In this positivist paradigm, quantitative methods such as statistical methods, surveys and experiments became popular and considered viable for social sciences, and they were dominant through the 1970s (Merriam, 2009). The case study researches were continued to be conducted during this period, yet they were usually criticized for lacking generalizability and providing insufficient validity (Harrison et al., 2017). Later, with the introduction of grounded theory which basically merged quantitative methods with qualitative field study methods that resulted in "an inductive methodology that used detailed systematic

procedures to analyze data”; a renewed interest in the application of case studies emerged (Harrison et al., 2017, p. 3).⁷² Today, case studies are conducted by scholars from disciplines like medicine, education, political science as well as sociology and anthropology.

Based on the epistemological and ontological stance taken, there can be various approaches to applying a particular methodology. Similarly, there are different perspectives on the case study research which are reflected in the ways its methodology is applied (Merriam, 2009). However, as a form of qualitative methodology, case studies have several common characteristics. As was observed by Denzin and Lincoln, qualitative methodologies generally aim at “reducing the use of positivist or post positivist perspectives; accepting postmodern sensibilities; capturing the individual's point of view; examining the constraints of everyday life and securing rich descriptions” (Denzin & Lincoln as cited in Harrison et al., p. 8). In this regard, case study research is essentially “a comprehensive, holistic, and in-depth investigation of a complex issue (phenomena, event, situation, organization, program individual or group) in context (Harrison et al., 2017, p. 12).

Within this methodological framework and following the sociologists conducting case study research basically in order to gain a subtle and detailed understanding of the social organization of everyday life; I focus primarily on the stories of Gülay and Zeynep. In constructing the cases I present here, I mainly

⁷² In this vein, Burawoy (1998) proposes a “methodology duality” of positive and what he calls reflexive science as he argues that both of the perspectives are “necessarily flawed” (pp. 4-14) While the former is limited by the inevitable “power effects” like domination, silencing, objectification, and normalization”; the latter is weakened by the context effects that occur due to the “interview, respondent, field and situational effects” (p. 4). He formulates an alternative model, namely the extended case methodology, which basically thematises the existence of the researcher in the research context primarily through the application of participant observation.

studied the interviews I conducted. However, interview can be a “distorted conversation”, “in which the conversation follows a predetermined trajectory with prescribed responses and in which dialogue is precluded” (Burawoy, 1998, pp. 12-13). Therefore, he observes, “the interviewer cannot avoid misunderstandings and mistakes” when she cannot establish a relation with the respondent. Instead of forcing a standardized interview on Gülay and Zeynep and to avoid precluded conversations, I generally followed through the dialogues. As I was motivated to find commonalities and differences in their stories, I occasionally conducted semi-structured interviews with both Gülay and Zeynep, during a period of four months. Many times I had the chance to have informal conversations with them as we actually became friends over time. Here I do not treat their stories as representatives of the experiences of all the other women caregivers. From the perspective of positive science; this would pose a valid critique to my analysis as representativeness is a fundamental criterion of it. By applying a more “reflexive approach”, I sought “falsifiable” as well as “generalizable” explanations in my analysis (Burawoy, 1998, p. 11). Therefore, each case study is essentially self-constitutive as much as it is heuristic. Yet in the events portrayed, they do reflect “features which may be construed as a manifestation of some general abstract theoretical principle” (Mitchel, 1983, p. 192). In this regard, the patterns I point at are demonstrated in the interviews I conducted with other caregivers and are in resonance with the psychiatric literature I examine in the second chapter.

On the other hand, in examining the narratives below, my theoretical assumptions about the social and the narrative urges me to engage myself into the debates on a particular historical approach to narratives. In this regard, I treat the cases at hand as the manifestations of the experiences of women who apply different

strategies in order to cope with their afflicted relatives' troubles. Therefore, I basically frame their narratives as “modes of resistance to existing structures of power”; while refraining from victimizing them as exploited women (Andrews et al., 2013, p. 4). Simultaneously, in my analysis I shed light on the social yet largely implicit mechanisms causing the exploitation of these women. My examination does not necessarily focus on the unconscious elements of human experience that would make my analysis sceptic on the probability of individual agency. It regards them as personal accounts which, although are always socially constructed and are reinterpretable, demonstrate their subject position within the context of power relations in question.

4.2.2 Living without the hope of “full-recovery”: Gülay’s story

Gülay wanted me to keep our conversations secret from her daughter and not to write her story by using the real names. She was especially afraid that her daughter might get angry. She invited me to their home in one of our interviews where she lives with her daughter and husband on the outskirts of İstanbul. Yet I was never able to meet with Sıla (her daughter) in our meetings. Gülay, born in 1961, grew up in one of the Kurdish and Alawi villages in Sivas, a city located in the east side of Turkey.

Agriculture and cattle farming used to be main occupations for the villagers until people began to migrate to big cities in the late 1970s in search of job opportunities. In contrast to conditions in the villages, these relocations also introduced migrants to basic services like healthcare and education. Gülay migrates to İstanbul for similar reasons when she was 17. This decision to move is also underpinned by her desire to get married with her lover who is also her cousin. Nonetheless it was “not a simple love story that dragged both of us [them] to the

city”.⁷³ Although they are Kurdish and Alawi, their ability to speak Turkish limited the amount of hardship they could potentially face. They found no trouble in any of their public encounters, including doctor visits, parents’ meetings at the school or in their daily affairs with the neighbors. Yet their ease of assimilation was underscored by a more sinister reality of a structural inequality. Public authorities tolerated the migrants as part of a dubious process of compensating the insufficient supply of manual labor in the wake of the city’s rapid industrialization (Keyder, 2005). “In one night, we built our houses [gecekondu].⁷⁴ In the other, we helped the newcomers to build theirs. So our neighborhood was built in nights”⁷⁵ said Gülay, describing their early times in the city:

The municipality officers (belediyeciler) came for inspection three times and wanted to demolish some houses. We do not have title deeds, you see. But they allowed us here at the first place; letting us have the electricity and water. They even paved our roads with asphalt. We came here from different hometowns like Giresun, Rize, Kastamonu, Çankırı and Sivas but our children went to same school. No municipality was able to throw us out. We did not let them when our neighborhood began to offend their eye.⁷⁶ (G. Karaman, personal communication, 2018)

It is indeed an “ethically mixed and culturally heterogeneous” (Ayata, 2008, p. 27) neighborhood as Gülay was telling me. People from different regions across the country ended up in the same place; escaping from similar impoverishments, pursuing similar hopes in the city. In our talks about the neighborhood, Gülay never mentioned any kind of animosity among the neighbors due to ethnic and religious

⁷³ “Öyle bizi şehre götüren basit aşk hikâyesi değildi yani.”

