**The Burden Experience of Immigrant Caregivers for Family Members with Severe Mental Illness**

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**Abstract**

Family caregivers experience high degrees of stress and burden in their daily lives. Immigrant caregivers, who are often simultaneously coping with cross-cultural transition, are exposed to multiple stressors. The aim of this qualitative study is to examine the factors that shape the burden experience among immigrants caring for a family member with severe mental illness (SMI). In-depth interviews were conducted with 32 immigrants in Israel from the Former Soviet Union, who care for a family member with SMI. The interviews were analyzed according to principles of the grounded theory approach. The participants described their burden as an accumulation of economic, linguistic, social, emotional, and health-related adversities that negatively affect their coping and adaptation on the personal and familiar level. The findings showed that the objective and subjective burdens they experience include dimensions pertaining to their role as family caregivers, dimensions pertaining to their immigrant status, and the circular interaction between these two, which intensifies the overall experience of burden. The study proposes a new term – the “double adaptation burden” – that can help promote the design of research, interventions, and policies suited to the multiple needs and challenges of immigrant caregivers.

**Keywords:** family caregivers, immigrant caregivers, former Soviet Union immigrants, severe mental illness, caregiver burden, adaptation, qualitative research

**Introduction**

Over the last several decades, the field of mental health has undergone a process of deinstitutionalization in Western countries, with the locus of care for individuals coping with severe mental illness (SMI) slowly transferring from psychiatric hospitals to the community. These changes have increased the responsibilities and subsequent stress of family caregivers and have made them a central, and sometimes the exclusive, instrumental and emotional support system for individuals with SMI. But what happens when, parallel to caring for a relative with SMI, family caregivers undergo other stressful changes in their lives, as occurs in the immigration process? How is the care for a family member “portrayed” during the cross-cultural transition? These questions and issues are at the focus of the present study.

**The caregiver burden and family adaptation for SMI**

Severe mental illness (SMI) involves a diagnosis of an illness such as schizophrenia, manic-depression, major depression, and personality disorders, the symptoms of which negatively affect an individual’s cognitive, emotional, and social functioning, making it difficult to achieve meaningful goals in life (Anthony, Cohen, Farkas, & Gagne, 2002). The onset of mental illness and the psychiatric hospitalization that sometimes accompanies it is often a difficult and traumatic event, both for the affected individual and his or her family members. It would generally be considered a catastrophic, stressful event that harms the normative life cycle of the family system, deeply affecting all of its members and forcing them to adapt to a new routine in the shadow of illness (Muhlbauer, 2002; Sounders, 2003).

“Family burden” is the commonly used term in the literature to describe the distress and stress experienced by family members as a result of providing intensive care for their loved ones (Awad & Voruganti, 2008; Gelkopf, & Roe, 2014). Two types of burdens can be distinguished: an objective and a subjective burden (Awad & Voruganti, 2008). Objective burden is related to the complexity of the family member’s actions vis a vis the daily challenges, problems, and disruptions brought on by caregiving. These challenges include time constraints, occupational and financial difficulties, and family and social disruptions. The subjective burden, on the other hand, has to do with the inner world, the perceptions and emotional reactions, of family members. The subjective burden often involves feelings like loss, guilt, and shame, and coping with the stigma associated with mental illness in the family. At the same time, family caregivers of individuals with SMI also feel great concern for the future and suffer from a high level of mental and physical distress compared to the general population and to caregivers for individuals with other health conditions (Gupta, Isherwood, Jones, & Van Impe, 2015).

When both objective burden and subjective burden are high, it negatively affects the recovery from family crisis and the ability of family caregivers to develop a resilience and support their loved ones with SMI (Sounders, 2003). Adaptive processes for SMI in the family largely depend on the ability of family members to organize and rally around crises, withstand uncertainty, acquire knowledge, overcome stigma, and utilize the care services and financial, social, and emotional resources available to them (Mackay & Pakenham, 2012; Muhlbauer, 2002).

**Family caregivers in cross-cultural transition**

The burden that family members experience may be especially heavy in the case of immigrant caregivers, who, alongside their caregiver role, are coping with cross-cultural transition in a new country. Adaptation during the immigration process is generally regarded as a multi-dimensional phenomenon, involving mutual interactions between various objective and subjective factors (Berry, 1997; Kim, 2001). The objective factors include social and employment mobility, language acquisition, residential and housing changes, and social relationships with other immigrants and with the host society. The subjective factors include emotional wellbeing, sense of cultural belonging, and satisfaction from various life spheres. Although in this contemporary era immigration is a normative and common life event, researchers agree that during the first years of transition, immigrants are exposed to high levels of stress that can be manifested in physical, psychological, and social distress (Ristner, Ponizovsky, Kurs & Modai, 2000; Yacknich, 2008).

Adaptation processes confronting immigrants may have a formative effect on their caregiver burden experience. Many of the immigrants experience a decrease in their economic status following transition to another country, and those caring for a family member with SMI may find themselves with “double trouble”: struggling for economic survival while simultaneously fulfilling their caregiver role (Topor, Ljungvist, & Strandberg, 2016). This situation may make it difficult for families to recruit professional help, finance treatments, and cope with family separateness processes (Guarnaccia & Parra, 1996). It can also negatively affect the emotional and physical wellbeing of immigrant caregivers; in studies conducted on immigrants who care for elderly family members, findings showed that they experience more psychological and health problems than non-immigrant caregivers (Soskolne, Halevi-Levin, & Cohen, 2007; Suwal, 2010).

