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### **Original Article**



# Stigmatization experiences of parents of individuals with schizophrenia: A qualitative study

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#### **Abstract**

**Objectives:** The aim of this study was to investigate the stigmatization experiences of parents of individuals diagnosed with schizophrenia.

**Methods:** This is a descriptive qualitative study. The study sample consisted of 16 parents providing care to individuals with schizophrenia. The study data were collected via individual interviews and analyzed using content analysis.

**Results:** Stigmatization experience is a multidimensional phenomenon. The data obtained in the interviews were categorized in four themes: the dimensions of stigmatization, the effects of stigmatization on life, coping with stigmatization and recommendations for reducing stigmatization.

**Conclusion:** The parents were adversely affected by stigmatization both in their emotional and social lives, and they have difficulty coping. The parents emphasized that society should be informed about fighting stigmatization and be encouraged to empathize with people who suffer from stigmatization. It is important for health professionals to be aware about parents' stigmatization experiences and their effects.

**Keywords:** Parents; schizophrenia; stigmatization; qualitative research.

#### What is known on this subject?

 Stigmatization of and discrimination against schizophrenia affect not only patients, but also their loved ones, including parents, siblings, spouses and friends.

#### What is the contribution of this paper?

 This study indicates that parents experience both social stigmatization and internalized stigmatization, and that this experience results in emotional burden and social losses. It also indicates that parents use avoidance and active methods to cope with stigmatization.

#### What is its contribution to the practice?

 The results of this study show that parents, who act as caregivers, are also affected by stigmatization and discrimination, and that this should be considered in structuring the mental health policies. New models should also be developed to support them.

Stigmatization of and discrimination against schizophrenia are universal problems. However, stigmatization negatively affect not only the individuals diagnosed with

schizophrenia, but also their family members.<sup>[1-6]</sup> Society also exhibits prejudiced and discriminative approaches to the patients' parents, siblings, spouses, friends and other relatives.<sup>[1,6,7]</sup> Stigmatization and discrimination pose a significant barrier for families and individuals with schizophrenia to manage the disease, and are associated with subjective and objective caregiving burden.<sup>[2,8-10]</sup> Reducing the effects of stigmatization on families is a top priority for strengthening families, the primary source of support for individuals with schizophrenia.<sup>[10]</sup> At this point, first of all, the nature of the stigmatization experienced by family members should be explained.

Stigmatization is a complex experience that affects all aspects of families' lives. Society thinks that the families of the individuals with mental diseases are unusual and affected by the disease, and that they engage in problematic behaviors [6].



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A qualitative study conducted in the Czech Republic determined that the family members of individuals with schizophrenia experience stigmatization and discrimination within their families, in society and in public support systems. [4] In another study conducted in China, 71% of the caregivers reported that they received less support from their friends and frequently experienced discrimination during their applications for shelter, school and job after diagnosis.[11] A mixed methods study conducted in India, in which most of the participants were family members, highlighted the negative effects of the caregivers' experience of stigmatization on their relationships and emotional well-being. They experienced negative reactions and exclusion, and avoided social interaction.[12] Family members report that others are reluctant to communicate with them, and that they feel rejected. Both family members and patients also reported denigration and attacks on their rights by others.[13] Other qualitative studies, in which most of the participants were parents, determined that families are affected by the stigmatization of patients, experience social exclusion, are exposed to curiosity, derision and criticism and are judged as guilty.[9,14] The siblings of the individuals with schizophrenia also encounter difficulties with finding jobs, marriage and career management, as well as family structure. [10] It is also indicated that family members tend to internalize the stigmatic beliefs of others.[15]

Family members experience a sense of worthlessness, disappointment, shame, fear, concerns, loneliness, hopelessness, sadness, despair and guilt as a result of stigmatization. [10,13,16] Socially, families experience isolation and ignorance, and therefore, they hide the disease and avoid relationships. [16] Accusations, criticism and avoidance by others result in psychological distress, hopelessness and social withdrawal. [12] Shame also negatively affects families' acceptance of the disease and undertaking of caregiver roles. [17]

Reducing the effects of stigmatization is important for strengthening families during the caregiving process.[10] The literature includes qualitative studies that describe the stigmatization experiences of the families of individuals with schizophrenia. However, none of them focus directly on parents' stigmatization experiences. Some studies have been conducted with all family members, [9] while others have also included distant relatives such as cousins in their samples. [3,4,10] The data of the other qualitative studies reflect the experiences of both the patients and family members.[13,16,17] However, the stereotypes on which stigmatization and discrimination are based are also shaped by the roles and positions of family members within families. Being a parent, child or spouse may affect the nature of the experience of stigmatization and its effects.<sup>[1]</sup> This study aims to describe the stigmatization experiences of the parents of individuals diagnosed with schizophrenia. Its results can help to guide the efforts to reduce parents' burden due to stigmatization and to improve the nature of the efforts to fight stigmatization by rebuilding the societal systems.