⁷⁴ Gecekondu is a compound word referring to –generally illegal- squatter houses in Turkey. Gece means night whereas konu refers to the act of settling. So the overall meaning is close to settling overnight.

⁷⁵ “Bir gecede, bizim gecekonduları yaptık. Başkasında da yeni gelenlere yardım ettik. Mahallemiz gece yapıldı yani.”

⁷⁶ Belediyeçiler üç kere teftişe geldi ve bazı evleri yıkmak istediler. Tapumuz yok işte. Ama en başında izin verdiler buraya gelmemize, elektriğimiz ve suyumuz olmasına izin verdiler, yollara asfalt bile döktüler. Giresun’dan, Rize’den, Kastamonu, Çankırı, Sivas’tan başka başka memleketlerden geldik buraya, ama çocuklarımız aynı okula gitti. Hiçbir belediye kovamadı bizi buradan, mahalle gözlerine battığında izin vermedik onlara.”

diversity. She said once that they the only Allawi family in this neighborhood, but that she does not remember hearing anything hostile about it for the 35 years that they have been there. However, after the diagnosis of her daughter's illness, there was constant fear that the neighbors will discover her schizophrenia:

Sometimes we start quarrelling at home and things go out of control. Her father was so impatient at the beginning. He even beat her for a couple of times. I'm one of the few women in this neighborhood who does not wear headscarf, who is not even Turkish. I never felt shame. But this malice was so heavy. It still is. I tell him not to raise his voice, or engage in quarrel with her. I did not want the neighbors to be suspicious.⁷⁷ (G. Karaman, personal communication, 2018)

Sıla was 18 when she was diagnosed with manic-depressive disorder. Over the fifteen years since then, she had three different diagnoses which are respectively manic-depressive disorder, schizophrenia and schizoaffective disorder. She was hospitalized four times and her longest stay in the hospital was one month. "The hardest was to accept that hers is a chronic disease" says Gülay," we lost our hope of full recovery".⁷⁸ When I ask her about the cause of the disease, her attributions were always on the biological factors which affect her daughter's emotions:

It is that yellow liquid in the brain, you see? Some people have it less and it affects their serotonin level. Then they get angry and become suspicious. You cannot help it. She has to take her drugs regularly. You should not blame her for not behaving properly. No. That only makes it worse.⁷⁹ (G. Karaman, personal communication, 2018)

Gülay never made a distinction among the diagnoses Sıla was given, despite her detailed explanations of the cause of her daughter's affliction. In fact, repeated

⁷⁷"Bazen evde kavgaya başlıyoruz ve işler kontrolden çıkıyor iyice. Başlarda babası çok sabırsızdı, birkaç kere dövdü de bunu. Bu mahallede kapalı olmayan, Türk bile olmayan, az hanımlardan biriyim ben. Hiç utanmadım bu yüzden. Ama bu lanet bir yükü. Hala öyle. Sesini yükseltmemesini, onunla tartışmamasını söylüyorum. Komşular şüphelensin istemiyordum."

⁷⁸"En zoru onun hastalığının kronik olduğunu kabul etmekte, tamamen iyileşeceğine dair umudumuzu yitirdik."

⁷⁹"Beyindeki o sarı sıvıdanmış işte, anlıyor musunuz? Kimisinde daha az varmış ve onların serotonin seviyesini mi ne etkiliyormuş. Öyle olunca sinirlenip, kuşkucu olmaya başlıyorlarmış. Önleyemiyorsun. İlaçlarını düzenli alması gerekiyor. Düzgün davranmıyor diye suçlayamazsın onu. Olmaz. Daha kötü olur öyle."

changes of the diagnoses and subsequent alterations in doctors' explanations did not have an impact on Gülay's attributions. In our conversations about her responsibilities towards Sıla, she was always confident of her own parenting and had clear explanations concerning the sufferings of her daughter. Regardless of its name, her daughter has a disease that made her unpredictable, unreasonably angry as well as suspicious from time to time and Gülay seemed convinced that neither she nor her daughter was responsible for any of these problems.

However, she strictly ensures the regular use of Sıla's medications and regards it as necessary. Here, her approach to medications points to a general pattern concerning the relations between the family and mental illness which is generally manifested in the culture of pharmaceuticals through family members' attributions to medications (Biehl & Moran-Thomas, 2009). Such that, the discontinuation of the use of medications is perceived by the family members as the reason triggering the afflicted person's paranoia and anger. Therefore, the afflicted family member is regarded as responsible for using the medications regularly and is blamed when that responsibility is not discharged. When I ask Gülay about the other family members' attitudes towards Sıla, she told me the following:

We all get paralyzed when we first learned about her disease. Her father used to accuse her for her actions, particularly for not getting a job. Her pills make her sleepy, you see. But he always blamed her for being lazy when she woke up in the afternoon. As for her younger sister and older brother, she turned two of them against herself. Her constant paranoia made them sick over the years. Sıla is 33 now and her sister does not even talk to her for the last 10 years. Now we all accepted that she will never fully recover and most of her reactions are not deliberate. She is too insecure, you see. They do know it, but they cannot forgive her for the things she did. Especially my younger daughter, she does not.⁸⁰ (G. Karaman, personal communication, 2018)

⁸⁰ Hepimiz donduk kaldık hastalığını ilk öğrendiğimizde. Babası davranışlarından dolayı suçları bunu, işe girmiyor diye özellikle. İlaçları uykusunu getiriyor işte. Ama o tembellik ediyor diye suçladı bunu öğlenleri uyanınca. Kardeşini, abisini hep kendine düşman etti. Sürekli paranoya duya duya bıktırdı bunları yıllarca. 33 yaşına geldi, kardeşi on yıldır konuşmuyor onunla. Şimdi hepimiz kabullendik asla tamamen iyileşmeyeceğini. Birçok davranışı kasti değil zaten. Çok özgüvensiz yani. Onlar da biliyor bunu, ama affedemiyorlar yaptıkları yüzünden. Özellikle küçük olan, etmez. “

Her son who is in his thirties is married and living away from home whereas her younger daughter is going to college in another city. Therefore, Gülay and her husband are the only members in the family living with Sıla. I tried and failed talking with the father twice who seemed uncomfortable with my presence during the interview process. I have never seen the other children. I had the observation that Gülay is actually the only person caring for or even choosing to communicate with Sıla. She did not want to give me details about their disputes or her own accusations towards her daughter. Each time she emphasized how “it is better now since Sıla also got older”.⁸¹

Sıla has not been hospitalized in the last two years and she continues to take psychiatric medications. There is no psychiatrist or psychologist she regularly meets. However, she has been one of the regular members of the Friends’ Alliance for Schizophrenic People. In Sıla’s visits to the association, her mother accompanied her several times and joined group therapies with her. She receives disability allowances, yet its amount “barely compensates for a decent wage she might have received if she could work”, as Gülay explained.⁸²

There are repeated changes in Sıla’s diagnosis and neither Gülay nor her daughter is sure about the course of the disease. Gülay is in constant uncertainty towards her daughters’ actions. Nevertheless, she accepts the psychiatric knowledge as it is demonstrated in her explanations about the cause of the disease and her loyalty to psychiatric medications. Yet, it does not save her from the fear of stigma that shapes their lives as neither disability allowances nor psychiatric treatment can legitimize her daughter’s “improper behaviors”. They cannot release Gülay from the

⁸¹ “Şimdi daha iyi, yaşlandı o da.”