An additional characteristic of immigrant caregivers is that they generally bring with them a unique cultural background that differs from that of the host country’s population. Incompatibility between the values espoused by assistance networks in the host country and those engrained in the immigrant caregiver’s culture may lead to conflict and tensions (Tse & Ng, 2014). Moreover, immigrant caregivers have linguistic-cultural barriers when they seek help for themselves or for their family member with SMI (Guzder, Yohaness, & Zelkowitz, 2013).

Cultural gaps and social adversities experienced by immigrants are reflected in the intensity of the burdens they experience. Kung (2003) conducted research on Chinese-American immigrant caregivers of family members with schizophrenia, and described the enormous burden they carry. Kung argues that, beyond the symptoms of illness and the accompanying stigma, the burden on Chinese families is related to the collectivist characteristics of their culture and their immigrant status. These findings are echoed in another study that found a higher level of subjective and objective burdens among immigrant caregivers as compared to local, non-immigrant families (Ryder, Bean, & Dyon, 2002). The empirical evidence attesting to this phenomenon is supported by the experience of professionals who work with immigrant caregivers in mental health service settings; these professionals report that in the course of their meetings with immigrant families, a flood of instrumental and emotional difficulties is expressed (Bradley et al., 2006; Kung, 2016).

**Immigrant caregivers from the FSU in Israel**

Israel is a multicultural country with a large immigrant population that has, since its establishment, absorbed millions of Jews from over the world. The present study focuses on immigrants from the former Soviet Union (FSU). They comprise a large ethno-cultural group in Israel, having immigrated to the country over the last three decades. From 1989 to the present, more than a million FSU citizens have immigrated to Israel, enlarging the Jewish population by more than 17% (ICBS, 2018).

 This immigration process began following the fall of the Soviet regime, which enabled Jewish citizens to immigrate to Western countries. Like most waves of immigration in the contemporary era, the prime motivation underlying immigration of ex-Soviet Jews related to socio-economic considerations and the wish to ensure a better future for their children (Dolberg, 2012; Remennick, 2007). Some of the Jews immigrated to the United States, Canada, and Germany, but the majority came to Israel, in the early 1990s (Tolts, 2009).

 One of the unique characteristics of the FSU immigrant population was their high level of education and their active participation in the workforce and cultural life prior to immigration (Remennick, 2007). For FSU immigrants, the process of adapting to Israeli society was rapid but was also accompanied by certain challenges. Due to the language barriers and the lack of social networks, in addition to the competitive structure of the Israeli labor market, many of them were forced to accept employment outside of their previous professional field, and to work for long hours in odd jobs and menial jobs, which often lacked minimal social benefits (Gorodzeisky and Semionov, 2011). As to their cultural adaptation in Israel, they encountered a divided society consisting of multiple cultures, languages, and traditions, plagued by ongoing internal and external ethnic conflicts (Ben-Rafael & Peres, 2005). Despite adjustment difficulties in the first years, over time, most FSU immigrants and their children managed to integrate into Israeli society while preserving the cultural characteristics of their country of origin (Remennick & Prashisky, 2019).

The uniqueness of the FSU immigrant population in Israel is also manifested in aspects of family life. Certain demographic characteristics can be discerned upon examination of the family structure in this population; they tend to have few children (usually one or two) and there is a high incidence of single-parent families (Remennick, 2007). Furthermore, ex-Soviet Jews tend to be suspicious of the establishment and its representatives due to their negative experiences in a totalitarian society, and therefore family and close friends are the main source of support in times of distress and crisis (Leipzig, 2006; Shor, 2006). This trend is especially prominent in the mental health field, where FSU immigrants are often on the receiving end of pronounced cultural stigma and negative attitudes, causing many to avoid seeking external assistance for mental health issues (Dolberg et al., 2019; Author, 2015). This situation can lead to an especially heavy burden for immigrant caregivers, and for women and mothers in particular, who often take on the bulk of caregiver responsibility (Remmenick, 2001). The immigrant caregivers must care for their family member in parallel to their process of adjustment to a new society, without the family and social support networks they had in their country of origin. In spite of these challenges, the burden experience of FSU immigrants caring for a family member with SMI has not yet been studied.

**The current study**

Most previous studies dealing with the burden experienced by immigrants caring for individuals with SMI focused on their cultural background; little is known about the influence of immigration adjustment in this context. The current study attempts to fill this gap, examining the burden experience of immigrant caregivers from the FSU, on the backdrop of their immigration to Israel. The main research question is: What are the factors that shape the burden experience among immigrant caregivers of individuals with SMI, and how do these factors influence their personal and family lives?

**Method**

The present study applies a qualitative research method in the constructivist tradition. The advantage of the qualitative approach is that it enables an inductive examination of reality as reflected in the eyes of individuals, their life outlooks, and subjective experiences (Lieblich, Tuval-Mashiach, & Zilber, 1998; Patton, 2002). The qualitative approach has become popular in recent years for studying individuals and families coping with stress situations and life transitions such as illness and immigration (Author, 2015).