#### **Materials and Method**

#### **Study Design**

The study has a descriptive qualitative design. This design is used when an event or phenomenon is described directly without intuitions.<sup>[18]</sup>

#### **Study Sample**

This study was conducted with the voluntarily participating parents of individuals with schizophrenia at a university hospital in Western Turkey from July to October 2019. It used purposive sampling, which is intended to ensure diversity in parameters such as age and duration of caregiving. The study included parents who were literate, responsible for the care of an individual diagnosed with schizophrenia based on the DSM-5 diagnostic criteria and had been providing care for the patient for at least two years. Literacy was the criterion for the parents to be able to sign the consent form. The exclusion criterion was the presence of another family member diagnosed with diseases other than schizophrenia that are stigmatized by society, whether physical (AIDS) or psychiatric (bipolar disorder, autism, etc.).

#### **Data Collection**

The data were collected through face-to-face in-depth interviews using a semi-structured interview form. All of the interviews were voice recorded. The semi-structured interview form includes open-ended questions about the parents' stigmatization experiences (Table 1). Two pilot interviews were held to determine the comprehensibility of the questions, and then the questions were finalized. To determine the participants, first the files of the patients followed in the polyclinic or clinic were evaluated in terms of the inclusion criteria. The parents of the individuals with schizophrenia who met the inclusion criteria were contacted in person or by phone. The participants were informed about the aim of the study and that voice recording would be used, and the time and place of the interviews were planned with the parents who agreed to participate. The interviews were held in a well-lit room where they would not be interrupted in the institution with which the researchers were affiliated. The longest interview lasted 27 minutes and 43 seconds. The shortest interview lasted 8

#### **Table 1. Interview questions**

- Do you experience stigmatization and discrimination as the parent of an individual diagnosed with schizophrenia?
- How does society approach you as the parent of an individual diagnosed with schizophrenia?
- What do people think about you as the parent of an individual diagnosed with schizophrenia?
- How do these thoughts and attitudes affect you?
- How do you cope with these thoughts and attitudes?
- What should be done to reduce or eliminate these attitudes and thoughts?

minutes and 42 seconds. The interviews continued until the saturation point, at which the data began to repeat, and no new information was being received. <sup>[19]</sup> The study sample consisted of 16 parents. Each participant was interviewed once.

#### **Data Analysis**

Content analysis was used to analyze the interview data. The data analysis was conducted independently by two authors with experience in qualitative research. The steps described by Erlingsson and Brysiewicz (2017)[20] were used to guide the analysis. Before the data analysis, all the interviews were transcribed with no changes. The researchers listened to the interview recordings and read the transcriptions repeatedly to describe the nature of the experience. At the first stage, the texts were divided into small meaningful units by remaining faithful to the nature of the experience. At this stage, preserving the basic meaning is especially important. At the next stage, a code list was created from the meaningful units, and the code lists of both researchers were compared. The next stages of the analysis were conducted using the code list on which the researchers agreed. At the creation of categories stage, similar and different codes were grouped in categories. The categories were named in line with their meanings. At the next stage, two or more categories were grouped in themes that described the interviewees' experiences. Creating these themes was the upper synthesis stage. Then, the researchers discussed the themes and reached a consensus on four themes that explained the phenomenon.

#### **Trustworthiness**

Four main strategies were used to ensure the accuracy of the data: credibility, transferability, consistency and confirmabil-

ity. [21,22] All the researchers had received training in qualitative research, conducted a qualitative study and previously worked on stigmatization and the caregivers of individuals with schizophrenia. This study included parents with different education levels and durations of caregiving experience, and the interviews continued until no new information was being received. The interviews were conducted by the same researcher using a semi-structured interview form. Data analysis was performed independently using the code list created by the two researchers. For each theme, direct citations of the parents' statements are used as examples. [21,22] The concordance between the coders was 0.95, which is acceptable.

#### **Ethical Considerations**

Written permission was obtained from the institution where the study was conducted, and approval was obtained from the noninvasive research ethics committee (2019/18-37). The parents were informed about the study, and their verbal and written consent was obtained before the interviews.