⁸² “Düzgün bir işe girebilseydi kazanacağı parayı karşılamıyor ki aldığı aylık zaten.”

shame and fear she feels in a neighborhood where people from various backgrounds are living relatively peacefully, yet where Sıla might not be accommodated. Within this context, Gülay engages herself with a form of affective labor that appears in her interaction with Sıla, other family members and the neighbors. Therefore, along with the material labor she performs as the “housewife”, she has to manage the tensions, fears, angers as well as the anxieties in the household.

Leaving Gülay’s case to elaborate further in the chapter, I will continue with Zeynep’s story which reveals different aspects of psychiatric caregiving:

4.2.3 Growing up as the mother of one’s mother: Zeynep’s story

I met with Zeynep in RUSİHAK when she was one of the volunteers there. When I told her about my thesis, she agreed to meet with me on a regular basis and tell me about her life with her mother. We met in different places and once I had the chance to meet with her mother as well.

Zeynep was born in 1992 and since then, she has been living in Sarıyer with her mother Ayten who is diagnosed with atypical psychosis. Similar to Gülay, Ayten is an urban working class woman residing with her mentally afflicted relative. She does not know who her father is: Ayten has an affair with a man who leaves before Zeynep was born. Zeynep’s grandfather was a fisherman in another city, who later migrated to İstanbul, seeking a better income as a fisherman. Yet the grandfather passes away long before Zeynep is born and when the mental problems of Zeynep’s mother begin to appear. The allowance Zeynep’s grandmother receives by virtue of her dead husband becomes the family’s only income during Zeynep’s childhood. She also has a sister born from Ayten’s first marriage, yet she leaves home and moves to another city when she got married. With her sister leaving the

home and her grandmother passing away when Zeynep was 10, Zeynep becomes the only person living with her mentally afflicted mother.

Although Ayten is diagnosed with schizophrenia for a long time, she is diagnosed with a-typical psychosis for the last couple of years. “My mother was sick since I knew myself; at least I have grown up knowing that” told me Zeynep, explaining her mother’s affliction. Ayten is now in her fifties and she was hospitalized twice. As Zeynep accounted, she has been in a relatively stable mood since her last relapse. In our conversations, she explained to me how her mother was constantly in an acute mood before her first hospitalization and how that mood stimulated a chaotic atmosphere, or in her words, “a situation of constant yelling, breaking and beating”, at their domestic sphere.⁸³

Zeynep’s account revealed that Ayten’s first hospitalization did not change her condition. As she observed, this caused Zeynep to lose hope as she thought her mother will never be “fixed”. The second hospitalization took place with the efforts of Zeynep and her high school teacher, when Zeynep decided that “it should be stopped”. She made the following explanation when I asked her about neighbors’ and her relatives’ approach to Ayten’s affliction:

I have an aunt and an uncle, but we do not really have a strong connection. They could not solve this problem; the neighbors were not of any help either. Whole neighborhood witnessed it, they knew about it. Yet it could go on like that for years. Things only changed when I took the step to change it. I find this really strange.⁸⁴ (Z. Boztemur, personal communication, 2018)

Here Zeynep’s statement reveals the social abandonment she lives through while coping with her mother’s affliction. Contrary to the situation in Gülay’s story,

⁸³ “Devamlı bir bağırma, kırma ve dövme hali (...)”

⁸⁴ “Teyzem ve dayım var, ama bağlarımız çok güçlü değil. Bir çözüme ulaştıramadılar, komşular da işe yaramadı. Bütün mahalle şahit oldu, hepsi biliyordu. Ama yine de bir şekilde böyle yıllarca gidebildi. Bir şeyler ben adım attığımda değişti sadece. Ben bunu çok garip buluyorum.”

people in Zeynep's social circle know about the affliction. Yet Ayten's affair, accompanied with her "improper behaviors" as a woman, makes her an object of blame in the neighborhood. So her affliction does not earn her people's sympathy while leaving Zeynep without any support. On the other hand, despite Zeynep's low expectations, Ayten's condition changes after her second hospitalization. Particularly her medications appear to have a positive impact on her affliction. As Zeynep explained:

My mother used to talk a lot. Mostly with the people who she imagines to be in sky. She stopped talking after her second hospitalization. Back then, my sister and I thought that the medications are a miracle. Whenever the possibility appeared that she will not take the meds; we got infatuated. She used to say things like 'people are trying to poison me with the meds, my father in the sky told me to not to take the meds anymore'. Yet when she stopped taking the meds herself, her look used to change. When that was happening, I was realizing it and was trying sobbingly to convince her to take the meds.⁸⁵ (Z. Boztemur, personal communication, 2018)

As it was also the case in Gülay's story, psychiatric medications and their regular use appear to play a fundamental role in the shaping relations between the afflicted people and their caregivers. However, our conversations revealed the confusing predicament Zeynep is in with regards to her mother's use of medications:

When she does not take the meds, she starts telling stories about her sibling being held prisoner. I feel very bad when that happens, as if my life ended. On the other hand, many times I wish that there is another solution to this and I'm feelings self-conscious. But at this point, I'm choosing my life. Because otherwise there is no chance for a life for me. My biggest fear is that she cannot take her meds and all her symptoms return. I do not know why, sometimes I dream about it, very very bad dreams...⁸⁶ (Z. Boztemur, personal communication, 2018)

⁸⁵ "Annem zaten konuşan bir insandı sürekli. Gökyüzünde hayal ettiği insanlar vardı, orayla konuşuyordu. İkinci yatışından sonra konuşmayı kesti. O dönem biz o ilaçları mucize gibi bulmuştuk ablamla. O ilaçları kullanmama ihtimali olduğu an ayılıp bayılıyorduk ablamla. 'Beni zehirlemek için bunları veriyorlar, yukarıdaki babam artık kullanmamamı söyledi' gibi şeyler söylüyordu. Kendi kendine kestiğinde bakışları değişiyordu. Ben de fark edip ağlaya ağlaya ikna ediyordum."