**Participants**

The two criteria for inclusion of participants in the study were that the individual (1) cares for a family member with SMI who is recognized by the National Insurance Institute of Israel as psychiatrically disabled (at least 40% disability) and (2) is an FSU immigrant who emigrated to Israel after 1990.

 Thirty-two respondents from 30 families participated in the study: 28 single family representatives (22 mothers, 2 fathers, 2 spouses, 1 sister, and 1 grandmother) and 2 parent-couples. Of the 32 participants, 87.5% were women and 12.5% were men. Participants were ages 40-75 (average age: 61.12). In 60% of the families, the participants were single mothers (divorced or widowed). Single-child families comprised 43.3% of the families, and each of these children is dealing with an SMI. The average number of children in the family was 1.6. Most of the participants immigrated to Israel in the 1990s (66.7%) and some after the year 2000 (33.3%). The average number of years since arrival in Israel was 17.96.

 In contrast with the demographic characteristics of the caregivers, most of the individuals with SMI were male (77.7%). The average age of those with SMI was 35.9. The average number of years since receiving a psychiatric diagnosis was 14.56 and the average number of hospitalizations was 3.06. The psychiatric diagnoses among them were: schizophrenia (17), schizoaffective disorder (3), bipolar disorder (4), major depression (4), and borderline personality disorder (2). In most cases, the onset of illness was after immigration (73.3%). Most of the individuals lived in a joint residence with their family (70%).

**Study Procedure**

The participants were recruited via two main channels: 1) approaching family counseling centers in the community that assist family members of individuals with mental health problems, and 2) the “snowball” method, requesting names from family members and professionals from the mental health field.

The research instrument was a two-part in-depth interview (Patton, 2002). The first part of the interview was unstructured, focusing on the spontaneous narrative of the participants, and the second part was semi-structured. The questions in the second part addressed various aspects of the adaptation process to the illness and to immigration. For example: “How has your life changed after the onset of mental illness in the family?”; “How does the role of a family caregiver affect your personal, social, and occupational life?”; “Tell me about the changes that took place in the family after immigration.” At the end of the interview, participants were asked questions to complete missing demographic details about their life and their family member with SMI.

The interviews were individual, with the exception of two interviews conducted with a parent-couple. Each interview lasted between one and two and a half hours, and was conducted in the participant’s setting of choice (e.g. home, family counseling center, coffee shop). The interviews were conducted in Russian – my own mother tongue and that of the participants. The interviews were audio-recorded, transcribed, and then translated into Hebrew/English.

**Ethics**

An institutional ethics committee at Ben-Gurion University of the Negev approved the research. The participants’ written informed consent was obtained before each interview, and they were provided with a written assurance of confidentiality and voluntarily from the researcher. To preserve confidentiality, the names of the participants, as well as any other personal information that might identify them or their family members, have been deleted or changed here. If, during the interviews, there were noticeable emotional difficulties among some participants or specific questions about help they could receive for themselves or their family members, the researcher referred them to relevant social and health care services that could assist them.

**Data analysis**

Analysis of the findings was based on the principles of grounded theory approach (Corbin & Strauss, 2014). The first stage of categorical content analysis involved open coding for each interview. Line-by-line coding was performed and repetitive mortality and concepts defined as primary categories were identified. In the axial coding phase, categories were mapped more precisely, setting “entry criteria” for each category. At this point, some of the categories were renamed, categories were transferred from category to category, major and sub-categories were reorganized and re-categorized and their connections revealed. In the selective coding phase, a hierarchy was created between the different categories, and core categories were identified. This created an integrative and orderly category system, which served as the basis for a new theoretical conceptualization of the findings in light of the research question.

The transition from the individual-level analysis to a cross-sectional one was guided by the principles of the constant comparative method, involving simultaneous inductive and deductive processes (Glazer & Strauss, 1967). This analysis was achieved through repeatedly moving between the individual stories, common categories, and theory.

**Trustworthiness**

To ensure the trustworthiness of the analysis, several steps were taken: first, the results are reported as a “thick description,” which includes detailed information about the research process, context, appropriate citations, and open conceptual discussion. This type of reporting ensures adherence to the text and allows the reader to appreciate the researcher’s interpretation. Second, after completing the study, the researcher returned to several of the participants (member checks) and shared the research findings with them. Their feedback was that the findings properly reflected their family story, and the voice they sought to express in the research (Lincoln & Guba, 1985). In addition, the analysis process and its results were presented in several academic forums and conferences to researchers and mental health professionals who encounter immigrant caregivers in their daily work. They found the study to be a close representation of the reality they encounter in the field.

**Reflexivity**

In qualitative research, the process of self-awareness and self-reflection is necessary to control the possible influence of the researcher on the participants at every stage of the study. The influence of my own cultural and professional identity as an FSU immigrant and social worker in the mental health field is reflected in my choice of subject and research population. As such, I have a close personal and professional connection to the research topic. The cultural closeness and immigration experiences that are familiar to me from a personal and family perspective have placed me in the “insider” position with respect to the participants. Being an “insider” enabled me to recruit participants and build rapport relatively quickly during the interviews. Unlike the participants, I have not experienced caregiving for a family member, and I am a younger male (while the majority of participants were middle-aged women). My “outsider” status as a younger man allowed me to adopt a natural novice attitude, helping some participants feel at ease, rather than intimidated by my position as a researcher and social worker.