#### Results

Table 2 shows the socio-demographic characteristics of the parents. The parents' mean age was 67, and the mean duration of their caregiving was 16 years. Of them, 11 were mothers, and 5 were fathers. Of them, 4 had completed primary school, 1 had completed middle school, 4 had completed high school, and 7 had completed university. Of the parents, 13 were unemployed. The patients' mean age was 39, and the mean duration of the disease was 17 years. Of the patients, 5 had completed middle school, 6 had completed high school, and 5 had completed university. Of the patients, 12 were unemployed, 2 were female, and 14 were male.

Table 2. The parents' sociodemographic characteristics (n=16)					
No	Age	Education level	Employment status	Relationship	Duration of caregiving (years)
1	83	Primary school	Unemployed	Father	20
2	67	Primary school	Unemployed	Mother	10
3	62	University	Employed	Mother	5
4	72	High school	Unemployed	Mother	5
5	75	University	Unemployed	Father	30
6	74	Middle v	Unemployed	Mother	26
7	59	High school	Unemployed	Mother	10
8	50	University	Employed	Mother	5
9	70	Primary school	Unemployed	Father	20
10	70	University	Unemployed	Mother	20
11	70	Primary school	Unemployed	Father	30
12	68	University	Unemployed	Mother	24
13	66	High school	Employed	Father	24
14	66	University	Unemployed	Mother	3
15	61	High school	Unemployed	Mother	14
16	61	University	Unemployed	Mother	10

Table 3. Themes and subthemes regarding the parents' experiences of stigmatization				
Themes	Subthemes			
Dimensions of Stigmatization	<ul> <li>Stigmatization of patients</li> <li>Being stigmatized as a parent</li> <li>Internalized stigmatization</li> </ul>			
• The Effects of Stigmatization on Life	<ul><li> Emotional burden</li><li> Social losses</li></ul>			
Coping with Stigmatization	<ul><li>Avoidance strategies</li><li>Active strategies</li></ul>			
Recommendations for Reducing Stigmatization	<ul><li>Recommendations for society</li><li>Recommendations for systems</li></ul>			

The analysis yielded four main themes for the caregivers' experiences of stigmatization: dimensions of stigmatization, the effects of stigmatization on life, coping with stigmatization and recommendations for reducing stigmatization (Table 3).

#### **Theme 1: Dimensions of Stigmatization**

The parents of individuals diagnosed with schizophrenia reported that stigmatization was a negative part of their lives. The parents mentioned stigmatization of patients, their own experiences of stigmatization and their experiences of internalized stigmatization.

Stigmatization of Patients: Although the parents themselves experienced stigmatization, they reported that the stigmatization of patients was a more significant problem. They described themselves as inseparable with the patients and said that any kind of negative labels or discriminative approaches toward the patients also affected them. "He is my child, he chose me, and I chose him, which means this struggle belongs to both of us. Well, there may be people who stigmatize... 'Why are you not working? You finished school, why are you not working?' I mean, when I hear a question like that, it hurts me so bad because I know that he/she gets upset at that moment" (Parent 3, mother).

Being Stigmatized as a Parent: The parents reported being stigmatized directly. They said that the society believes that parents have responsibilities regarding parents' sufficiency, conflicts in the family and seeking help in a timely manner, and that they are accused of neglecting these responsibilities. "Like 'you let your child well alone and free so much. Or you forced him/her to do something.' Criticisms like 'the child is like this because you did not do this..." (Parent 13, father). Another negative belief was that the parents were also affected by the mental disease. "Even my sister said, 'You are mentally depressed... You, too, should go see a doctor" (Parent 7, mother). Some parents mentioned negative beliefs such as the dangerousness of schizophrenia were also directed toward them. "Well, when I encounter people on my way back from the association, and when they ask, 'Where are you coming from?' and I say, 'From the schizophrenia association,' their facial expressions change suddenly. And they leave shortly afterwards. I mean, I really do not know what they perceive" (Parent 8, mother).

Internalized Stigmatization: Some parents indicated that they identify with society's negative beliefs toward them, that they always question their parental skills, and that they feel responsible. "When they see such a patient, society makes statements as if the patients' relatives are responsible for it. You also think that the society thinks this and will see you like this. I questioned myself, too. I also thought what mistakes I did... I mean, I always question myself; what did I wrong at which point?" (Parent 3, mother).

#### Theme 2: The Effects of Stigmatization on Life

The parents indicated that their lives were negatively affected by stigmatization in both emotional and social aspects.