⁸⁶ "İlacını almadığı zaman yine hikâyelerini anlatmaya başlıyor, kardeşlerimi esir aldılar diyor, devamlı anlatıyor. Öyle zamanlarda çok kötü hissediyordum, hayatım bitmiş gibi. Keşke bunun ilaçsız bir çözümü olsa diye düşünüp, bunun vicdan azabını çektiğim çok oluyor bir yandan. Ama kendi hayatımı tercih ediyorum bu noktada, çünkü diğer türlü bana bir yaşam şansı yok. En büyük korkum ilaçlarını alamaması ve tüm o semptomların geri dönmesi. Bazen bunun nedense hayalini kuruyorum, kötü kötü hayaller..."

One day I ask Zeynep what she meant by choosing her life. She told me how she thought for a long time that she cannot have a life separate from her mother. “All my plans and dreams were based on her life”, she observed, “it is only now that I started dreaming about my own life”.⁸⁷ At this point I asked Zeynep about her sister, Meltem, who refused to take care of her mother long ago. She observed that she was angry with her sister for a long time, as Meltem never shared the responsibility with her:

But I can understand her better now. Neither of us is responsible for our mother. She is our mother, not our child. It was not we who decided to have her. I used to think that my sister also has a responsibility towards my mother, like I do. I thought that at least she has a responsibility towards me.⁸⁸ (Z. Boztemur, personal communication, 2018)

Meltem rarely visits Ayten and Zeynep, and unfortunately I was not able to meet her. On the other hand, Ayten visits Meltem for short times mostly when her husband is not at home. “We coped with our mother’s situation in different ways”, Zeynep told me, “unlike her, I mostly introduced my friends to my mother”.⁸⁹ Here, the difference between Zeynep’s and Gülay’s attitude towards other people with regards to keeping the affliction secret reveals itself again. Unlike Gülay and Meltem, Zeynep chooses to tell people about the affliction. In fact, as she states in the following, she secretly enjoys declaring that her mother is schizophrenic, although Ayten has been diagnosed with a-typical psychosis for a long time:

When I say schizophrenia, people recognize it and they can empathize how hard it must be for a relative. It is a short cut to say schizophrenia, yet a-typical psychosis is not like that. When I tell people that my mother is schizophrenic, I also feel proud of it. ‘Yes, I had a tough life and a tough childhood, but I’m here, standing before you. And I’m a person like that’. It

⁸⁷“Bütün planlarım ve hayallerim onun hayatı üzerineydi. Şimdi şimdi kendi hayatım hakkında hayal kurabilmeye başladım”.

⁸⁸ “Ama onu şimdi daha iyi anlayabiliyorum. İkimiz de ondan o kadar sorumlu değiliz çünkü. O bizim annemiz, çocuğumuz değil. Biz ona sahip olmaya karar vermedik. Önceden ablam mecburdu ama yapmadı gibi bir düşüncem vardı. Şimdi öyle değil. Bana karşı bir sorumluluğu olduğunu düşünürdüm ablamın. Annem için yapmasa da benim için yapmalı gibi düşünüyordum.”

⁸⁹ “Ablamla ben annemin hastalığıyla farklı şekilde mücadele ettik. Mesela onun aksine ben çoğunlukla arkadaşlarımı annemle tanıştıırıyordum.”

made me proud in this way. But a-typical psychosis sounds too hygienic. Schizophrenia is more ancient, more known whereas the other is so, I do not know, modern.⁹⁰ (Z. Boztemur, personal communication, 2018)

These accounts reveal Zeynep's comfort with telling people about her mother's affliction. However, she also told me about the hesitation she feels when she is in public with her mother. "I feel as if everyone can understand that she is crazy" she said in one of our conversations, explaining her fear that people might think that "my (her) mother's affliction says something about me (her)".⁹¹ When I met with Ayten during one of my interviews with Zeynep and she appeared to me as a gentle, old woman who was mostly silent. I did not observe any "abnormality" in Ayten's behavior that would reveal her affliction as Zeynep would fear. I did not ask Ayten directly about her affliction or about her relation with Zeynep. However, one day Zeynep told me about Ayten's approach to her affliction and how she generally articulates it:

She never thought that she is sick, yet she insisted that her nerves are sick. For her, mental problems refer to a sick mind which cannot be rational. So she says that it is her loose nerves which cause her problems. Lunatic means incapability of thinking as well, so she does not accept it. Nerve problems sound more solid whereas mental ones are not known much. For her, it also means being very witless.⁹² (Z. Boztemur, personal communication, 2018)

Here, Ayten's interpretation of her affliction reveals her fear from being associated with any mental incapacity. This is sustained with the lack of knowledge

⁹⁰ "Şizofreni dediğimde biliyor insanlar, yakını için ne kadar zor olduğunu da tahmin edebiliyorlar. Ve daha kestirme bir şey şizofren demek, ama a-tipik psikoz nedir ki... İnsanlara söylediğimde, annem şizofren diye, bundan bir yandan gurur da duyuyordum. 'Evet, çok zor bir hayatım, çok zor bir çocukluğum oldu ama bak buradayım, karşıdayım ve işte böyle bir insanım' gibi bir gurura yol açıyordu. A-tipik psikoz çok hijyenik bir ifade gibi geliyor bana. Ama sanki şizofreni daha bir kökeni eskiye dayanan, bilinen bir kavram; a-tipik psikozsa, ne bileyim, daha modern."

⁹¹ "Herkes onun deli olduğunu anlayabilir diye korkuyorum. Sanki onun hastalığı benimle de ilgili bir şeymiş gibi görünecek diye..."

⁹² "Hasta olduğunu hiç düşünmedi zaten, ama sınırlarım hasta diye ısrar ederdi. Akıl hastalıkları akılda bir sorun olduğunu çağırıştırdığı için, onun gözünde delilik ve mantık çok uymadığı için; sınırlarım gevşek benim derdi. Deli demek düşünemeyen de demek, bunu kabul etmiyor o yüzden. Sinirsel denilince daha elle tutulur bir problem varmış gibi, ama ruhsal denilince çok bilinebilen bir şey gibi olmuyor. Çok zekâsızlığı da getiriyor sanki onun için."

as to the cause and the course of her affliction. Once, I asked Zeynep about her relation with the psychiatrists and if she was able to talk to them about the affliction or not. She explained to me the impossibility of seeing a particular psychiatrist regularly, both in Bakırköy Psychiatric Hospital and in other small public hospitals. The first and the only time she was able to see a psychiatrist was during a relatively short examination of her mother. In that encounter, neither she nor Ayten were able to ask their questions. In fact, as Zeynep observed, she learned about the change in her mother's diagnosis by coincidence. She saw it when Ayten needed the document proving her disability to receive the disability salary. That salary is approximately 1500 Turkish Liras and she receives it in every three months.⁹³