**Findings**

In their interviews, immigrant caregivers described at length the multiple hardships and the distress and burden they cope with while dealing with family members with SMI, resulting from both the mental illness and their cross-cultural transition. I have divided these difficulties into two main categories: the objective dimensions of burden – the instrumental “price,” and the subjective dimensions of burden – the emotional “price.” Each of these categories is composed of sub-categories that provide a more specific and multifaceted breakdown.

**Dimensions of objective burden**

From among the various difficulties that characterize their lives, the participants mainly emphasized three objective factors that create most of their burden as immigrant caregivers: 1) economic and employment difficulties; 2) housing problems; 3) language difficulties. These categories highlight social adversities and barriers that immigrant caregivers suffer from, and the negative implications of these for the caregivers and their family members with SMI.

***Economic and employment difficulties:***

Participants indicated that there economic difficulties stemmed from two primary, interconnected reasons: difficulty in immigration adaptation and caring for a family member with mental illness. Because most people with SMI have a hard time finding steady employment, they often subsist on a disability allowance from the National Insurance Institute and also depend on the economic assistance of their relatives. Participants spoke of the economic burden this entails; this was the main theme in many of their narratives. For instance, Michael began his story with this:

*Well, what can I say? The burden is mainly economic. I am already an older man, retired, and I must work in order to support my sick daughter… the money is not enough for her…she doesn’t work, and because of her illness, she isn’t able to find anything suitable…I’m already tired of working and want to rest, but I have no other choice.*

Most participants described economic and employment difficulties they had had in the past, or (for some) were still experiencing, following immigration. These difficulties forced most of them to lower the standard of living they enjoyed in the FSU; In Israel, they often worked long hours and sometimes experienced periods of poverty*.*

Since her immigration fifteen years earlier, Paulina, an engineer by profession, has been working long hours cleaning offices:

*Here I work cleaning offices. I get up at 5:00 a.m., and at 5:30 a.m. I already need to be at work…I used to go to work and come back at 10:00 p.m. or 11:00 p.m. Only recently have I been working less because my health doesn’t allow me to [work for so long]. I work so many hours in order to survive, because the children’s needs are so great and the earnings are scant.*

Some of the participants used the word “survival” to describe their general adaptation hardships as immigrant caregivers, and some used it to refer to their economic adversity in particular. The economic difficulty is especially prominent among single mothers who immigrated to Israel alone and don’t have any family support:

*I had so many economic problems and I had to constantly survive and survive. I was constantly fighting for Adik (son with SMI), trying to find him a proper setup, and also economic problems. Now it scares me to look back and understand how I survived all that. (Kira)*

In most cases, immigrant caregivers are not able to cope with the double economic burden for long and have to choose what to concede and to which goal they will devote most of their resources – to the care of the family member or to their work and career development. Some of the participants said that because of economic adversity and the need to work long hours, they couldn’t fully fulfill their role as caregivers:

*They offered me an opportunity to participate in a group at the family support center, but I don’t have time... I work from morning to evening, and the only time I could participate is at 8:00 p.m., but all the activities are scheduled earlier. And I can’t get out earlier… (Michael)*

Other participants preferred to sacrifice their professional careers and their wishes for personal development in favor of dedicating themselves to caring for the family member with SMI:

*I was offered many jobs that I wanted. I could have also studied at nursing school. But I lost out. I was very involved with him (family member with SMI) and his rehabilitation. We are rehabilitating him, and it has affected us…I didn’t have time to learn and certify the degrees… I haven’t worked here in my profession for even one day. (Eva)*

***Housing problems***

The theme of housing problems came up in almost all of the interviews, proving to be a central, sensitive, and painful subject in the participants’ lives. The families living in rented apartments (n=18) expressed the greatest distress, and since they cannot afford to buy an apartment, they await solutions from the state. It is evident that moving from one rented apartment to another does not allow them to settle down and creates increased stress, both economically and in terms of the time and discomfort involved:

*Nine times I moved, and every move like that is very difficult and involves many related expenses for movers and moving. Landlords made problems, either they would evacuate us or they needed the apartment and once again we had to look for a new apartment. (Brunislava)*

The participants noted an association between their housing situation and the mental health of their family member with SMI. Oksana, whose brother had lived in several housing arrangements and at the time of the interview was living in a hostel for psychiatric rehabilitation, sees a connection between solving the housing problem and her brother’s recovery process:

*I wish a housing solution could be found. I would like for him [my brother with SMI] to be able to move out of the hostel and have an apartment where he could live with assistance. Therefore, public housing is a solution. It will solve many of our problems. Because he wouldn’t have to move from one place to the other and would be able to be mentally stable as well…. It could definitely help him feel like a human being.*