Emotional Burden: The parents reported that they experienced emotional burden as a result of stigmatization. The emotional effects of stigmatization on parents include worthlessness, sadness, guilt and anger. One parent described her feeling of worthlessness as follows: "Pity, stigmatization, labels and so on denigrate people. This feeling of unworthiness worsens the situation. We are exposed to more stress. You further stay away from life. You may even lose your desire for life. It gets you into depression and mental diseases" (Parent 8, mother). For the parents who identified with the prejudices toward them, guilt was one of the main emotions. "I mean, I felt quilty for a very long time. Guilt is a very strong feeling... It is the feeling that I am the reason why my son is like this" (Parent 8, mother). The parents stated that they needed society's support for both themselves and the patients, and not receiving this support due to stigmatization makes them angry. "You feel all alone. They do not understand you; you have a sick child at home, and you also have to take care of your husband. I cannot help getting angry when people do not understand me and accuse me of other things" (Parent 7, mother).

Social Losses: The parents said that people keep their distance from them as a result of prejudice. They stated that, although they need society's support, their friends, neighbors and relatives grow distant over time. "We lost our social circle. Neither the officer's club, nor this one nor that one... Neither a friend nor a companion remained..." (Parent 2, mother). Another parent described the social rejection he experienced as follows: "It is like they are avoiding a contagious disease. I mean, they do not want to accept us" (Parent 9, father).

Another reason for social losses is the fact that parents have to withdraw from society. The fact that patients withdraw from society due to social stigmatization results in the parents' withdrawal from society as their caregivers. "He lives an isolated life between these walls in a dark environment right now. If society saw this disease as a normal disease that can be healed with treatment, we would not experience any of this. He would not refuse treatment or refuse to go out in public... Of course, I have to be isolated from society with my son by my own choice" (Parent 8, mother).

#### Theme 3: Coping with Stigmatization

The parents indicated that they used avoidance and active strategies to cope with stigmatization.

Avoidance Strategies: The parents stated that they used inactive and avoidance approaches, such as hiding the disease, becoming introverted, desperate acceptance, and trying to normalize people's behaviors to cope with the emotional burden and social rejection due to stigmatization. Some parents indicated that they hid the disease and could not share it with anyone other than their immediate relatives because they were afraid of prejudice. "The first reaction came from my husband. He said that I should not speak of it explicitly because what I say may cause harm to our children and our family. When I talked about it, I tried to be careful about the people I talked to" (Parent 14, mother). Some parents said that they did not believe that stigmatization would end, and that they tried to cope with it through desperate acceptance. "I do not force anything. I let it be. There is not much I can fix anyway. I think to myself, 'May it not get any worse.' I consent to this" (Parent 11, father). Another coping method was trying to normalize people's negative points of view and approaches. Some parents indicated that such behaviors of people who do not know about schizophrenia are normal, and that they try to understand. "It should be considered that no one knows what they do not experience, so they may have different attitudes" (Parent 3, mother).

Active Strategies: Although stigmatization is a part of the parents' lives, some parents stated that they make active efforts to change this. These strategies were being open to society and explaining the disease to people. One parent said that she did not hide the disease and actively struggled: "By being open. I mean, we never hid it. We already learned that this is not our fault in the education we received. It is not our fault..." (Parent 12, mother). The parents thought that people's negative attitudes are mainly based on not knowing about the disease. They stated that for this reason, they tried to explain the disease to people as a coping method. "We learned about the disease, too. And

as we learned, as we accepted it, we found solutions. I tell people around me that if patients take medicines and are under control, there is no need to be afraid" (Parent 7, mother).

#### Theme 4: Recommendations for Reducing Stigmatization

The fourth theme regarding the stigmatization experiences of parents is recommendations for reducing stigmatization. The parents made recommendations about the solutions for the stigmatization they experienced. These recommendations consisted of two subthemes: recommendations for society and recommendations for systems.

Recommendations for Society: The parents indicated that caring for an individual with schizophrenia was a difficult experience, and that stigmatization brought an extra burden. They said that society should be provided with an empathetic approach to both themselves and the patients. "Well, I think some activities should exist to improve their ability to empathize and approach to the patients, just like their approach to other disabled people. I mean, they know if someone is missing an arm, but they do not see this" (Parent 3, mother). They also said there is a need for increasing the knowledge and raising society's awareness about the disease. "Education on this should be expanded... This education should be provided not only to patients' relatives, but also to people who are not relatives of patients so that their approach to the patients will change as a society. Then society will get much better, their behavior will be better, and patients will recover more easily. Then patients' treatment will be easier. The patients are disturbed and get sicker as they see this marginalization and are pushed. I mean, they are continuously belittled" (Parent 9, father).

Recommendations for Systems: The parents also highlighted that changes should be made in the educational system. They suggested that contents/programs that will develop positive attitudes toward the mental problems such as schizophrenia should be included in the educational system starting in primary school. "It should definitely be included in education process... I mean, psychological issues, human psychology, empathy, etc., the things in the subject of psychology should be taught to people as fundamentals... These things should be taught starting in primary school" (Parent 12, mother).