Her account shows that Zeynep never had the chance to discuss her condition with any of Ayten's psychiatrist. She told me about her own decision to see a psychologist, to receive the support she had been seeking for many years. She has been going to therapy sessions for months now and sees the psychologist who does not demand any payments from her. Unlike Gülay, who never wanted to share a detailed account of her own condition, Zeynep told me many times about her feelings of guilt regarding Ayten and her affliction. "I was feeling guilty for not being a good daughter for my mother"⁹⁴ she observed once, admitting how Ayten's affliction left a permanent impact on her life:

I was feeling very unstable. My mother used to go from beating and loving me and there was no rationality behind her beatings. You could not predict if she will beat you for doing this or that. It could be for everything. This brought an uncertainty in my life, more than everything else. I believe that he loves me for that day and will stop loving me tomorrow.⁹⁵ (Z. Boztemur, personal communication, 2018)

⁹³ This amount does not reflect the current disability allowance, see page 74 for accurate information regarding the adjustment for disability allowances in 2019.

⁹⁴ "Anneme iyi bir kız çocuğu olmadığım için suçlu hissediyordum."

⁹⁵ Çok dengesiz hissediyordum. Annem beni bir dövüp bir severdi ve dövmelerinin bir mantığı olmuyordu. Her şey olabilirdi. Bu benim hayatıma bir belirsizlik getirdi.. Bir gün beni seviyorsa ertesi gün sevmeyi kesecek diye düşünüyorum."

By the time I was finishing my thesis, Zeynep gained her bachelor's degree and made a decision to live by herself. She was negotiating with her mother the terms of their separation. In most of our conversations, Zeynep emphasized the permanent impact her mother's affliction had on her life and how she can always detect those problems in her romantic relations. She was determined to live apart from Ayten, although she never wanted to leave her permanently. She still provides for Ayten in their households and Ayten contributes to that by the disability allowance she receives from the state. Before finishing my elaboration on Zeynep's account, I will dwell on the resemblances and differences the two cases have. What can be taken from the stories of Gülay and Zeynep with regards to their affective labor and the reality of living with a mentally afflicted person?

In both stories, the families in question live on the outskirts of İstanbul and have a very low income. Both Sila and Ayten only receive disability allowance, which is considerably less than the minimum wage and hardly meets their needs. They use public psychiatric services in the case of hospitalization yet neither of them can see a psychiatrist regularly. In addition to this, their low class status positions them in a structural inequality which limits their access to medical resources. This is demonstrated the most in the fact that only when it becomes an acute case requiring hospitalization that Ayten and Sila as well as Gülay and Zeynep can be allowed to have a clinical encounter with the psychiatrist, for a very short time. In both cases, the afflicted people are hospitalized more than once and received electro shock treatment in every relapse. The factors triggering their relapse are discussed neither with the afflicted people nor with their caregivers. They know very little about the cause or the course of the affliction which has a tremendous impact on their lives; it pushes them in a vulnerable position stemming primarily from the unpredictability of

the mental affliction. In addition, in both cases the affliction in question is associated with different diagnoses over time. Ironically, this alteration in the diagnosis does not appear to have an impact on their lives. Diagnoses are recognized with the kind of medications prescribed for them and it is only through the impact of the medication that alteration in diagnoses are recognized and elaborated on by the caregivers and the afflicted people. This demonstrates the role of pharmaceuticals' in shaping the relations in the domestic sphere. Zeynep continues to introduce her mother as a schizophrenic, while finding the name of atypical psychosis too "hygienic" or "modern" to be understood by other people. Sila's diagnoses are not known in detail by Gülay either, yet she uses the biomedical language in explaining Sila's troubles. In this language, "the yellow liquid in the brain" is attributed a significant role despite the differences between psychiatric categories such as personality disorders or psychosis, which are unknown to Gülay.

On the other hand, family caregivers are still seen as the medical agents of the state within this context. This is especially due to their role in ensuring the regular use of medication and both stories reveal caregivers' voluntary agreement with this role. Despite her hesitations, Zeynep wants her mother to continue using the medications. She and her sister perceive the medications' impact almost as "a miracle" that stopped Ayten from talking with the people in the sky or from being unpredictable and angry most of the time. Similarly, Gülay and the other members in the family, although they rarely pay attention to Sila's treatment, see it as Sila's responsibility to continue using her medications which help her control her mood swings and temper. All in all, the sedative impact the medications have on the behavior and the emotions of the afflicted people, whose care needs are distinctive and who belong to the unproductive portion of the population; is affirmed by the

medical and state authorities, while caregivers appear to accept this pattern. This agreement can be explained by the unpredictability and violence that appears in afflicted people's interaction with the caregivers, when they stop using the medications. Within this framework, families, particularly the caregivers, appear as the medical agents of the state in their role of ensuring the use of medications. On the other hand, the afflicted people are also assigned responsibility to regularly consume the medications while becoming "proletariat patient-consumers, hyper individualized psycho-biologies doomed to consume diagnostics and treatments" for themselves and the surrounding others (Biehl & Moran-Thomas, 2009, p. 271).

Here, I should also mention that both of the mentally afflicted people in question refuse to be admitted to a rehabilitation program in a TRSM and to visit it regularly. In this regard, despite the emphasis of this thesis on the deinstitutionalization processes and the establishment of the community centers; these cases do not give an idea about the working of the TRSM on a daily basis and its direct impact on the caregivers' everyday lives. Yet, the fact that Sıla and Ayten refuse to go to TRSMs reveals important aspects concerning state's policies while, from another perspective, it exemplifies families' role as state's medical agents. As Gülay once explained, Sıla goes to a TRSM close to their neighborhood for two times but quits the program as she does not like the people there. Gülay never forces Sıla to continue her visits as she does not want to deal with any situation Sıla might have with the people in the TRSM. On the other hand, Ayten never considers going to TRSM as she finds herself too old to visit there regularly with the other members who, as she thinks, are going to be very young. In both cases, TRSM do not appear as a viable solution for the afflicted people who do not prefer to be rehabilitated and to socialize in a TRSM environment where the only common ground the service

users share is their mental affliction. Here, the fact that both Sila and Ayten eventually reside with their caregivers all the time, except when they are hospitalized in acute situations; further demonstrate state's reliance on caregivers' labor. Today, TRSMs are not presented by the Ministry of Health as mandatory services for the mentally afflicted and even if they were, their number is still insufficient to compensate for all the outpatients who are not hospitalized.