One of the frequent barriers to recovery is the inability of family caregivers and individuals with SMI to live in separate apartments. Living in crowded quarters under one roof creates tension and pressures, and negatively impacts the efforts of individuals with SMI and their family caregivers to create healthy physical and emotional boundaries:

*For psychological reasons as well, I don’t want to leave Peter alone, but the economic aspect affects us a lot. Sure, if I had the money to pay for the apartment all by myself, maybe I would have left a long time ago, and we would have split up. Because it’s hard for us to live together. But to throw him into a hostel now, I also wouldn’t want that. So yes, we are living together because otherwise I couldn’t afford it…And we are forced to live together, even when we don’t get along so well. (Natalia)*

 ***Language barrier***

Language acquisition is one of the central challenges in the adaptation process of immigrants to a new society. Most of the participants (n=18) reported that they have no command or only partial command of Hebrew, though some of them have been living in Israel for over 20 years. Even participants that have acquired the language have trouble understanding and speaking freely in their encounters with various bureaucratic systems, and they prefer to speak their mother tongue.

Some participants related that caring for their family member with SMI made it difficult to dedicate themselves to learning Hebrew in their first years in Israel:

*I went to an Ulpan [program for learning Hebrew]. But at the Ulpan…I wanted learn the language very much, but I had thoughts and worries on my mind. Half of my mind was listening to the lesson and the other half was worrying, what is Andrei doing now and how does is he feeling? (Nina)*

Most of the participants reported that language difficulties are their biggest obstacle in getting the external assistance they need, especially when it comes to obtaining vital information about benefits and services to help their family members through the rehabilitation and recovery process: “There is a definite lack of information in Russian, and perhaps there are good things, but you don’t know about them. And then we are forced to search almost blindly” (Raisa and Yaakov).

One of the roles of family caregivers for individuals with SMI is to help them take full advantage of their rights and to locate the proper services for them. The language difficulties of immigrant caregivers and the shortage of available translators in the mental healthcare system impede their ability to fulfill this role. Some participants said that, in their encounters with the system or in bureaucratic offices, they are unable to demand the rightful benefits for their family member, and therefore have feelings of frustration and helplessness:

*We can’t bang on the table in Hebrew. They give us a piece of paper and we leave, but what does it say? Because of this matter of the language barrier, you can’t demand what you are entitled to. And he [the son with SMI], you see, he also knows Hebrew very poorly… All in all, this really causes us to despair. (Janna and Anatoli)*

Participants said that due to the language barrier, they are forced to ask the family with SMI to be a language and cultural broker; in most cases, he or she acquired the language more rapidly because of being younger than the caregiver. But the role of language-cultural broker that is forced upon them doesn’t benefit individuals with SMI and may create an additional emotional burden for them and for the family caregivers:

*After my husband died, I had to deal with the burial and cemetery and tombstone, and I couldn’t do it all…and she [the daughter with SMI] helped me very much and actually did everything. Because I didn’t know Hebrew well, and she helped me with the translation and all the bureaucracy. She behaved so nicely that I took advantage of it…and in the end, it got her out of her schedule and once again she had an attack and had to be hospitalized…(cries). (Marina)*

**Dimensions of subjective burden**

In addition to the objective burden, participants described at length the subjective burden, that is, their emotional reactions to caring for a family member with SMI on the backdrop of their adaptation to the cross-cultural transition. The emotional reactions relate to four interconnected categories: 1) multiple loss; 2) guilt and regret; 3) fear of stigma and social rejection: 4) health problems. These categories highlight the unique nature and intense pain associated with the dual adaptation that participants must cope with, as well as their efforts to give meaning to their difficult reality.

***Multiple loss***

Most participants described feelings of sorrow and loss that overcome them. These are especially prominent in the narratives of parents where the onset of their child’s mental illness occurred following immigration (n=22).

The participants described the sense of mourning and loss they experienced following the recognition of the mental illness. Many repeated the expression “life is all over”:

*When he became ill, I felt as if life was all over. A crevice had suddenly appeared, and you don’t know what will be from now on. Nothing could make me happy. It’s as if you’re dead. You’re alive, but you’re actually dead… (Tamara)*

Some participants, especially those who immigrated *because* of their family member’s illness, said that the immigration to a foreign country aroused feelings of sadness and loss:

*I didn’t intend to immigrate at all… Immigration is enjoyable for young people, but in my case, immigration is a punishment. His illness [son with SMI] is actually the most profound factor. Otherwise, it would have been better to remain in familiar surroundings, under regular conditions, with familiar people... In other words, not only did I have to immigrate but I also have to cope with his difficulties, and when it all piles up on you together, it’s even harder. (Natalia)*

Non-immigrant family caregivers usually must cope with one loss, namely the expectations and hopes for a “healthy” family member. By contrast, immigrant caregivers also mourn the loss of resources they had prior to immigration and unfulfilled expectations from their new country. Alyna, for example, who immigrated to Israel because of her son, mourns and grieves his illness as well as the loss of the support network she left behind in her country of origin:

*After a while, I began to realize that my son [with SMI[ had severe difficulties, and it was very painful for me to see…because I actually came to Israel because of him. There I had connections, there I had everything. I had such good friends there, such connections. Why did I need all this pressure?*

Mourning for the resources left behind in the FSU in addition to mourning their hopes of having a “healthy” family member, is not unique to families in which the onset of mental illness was after immigration:

*Because of him [the son with SMI[, we immigrated very quickly… We wanted him to go through all the stages of rehabilitation and not waste time… We arrived with only four suitcases…We left everything there – friends, an apartment, furniture, clothes, everything. In any case we would have immigrated, but in a more natural and planned out way, with everyone. We wouldn’t have left everything in such a way. (Raisa and Yacov)*

It seems evident that the theme of double loss has become central in the families’ narratives, repeating itself in various ways and contexts. It was sometimes the main narrative message that the immigrant parents expressed in the interviews.