It is important to note here the impact of this unpredictability on the lives of caregivers. Both Gülay and Zeynep told me several times about the difficulty of adjusting themselves to the unpredictability in Sila's and Ayten's behaviors and moods. Gülay told me about her hesitations to invite the neighbors to their home as she was afraid of Sila's unpredictable and possibly inappropriate behaviors that might offend the visitors. Similarly, Zeynep grows up insecure about her mother's affection, as she could never predict if her actions would cause Ayten to beat her or not. Here the violence appears as another aspect that accompanies this unpredictability, which almost becomes a routine in both cases I present here.

What follows this routine of violence and consequent chaotic atmosphere in the domestic sphere is the abandonment of the other family members. Neither Sila's siblings nor Ayten's older daughter choose to reside with or to be in regular contact with them. Gülay and Zeynep are seen as responsible for taking care of the afflicted person's needs. The normative, familialist framework assigning women the caregiver responsibilities are sustained in the domestic sphere by the disregard, anger as well as resentment of the other family members towards the afflicted person.

However, it cannot be argued that both Gülay and Zeynep are completely alone in their struggle with their afflicted relative's troubles. I met with both of them through my contacts in RUSİHAK. Sila has been a regular of the Friends' Alliances

for Schizophrenic People for years and Gülay accompanied her several times in her visits to the association. Similarly, Zeynep volunteers for RUSIHAK and introduces Ayten to other afflicted people through that network. In this regard, these networks function as “cults of affliction”, through which the members share “a common experience of illness” despite their different background or purposes (Elliot, 2003, p. 219).⁹⁶

The accounts above point at the abandonment the caregivers are faced with when medical and state authorities pay selective attention to their problems. Their role in caregiving is taken for granted while the affective labor they perform is rendered invisible in this process. Other family members contribute to this abandonment with feelings of anger and resentment towards the afflicted person. However, despite these striking similarities in both cases, they represent different aspects peculiar to the experience of caring for mentally afflicted people as well:

Such that, Gülay and Zeynep choose different strategies in coping with their afflicted relative’s troubles. In Gülay’s case, the affliction never becomes public as she constantly struggles to hide it from the neighbors. Despite the ethnically mixed structure and relatively tolerant atmosphere in the neighborhood, stigma on mental illness becomes a threat to Gülay and Sıla who do not want to share their troubles.

With this constant tension, Gülay performs diverse strategies (coming up with

⁹⁶ In 1950s, Victor Turner uses this term in his analysis of Ndembu people in Africa. He defines the cults of affliction as performances done for the individuals, “who are said by Ndembu to have been ‘caught’ by the spirits of deceased relatives om they have forgotten to honor with small gifts of crops and beer, or whom they have offended by omitting to mention when prayers are made at the village shrine-trees (nyiyombu)” (Turner, 1975, p. 37). There are contemporary studies that on a similar phenomenon occurring in today’s virtual communities, in the cases of people who come together in activist groups, self-help groups and support groups. As Elliot (2003) argues, “they have different purposes, of courses, different from one another and different from Turner’s cults of affliction, but there is one important parallel, and that is the composition of the group” (p. 219).

different excuses for the noise, not inviting neighbors if Sıla is home) which obliges her to manage her emotions in her everyday life. On the other hand, Zeynep lives with another layer of abandonment due to the neglect of her neighbors about Ayten's affliction. In her case, not only Ayten's affliction but also her affair with Zeynep's biological father is known by the neighbors. Yet neither they nor the other relatives offer Zeynep support. She provides for their family while the unpredictability of her mother troubles her as she cannot be sure of her affection, love or anger. All in all, both women are made to perform different forms of affective labor in order to continue their lives with their afflicted relative.

4.3 Conclusion

At the intersection of neoliberal and neoconservative governmental rationalities, women are perceived as the ultimate source of care provision in the domestic sphere in Turkey. Within this context, the emphasis on caring as a moral responsibility of women strengthens the normative attributions about women's care provision, while this gender inequality makes men exempt from the provision of everyday care and makes them "free riders" on women's work. This moral imperative consequently impels women to do the most part of primary caring while making many of them believe that they do not have any choice in the matter (Lynch, 2009, p. 412).

The focus of this thesis is on the caregivers of the people with psychiatric diagnosis. The afflicted people in question here are largely seen as disabled people and are referred to as such in state's discourse. Current disability care policy of the Turkish state demonstrates the emphasis on women's role in care provision despite the current marketization of care provision. Over four hundred thousand people receive disability allowances in Turkey and the majority of them are residing with

their families (Directorate General of Services for Persons with Disabilities and the Elderly, 2019). Within this context, women are deprived from the care they need and are subjected to a peculiar kind of exploitation that is rendered invisible in the given context.

The theory of affective labor provides an insightful lens for understanding the particular caring labor in question. While the theory challenges the modern dualities between mind and body, it reveals the immaterial aspects of caring labor which are embedded in the complexity of human interactions. Thus it brings to light “intensified forms of exploitation” which are demonstrated in diverse laboring activities, as argued by Antonio Negri and Michael Hardt in their theorization of affective labor. It problematizes and politicizes the labor aspect of caring that is rendered invisible in the romantic approaches which define caring labor as an authentic expression of love. In addition, by emphasizing the immaterial aspect of the affective labor and the intangibility of its products; the theory of affective labor covers two dimensions of caring Himmelweit suggests in her conceptualization: caring for and caring about (Himmelweit, 1999, p. 29). Here while the former dimension refers to the desire for the afflicted person’s well-being, the latter implies the activity of catering to that person’s material needs. The concept of affective labor covers both of these aspects as it refers to the combination of material tasks and forms of relationships, cooperation communication as well as affects produced in a given context (Hardt & Negri, 2004).

However, in my examination of the affective labor in the cases of mentally afflicted people, I do not aim to present a comprehensive analysis of the care regime in Turkey. Doing so would require an approach to care which takes into account of the experiences of the privileged class as well. My analysis is limited to the

experiences of low income people, the urban working class, who only have access to public care services. On the other hand, the case studies I examine reveal the complexities of psychiatric caregiving. The affliction of Sila or Ayten does not enable them to take care of their everyday lives; they are able to cater to their basic, material needs. Yet they do require constant attention and care, especially in acute times of anger or in the moments of hallucination. Moreover, their affliction causes unpredictability in their interactions with the caregivers. In this sense, narratives of Gülay and Zeynep reveal the complexity of their labor, its burdensome aspects and their hopelessness in facing the chronicity of the affliction in question. An important dynamic that appears in this relation is caregivers' role in ensuring the use of psychiatric medications. The impact of psychiatric medications manifests itself in shaping the relations at the domestic sphere particularly as they sedate the afflicted person and changing her moods, behaviors as well as emotions. Ensuring the regular of these medications also demonstrate caregivers' role as the medical agents of the state since they provide for the distinctive care needs of the afflicted people, who are categorically seen as the unproductive population.

On the other hand, it is necessary to make a more nuanced explanation regarding the gendered division of labor for psychiatric caregiving in the cases of Gülay and Zeynep. As it can be seen from above, neither of them are the only women members in their family as there is another woman family member who could actually perform the affective labor for the mentally afflicted person. Gülay has another daughter who no longer lives with the family since she started going to university. Similarly, Zeynep's older sister lives in another city with her husband. In claiming that the psychiatric caregiving role is by and large attributed to the women members in the families, I do not mean that all the women members are influenced

by it equally since there are subtler gender dimensions at play. The caregiver role is attributed to Gülay fundamentally because she is the mother in the household. This further gives free passage to her younger daughter from any responsibilities regarding Sıla. In fact, as Gülay once explained, she is very protective towards her younger daughter and does not let her to be involved with Sıla's troubles. Similarly, Zeynep's older sister is freed from her responsibilities as she came of an age to marry a man and started taking care of her own family. As I mentioned above, by the time I was completing this thesis, Zeynep finished her university and started looking for a job that could provide her a decent salary. She told me several times that she never considered living with her mother for her entire life. Similar to her older sister, Zeynep considers leaving home when she come of an age to marry which would eventually change, if not completely end, her caring responsibilities towards Ayten. Looking at her life cycle closely, the changing attributions to her as the daughter and hence the caregiver of Ayten manifest themselves. All in all, these ever-changing perceptions demonstrate that caregiver roles are attributed to women in nuanced ways, without disturbing the gendered division of labor for psychiatric caregiving.

However, while the family rhetoric normalized in state discourse conceals the costs of caregiving shouldered by women; it also obscures the fact that care is an essential human capacity and it serves a universal human need. It is important to recognize the call to acknowledge human beings' dependency as well as interdependency and to not focus all the attention to dependent status of those who need care (Fineman, 2002; Lynch, 2009; Nelson, 2015). Yet, it is equally significant to not falling into the trap of romanticism when emphasizing dependency and care as an inevitable human condition; as the gendered division of labor for care provision and the affective inequalities women are subjected to are still predominantly existent.

CHAPTER 5

CONCLUSION

This thesis is an exploration of the affective labor of women caregivers who reside with their mentally afflicted relative in contemporary Turkey. I call this particular form of labor psychiatric caregiving and point at its distinctive characteristics. These characteristic attributes primarily stem from the unpredictability of the mental afflictions and the intense period of hardships, the fear of stigma as well as the suffering these bring to the lives of the afflicted people and their caregivers. Today, there are thousands of women who are engaged with this type of caring and their labor is by and large rendered invisible due to AKP regime's sacred familialism which defines caring as women's social responsibility. This thesis ascertains the abandonment of women caregivers by the state which is made more possible by the psychiatry institution and it shows how this abandonment is further maintained by the other family members who refuse to engage in with the troubles of the mentally afflicted person. It brings into light the affective labor the women caregivers are engage with in their everyday lives with the mentally afflicted people.

Families are usually left alone in their struggle with the mentally afflicted person's troubles and Chapter 2 examines the contemporary state policies which pave the way for this abandonment. It examines the neoliberal rationality informing state's healthcare policies by focusing on the transformation of psychiatric facilities in Turkey. Chapter 3 shows how this abandonment is supported by the psychiatric authorities as family involvement in the recovery process is encouraged increasingly as an efficient model of treatment. It is an investigation of the political nature of the psychiatric truth produced in the psychiatric literature on caregivers of the mentally

afflicted people. Chapter 4 explores the dynamics in the households and analyzes the affective labor of women caregivers who are coping with the afflicted person's troubles by themselves. The analysis also reveals another factor contributing to women caregivers' abandonment as other family members refrain from caring for and about the mentally afflicted person.

Chapter 3 sheds light on the contemporary landscape of mental healthcare policies which has changed dramatically over the last decades. Introduction of psychiatric medications converted numerous mentally afflicted people across the world into consumers of a million-dollar pharmaceutical market while changing their experience of mental affliction into objects of standardized knowledge (Biehl & Moran-Thomas, 2009; Biehl, 2012; Braslow, 2013; Lakoff, 2005). The impact of these medications on the modes, behaviors as well as the emotions of the mentally afflicted people, predominantly in terms of sedating them, has increasingly become integrated in "the moral and organizational furniture" of the domestic sphere, while family members are increasingly attributed the role of ensuring the use of these medications (Biehl & Moran-Thomas 2009, p. 273).

On the other hand, the recovery model of treatment is another factor contributing to women's abandonment in psychiatric caregiving. As I demonstrate, this model of treatment dominates most of the psychiatric debates in 1990s while influencing the healthcare policies in that era (Braslow, 2013; Roberson et al., 2017). The recovery paradigm in question here promotes the idea of the of community treatment, while it heralds the end of incarceration as a dominant treatment model. The implications of the emphasis on community are important to note as community treatment model takes for granted the role of families in the recovery process: they are assigned the caregiver role primarily as they are expected to reside with the

afflicted person in the households since the community services do not provide 24-hour treatment. However, as Chapter 3 reveals, there are more expectations from family members than simply just providing the afflicted people the space to live and, this is demonstrated in the family recovery approach and the family assemblage theory. As I demonstrate, family members' involvement in the rehabilitation and treatment plan is highly promoted while they are assigned a supportive role. These attributions conceal the fact that families have a political nature in themselves and that normative familial conventions can be sources of stultification or oppression. Therefore, although the relations of togetherness, commitment, obligation and care can be characteristics of families; families can be implicit sources of inequalities in the division of labor, subordination and oppression through domestic abuse and violence as well (Edward & Gillies, 2012). Moreover, these attributions to family members imply an "ideal family" that is highly linked with the problematics of the government. In the context of Turkey, this association and its political nature manifests itself in the workings of the TRSMs which are by and large based on the involvement of the family members.

In Chapter 2, I analyze how AKP regime's sacred familialism relegates the role of care provision to families and I show its manifestation in the healthcare policies which rely on families as mandatory resource of care. This policy regime is sustained more with the wide and regular use of tranquilizers and the establishment of community services providing daily care. Within this framework, the governmental rationality informing the state's healthcare policies under the AKP regime stems from a paradoxical association of neoliberalism and neoconservatism. By the neoliberal governmental rationality, I basically refer to the attempts to inform the basis of the governmental policies with the principles of the market economy

whereas the term neoconservative stands for a particular kind of governmental rationality that considers the family as the core of the social order. In this intersection, while healthcare services are increasingly designed to address the demands of neoliberalism, simultaneously the state relies on families' role in welfare provision in various ways. Their intersection is manifested in the "cash for cash system" that transfers cash for family-based care. On the other hand, increasing numbers of families benefiting from this system demonstrates their negotiation with the normative framework concerning the care provision system in Turkey (Akkan, 2017; Altuntas & Topcuoglu, 2014). However, while this system conceals the labor of women caregivers who are confined more to domestic sphere, it makes them more vulnerable in the labor market.