***Guilt and regret***

Guilt is a component of the subjective burden that accompanies family coping with mental illness. It mainly characterizes parents, who wonder “why this happened” in their family, and what their part was in the development of their child’s mental illness. Participants reported that they feel guilty about their decision to immigrate and its timing, a lack of sufficient parental presence in their children’s lives in light of the challenges of adapting as immigrants, or the decision to allow their children to immigrate alone. Darya spoke about her son being young at the time of immigration and about her insufficient presence in his life due to her own acculturation difficulties:

*He immigrated at the age of two, and he had many difficulties, and later on became ill, and they said that children adjust more easily to immigration pressures than adults. It’s too bad that we didn’t immigrate when he was a bit older, because he had many problems in kindergarten as well as in school. He studied in a class where there were no Russian-speaking teachers and he stayed there each day until four because I felt that I needed to work, that I must learn the language well. And now I think that all this together had a negative impact on him.*

Nina felt guilty that she couldn’t look after her son and protect him from the social dangers lurking for an adolescent boy:

*When he was still in school, the outbreaks began. You see, I worked very hard, at two jobs. I am to blame. I should have watched over him more. I didn’t notice that he had depression.*

All of the participants whose children had immigrated through Jewish Agency programs for adolescents, such as “Na’aleh” and “Sela” (n=4), felt guilt and regret for letting their children immigrate alone and not being nearby to protect and support them:

*If I would have been here, I would have looked after her when it came to drugs, because she was so good and well-educated. I blame myself for this. If I hadn’t allowed her to come to Israel by herself, but instead had said that we would all travel to Israel together, as a family, then perhaps it wouldn’t have happened. That was my big mistake [cries]. (Marina)*

***The fear of stigma and social rejection***

Attitudes, reactions, and negative behavior of society towards individuals with SMI and their family members contribute to the subjective burden that the participants experience. Some of the participants also described fear of rejection or actual experiences of rejection due to their different cultural background as FSU immigrants.

Most participants reported that they had encountered a discriminating attitude towards them on the part of native-born Israelis or veteran immigrants, and some of them continued to experience discrimination against FSU citizens in many life spheres through the present: *“It happens all the time that when Russians come to request something, they are refused, and when Israelis come, they agree…and it doesn’t matter how long those people have been here, 10 or 20 years. This exists in all fields… there is discrimination” (Oksana).*

Other participants reported that they experienced stigma and rejection in the context of the mental healthcare field. As is evident from Alexandra’s story, this stigma was especially prominent among welfare professionals toward single mothers:

*When they [welfare workers] saw me, they immediately labeled me. They said that Grandmother is very dominant, very involved, and that this had a negative influence [on the daughter]. So, no one spoke to me very much over there, but when we were at the court session, the judge said: “What do you have against her, there is a very good grandmother sitting here. Give the granddaughter to her grandmother.” And they said: “No, this grandmother wasn’t successful in raising her daughter, who can’t raise her daughter, and therefore she can’t be handed over to her.” When I told this to the daughter’s psychiatrist, he really laughed and said: “What? That’s what they said? Raised her daughter who became ill and from that they conclude that the mother is to blame for it?... and the welfare people said that because she’s mentally ill, I’m not able to raise her daughter. Here you have another example of stigma. (Alexandra)*

Participants felt that in some of the cases, the negative attitudes they experienced at the hands of institutions stems both from their minority status as immigrants and their role as caregivers of a family member with SMI. As a result, they lose trust in the health care services and feel abandoned and rejected:

*… At the Family Center they give us lectures saying that we should cooperate with the doctor. In other words, they ask us to cooperate, but the doctors don’t aspire to this so much. That’s how it was in Russia, I must say, and here it’s the same thing. But here it’s twice as insulting. Because when you belong, when you are in your own country, and a person speaking your language tries to ignore you, it’s insulting, but when you arrive in a host country, it has a doubly destructive influence. That is to say, here you also get the feeling that you’re not wanted at all. (Natalya)*

***Health problems***

The participants reported that they suffer from a variety of health problems as a result of coping with the double stress of immigration and mental illness in the family.