In the second section of Chapter 3, I focus on the psychiatric literature that examines the burden of care that the caregivers are troubled with. The studies on expressed emotion address the challenges caregivers face in coping with their mentally afflicted relative's troubles and the burden of care it inevitably brings to their lives. Nevertheless, these studies do not capture the complexity women caregiver's lives and the strategies they apply in coping with their troubles. The sociopolitical mechanisms bringing inescapable inequalities to women's lives are nearly neglected particularly as main focus continues to be on the wellbeing of the afflicted people or the role of the caregivers on the prognosis of the affliction. However, despite these particular characteristics, this literature provides significant insight into the burdensome aspects of the lives of the mental afflicted people and their caregivers (Gülseren et al., 2010; Tel, Saraç, Günaydın, Mesik & Doğan., 2010, Kızılırmak & Küçük., 2016). They demonstrate how the stress level and the wellbeing of the majority of the caregivers in Turkey are severely affected as they live

out their entire life with the mentally afflicted person. A substantial amount of data is gathered from researches conducted in different parts of the country, with the involvement of numerous caregivers. In addition, these studies strengthen the argument of this thesis by showing that the caregivers are predominantly the women, “mostly mothers”, in the families (Gülseren et al., 2010).

In Chapter 4, I examine closely the lives of the caregivers and the experience of psychiatric caregiving which, as I show, has a tremendous impact on their lives. I use the theory of affective labor particularly as it provides a more comprehensive lens to understand the complexity of labor that stems from the combination of material tasks and forms of relationships, cooperation communication as well as affects produced in a given context (Hardt & Negri, 2004). In this regard, it unearths the immaterial aspects of caring labor which are embedded in the complexity of human interactions. Moreover, the theory moves beyond the romantic approaches to caring and it brings to light the intense forms of exploitation. Thus it problematizes the labor aspect of caring that are, as I demonstrate in Chapter 2, rendered invisible in the discursive and institutional level.

In this regard, accounts of Gülay and Zeynep reveal significant insight into the lives of women who constantly engage in affective labor in order to cope with their afflicted relative’s troubles. Both of them point at the difficulty of adjusting one’s self to the unpredictability in the afflicted person’s behaviors and moods. Violence appears as another aspect that accompanies this unpredictability, which almost becomes a routine in their households. Gülay constantly strives to hide the affliction from the neighbors and therefore it never becomes public in the neighborhood where stigma on mental illness is strong, despite its ethnically mixed structure and relatively tolerant atmosphere. She manages her emotions in her

everyday life while performing diverse strategies to hide the affliction, by coming up with different excuses for the noise or not inviting neighbors if Sila is home etc. In Zeynep's case, although Ayten's condition is known by the neighbors, they refrain from supporting Zeynep and her mother, while leaving Zeynep abandoned as she endeavors to seek treatment for her mother from her early ages.

In their role of ensuring the use of medications, both Gülay and Zeynep become the medical agents of the state while the sedative impact of the psychiatric medications sustains their relations with the Sila and Ayten. Despite the ambiguous repercussions of these drugs on the well-being of the afflicted person, they basically create "proletariat patient-consumers, hyper individualized psycho-biologies" who consume treatments in the market (Biehl & Moran-Thomas, 2009, p. 271). Within this framework, as a novel social reality, pharmaceuticals shape the human values as well as family complexes in the domestic sphere.

In other respects, the interviews I conducted bring to light several characteristics that appear to be common in the lives of the caregivers. Majority of them feel obscurity with regards to the prognosis of the affliction and the pathogenesis of it. This is usually substantiated with the lack of a stable diagnosis offering a particular explanation and a pattern. In their cases, there is a chronic fear towards the afflicted person's unpredictable actions. During our conversations, most of the caregivers dwelled on their feelings of shame and guilt which appear to draw them into affective states in which diverse negative feelings are articulated, while emphasizing their isolation from the social circle in the neighborhood.

On several counts, my findings here resonate with the psychiatric literature I examine. As I mentioned above, they provide significant figures on the burden of care and the disproportionate role of women in shouldering that burden. However, in

my examination, I apply qualitative methodology of case study which provides closer insight into lives of caregivers and enables an in-depth analysis that can account for socio-economic structures paving the way for particular relations, subjects and forms of labor to emerge. Following the feminist accounts on affective labor, I call attention to the inequalities and exploitations that are generated in the “affective domains of life” which emerge at the intersection of diverse cultural, political and economic spheres (Lynch, 2007, p. 553). In problematizing these affective domains, I point at the labor aspects of caring which are largely rendered invisible in the discursive and institutional levels dominated by a normative framework that assigns the caring responsibilities to the women members in the families. The ideological and moral stance underlying this approach became prominent in the recent years under AKP’s sacred familialism while it largely maintains the gender inequality in Turkey today (Acar & Altunok, 2013; Yılmaz (2), 2015). These affective inequalities are further maintained in the domestic sphere by the feelings of anger and resentment of the other family members towards the afflicted person as they abandon the women caregiver thus implicitly assign the caring responsibilities to her.

In this thesis, I refrain from defining care in neoclassical economic sense, as an exchange relation between different autonomous selves. While the strong family rhetoric in state discourse conceals the costs of caregiving for women, at the same time it obscures the human capacity for diverse forms of caring. The modern dichotomy between dependency and independency fails to reflect our empirical reality as dependency is an inevitable human condition (Feder & Kittay, 2003). Despite affective inequalities that are generated in the context I examine here, there is a possibility of relationality and solidarity among individuals and this is

demonstrated in our inevitable need and universal capacity for caring labor (Davis, 2017; Nelson, 2015). However, it is important to be aware of risk of conceptualizing caring without attention to the varieties of -and the asymmetric relations in- caring. Those who care for the afflicted at significant cost to themselves should be recompensed and as would Martha Fineman argue, this would require a collective obligation in a just society (Fineman, 2002).

I leave here the debate on the organization of care for further discussion. I should note that this thesis lacks a comprehensive perspective that could also acknowledge “privileged” women’s experience of caring. It mainly focuses on the experiences of those who cannot afford marketized forms of care and who receive beneficiaries or disability allowances, which are given on the basis of welfare dependency evaluation. Therefore, the discussion on the organization of care should be informed by the experiences of all others; without ignoring the fact that care is a labor process as much as it is an inevitable human need and a universal human capacity.

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