Most participants experience daily anxiety and fears as part of their caregiver role*:*

*The experience of a main caregiver, the parent caregivers, is one of constant stress. Because it’s many situations of uncertainty and waiting…and also you mustn’t relax and rest. Once I wasn’t on my guard and I gave her [the daughter with SMI] too heavy a load, and it caused her to get off track. Therefore, it’s always being on the alert as to what is about to happen. (Karina)*

The participants said that the caregiver burden affects their mental health negatively, and some of them have been diagnosed with depression, anxiety, and insomnia. Nine participants noted that they take medications for their mental health issues:

*I look healthy and like everything is fine by me, but I also have many problems. I take three Clonex, two Elatron and two Vaben because I can’t sleep. And I also have fibromyalgia with body pains, and then even if I want to sleep, I can’t and I can’t relax. (Yana)*

The emotional stress experienced by the participants is intensified by the pressures of their first years following immigration:

*I was also depressed because of housing problems. I didn’t have money…. It causes depression, even without the problem of caring for a disabled family member. A healthy person can also become depressed because of this situation. (Arkadi)*

The stress and heavy burden that family caregivers experience have implications on their physical health as well. The participants said that they or other family members have suffered from numerous physical problems as a result of their tense relationships with the family member with SMI*:*

*We’re already older people, we are going through hell with the daughter, and it affects our physical condition as well. After she [the daughter with SMI] divorced and returned home, my wife developed diabetes and my blood pressure got higher, and I began to take medication regularly. And this is all because of the pressure that we experience at home with her… a lot of confrontations and shouting. (Michael)*

**Discussion**

The current study aimed to explore the factors that shape the burden experience of immigrant caregivers and its influence on their personal and family lives, based on the particular case of FSU immigrants in Israel. The findings show that objective and subjective stress factors associated with immigration such as emotional, social, and economic adversities cause difficulty in coping with mental illness in the family. Simultaneously, objective and subjective stress factors related to coping with SMI in the family contribute to challenges in the immigration adaptation process. This circular situation leads to the experience a “double burden” for immigrant caregivers. The double burden includes dimensions pertaining to their role as family caregivers, dimensions pertaining to their immigrant status, and the circular interaction between these two that intensifies the overall sense of burden. The cultural background of immigrant caregivers also influences their subjective burden. These effects, as evidenced by the findings of the present study, are shown in Figure 1:

INSERT FIGURE 1 HERE

**Double objective burden**

The primary factor that shapes the double objective burden experienced by caregivers is related to economic difficulties. The findings of the present study are consistent with previous findings, according to which family caregivers must provide financial assistance to their family member with SMI, and find themselves facing economic hardship (Azman et al., 2017; Iseselo, Kajula, & Yahya-Malima, 2016). Caregivers who are also middle-aged immigrants have a very limited or non-existent economic capacity, due to economic and employment challenges that they themselves face following immigration (Dolberg, 2012). This situation forces many immigrant caregivers and their relatives with SMI into an economic crisis and a struggle to survive, pushing some of them below the poverty line and into social marginalization.

One of the main sources of immigrant caregivers’ economic difficulties is unstable housing. The high cost of living in Israel and the lack of public housing increase the feeling of stress among both caregivers and individuals with SMI, because are often forced to dwell in common living quarters, even in situations of prolonged conflict and uncertainty. Prior studies on immigrant caregivers and ethnic minorities reported a high level of emotional distress and family conflicts due to financial and housing difficulties, and indicated the need for the system to provide this population with public housing (Guada et al., 2011; Guarnaccia & Parra, 1996).

Another objective dimension of burden, which is exclusive to immigrant caregivers, is related to the language barrier. On the one hand, mastering a new language requires emotional availability to invest effort, time, and energy, which, as caregivers, these individuals do not have. On the other hand, not having mastery of the language diminishes their ability to engage external support and obtain the rights and services to which they and their relative with SMI are entitled. These findings are consistent with other studies that found that caregivers’ ability to help their loved ones is impeded by language barriers (Guzder et al., 2013). This negatively effects their sense of burden (Zamora et al., 2016) as well as the burden experienced by family members enlisted to help with language or cultural brokering (Oznobishin & Kurman, 2009).

**Double subjective burden**

The primary factor that shapes the subjective burden of caregivers is their own emotional responses, which often include loss, sadness, guilt, shame, and concern for the future. Beyond the burden associated with the intensive care for individuals with SMI (Sounders, 2003), the psychological distress of immigrant families, particularly immigrant parents, is intensified by grief over the loss of resources available to them in their country of origin and the hope of providing a better future for their children by moving to the host country. Indeed, in this study, the fact that in some cases children became mentally ill after immigration intensified the parents’ feelings of loss, guilt, and shame.

An additional subjective dimension of burden for immigrant caregivers is the fear of social rejection. Immigrant caregivers are at a double-risk for stigma and exclusion, owing to their minority status as immigrants in a new society (Yakhnich, 2008) and the stigma associated with families of psychiatric patients, who tend to bear the most responsibility for the onset of mental illness (Larson & Corrigan, 2008). The experience of institutional exclusion seems to be the most painful and hurtful because of how much immigrant families, especially single mothers, depend on the help of state services and systems. Such experiences of rejection intensify feelings of anxiety, suspicion, and loneliness and reduce caregivers’ ability to engage essential resources.

The negative impact of the subjective burden of caregivers is reflected in high rates of mental and physical morbidity among them, compared to the general population (Gupta et al., 2015; Perlick et al., 2005). In the case of immigrant caregivers, the accumulation of stressful events due to both illness and migration appears to lead to the development of health problems. Indeed, post-migration social adversities are known to increase the risk of mental and physical illness (Ristner et al., 2000), while improvement in socio-cultural integration is associated with improved health status (Chen et al., 2017).

**The double burden as nexus between health and social issues**

From a broader, integrative perspective, the findings indicate that the double burden experienced by immigrant caregivers leads to a partial blurring of the subjective and objective dimensions of burdens. While differentiation between subjective and objective burdens is very common in the research literature (Awad & Voruganti, 2008), and, out of convenience, were also differentiated in the current study, some of the findings cast doubt upon the relevance of this distinction regarding immigrant caregivers’. Instead, the participants experienced their burdens as a stress pile-up, with an intersecting complex of social, emotional, and health-related adversities with reciprocal and circular relations between them.

For example, a seemingly objective hardship, such as a housing problem, may intensify both the objective burden on immigrant caregivers (gathering the resources to find an apartment and move) and the subjective burden (feeling unsettled and concerned about the future). In the experience of immigrant caregivers, moving from one apartment to another involves not only physical transitions but an emotional experiences of unsteadiness, which prevents them from pausing and developing a sense of belonging in their new surroundings.

There are also circular, reciprocal relations between the caregiver burden and the language barrier familiar to immigrants, which each factors intensifying the other. A language barrier may intensify both the objective burden, making caregivers unable to take advantage of rights and services, and the subjective burden, contributing to family conflicts and a sense of frustration and helplessness in their encounters with state systems and services. Certain aspects of the subjective burden, such as the experience of stigma and social exclusion, may also affect the objective burden of immigrant caregivers, in that it prevents them from obtaining vital resources.

A combination of the various, interconnected dimensions of burden creates an ongoing threat to the social and health status of immigrant caregivers, which further exacerbates their problems. These findings clarify those from previous studies that highlighted the particularly heavy burden experienced by immigrant caregivers as compared to non-immigrant caregivers, which were not able to sufficiently pinpoint the factors contributing to it (Bradley et al., 2006; Kung, 2004; Ryder et al., 2000).

**Limitations and future studies**

The present study has some limitations. Firstly, there was significant variety among the participants in terms of the timeline of illness and immigration, as well as their cultural background within the borders of the FSU. Secondly, although this study aimed to investigate all kinds of family caregivers (parents, spouses, siblings), in practice, the vast majority of those who agreed to be interviewed were parents, and especially mothers. Thirdly, the lens adopted in the present study focused primarily on examining immigration adaptation processes; it gives less attention to the unique cultural background of FSU immigrants and the cultural changes they undergo upon immigration to Israel.

It would be informative for quantitative follow-up studies to compare the burden experienced by immigrant caregivers with the burden of non-immigrant caregivers. Moreover, it is important to examine whether the double burden identified in this study among FSU immigrants in Israel is found among immigrant caregivers from other ethno-cultural backgrounds and in other developing countries.

**Implications and conclusion**

The present study offers several important contributions. On the methodological level, the study investigates a hard-to-reach group – immigrant caregivers. It is empirically difficult to interview this group and to map its characteristics and needs (Bradby et al., 2007).

 On the theoretical level, this study illuminates the complex dynamics between two processes that occur simultaneously in the lives of immigrant caregivers: coping with mental illness and coping with cross-cultural transition. To conceptualize the two processes and the reciprocal relations between then, I would like to propose a new term: “the double adaptation burden.” This concept makes it possible to focus on immigrant caregivers’ experiences in a context that is uniquely their own, distinct from the burden experienced by non-immigrant family caregivers and to the stress experienced by immigrants who are not coping with SMI in the family. In addition, this term could contribute to the recognition of immigrant caregivers as a “dual-risk population” and to design interventions and social policies that better suit their unique needs and challenges.

In terms of clinical practice, the study makes a practical contribution to mapping the needs and difficulties of FSU immigrant caregivers. The study emphasizes the need to adapt family psychoeducational interventions to the emotional, social, and cultural-lingual needs of immigrant caregivers. Such interventions have been found to be effective in reducing the sense of burden among family caregivers (Dixon et al., 2001). For example, many immigrant caregivers, especially parents, experience significant emotional and symbolic losses, which strongly shape their subjective burden. Therefore, in clinical practice, it is important to recognize, legitimize, and validate this painful multiple loss experience, in addition to the feelings of guilt, shame, and anxiety that can arise in the context of adaptation during immigration. Furthermore, cultural adaptation of psychoeducational groups may assist immigrant caregivers in acquiring essential knowledge and information as well as expand their social support and feelings of cultural belonging. These groups can provide a comfortable and safe social arena for immigrant caregivers, not only for dealing with their family member’s illness, but also for coping with bureaucratic and acculturation difficulties they face as immigrants in a new country.

On the policy level, this study points to the need to recognize immigrant caregivers as a high-risk group and to broaden the range of resources offered to them. The study identifies two of the highest-risk types of immigrant families: families in which the onset of mental illness occurred shortly after immigration and families headed by single mothers. These two groups are particularly in need of comprehensive emotional and instrumental support. Providing adequate public housing and incorporating cultural competence into mental healthcare systems are of great importance for improving the adaptation and recovery processes of immigrant caregivers and their family members with SMI.

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