The parents said that negative news regarding patients in the media affects society's attitudes and that projects should be conducted to change stereotypes such as the dangerousness of schizophrenia in the media. "They should know and introduce the disease in the media. Media is very important. They will introduce the disease on it" (Parent 10, mother).

The parents recommended that all of the groups, units and organizations such as associations that are affected by stigmatization should work together in cooperation. "Well, it is impossible to change opinions in society. It will take a lot of time... But if there are people who want this, they will come together. This will happen by way of either the associations, or the community mental health centers or other things, but somehow, this will disappear over time" (Parent 8, mother).

#### Discussion

#### The Dimensions of Stigmatization

This study shows that the parents experienced both social stigmatization and internalized stigmatization. The parents were also indirectly affected by the patients' experience of stigmatization. These findings are similar to those of studies conducted with family members who provide care for individuals with schizophrenia. [4,9,11,12,14] Stigmatization and discrimination are based on stereotypes.[24,25] In this study, the parents said that they were criticized for inadequate parenting, impaired family relationships, and being affected by the mental disease. They also said that society generalized negative beliefs about individuals with schizophrenia, such as dangerousness, to them. The society's main beliefs about the families of individuals with mental diseases are that they are unusual and have problematic attitudes, that the families' unusualness will also negatively affect them, and that other family members are also affected by patients. [1,6] Similarly to the result of this study, other studies have reported that society holds parents responsible and accuses them for the occurrence of the disease and the inability to manage it.[1,26] In this study, the parents indicated that they were more affected by the negative beliefs about and discriminatory attitudes toward patients. It has been highlighted that patient relatives experience stigmatization twice, first with the patients, and then they experience it themselves.[14]

#### The Effects of Stigmatization on Life

This study shows the destructive effect of stigmatization on parents' lives. The parents described their experiences of emotional burden and social rejection. This finding is similar to that of a study conducted with family members.[10,13,16] One of the main emotional outcomes of the parents' experiences is guilt, which is an indicator of internalized stigmatization and results from the fact that parents identify with the stereotypes society exhibits against them. As a result of internalized stigmatization, families experience guilt and shame.[15] Society sees the presence of a family member with a mental disease as a shameful situation. In addition, society accuses parents by highlighting their inadequacy in terms of the occurrence of the disease and inability to manage it.[1] Similarly, a qualitative study conducted with the mothers of individuals with chronic mental diseases indicated that they accused themselves of being at least partially responsible for the development of the disease.[27] It is important to work on parents' beliefs about the occurrence of schizophrenia. In the present study, the parents had been providing care for the patients for a long time, and most of them had knowledge about schizophrenia, but the literature indicates that knowledge about schizophrenia, including its biomedical model, does not reduce stigmatization or social distance.[12,28,29] Providing specific information such as the nature of the symptoms and coping with symptoms in the management of particularly the feelings such as guilt may help to reduce stigmatization.[12]

In the present study, besides describing feelings of guilt, the parents said that they did not share the disease with people other than their immediate family members. Hiding the disease may be intended to protect patients or be the result of feelings of shame. [30] The parents also said that the experience of stigmatization resulted in deep sadness. It can be said that parents feel more responsible for their children's well-being and they are more sensitive to stigmatization and discrimination due to their affection for them.[14] Like the literature. in the present study, the parents reported a special affection for their children and devotedness to their well-being.[12] All of these factors can affect the nature and intensity of the emotions experienced. Another result of stigmatization concerns social life. The parents reported that people limited their relationships with them. Similarly, families report being ignored and deprived of their rights and interests by society.[13,16] In addition, parents had to isolate themselves from social life as a way of coping. This finding shows that the parents' social resources for coping with the disease are reduced.

#### **Coping with Stigmatization**

In the present study, the parents reported that they used the avoidance and active coping methods such as informing people and explaining the disease and their lives. Although they need society's support to fight the disease, they had to choose a lifestyle that avoids other people. Similarly, in a study conducted with the families of individuals with schizophrenia, the participants said that they live hidden lives or behind closed doors as a way of coping with stigmatization. However, such a lifestyle means fatigue, hopelessness, anger, a loss regarding the past, and uncertainty about the future.[10,12] In the present study, while some parents were inclined to hide the disease due to fear of stigmatization and as an effort to protect patients, others said that they did not hide the disease, and that they explained it to people. This finding is similar to those in the literature.[12] Another reason for hiding the disease is to protect family reputations. Family reputation is one of the main values threatened by stigmatization.[10] Parents may attempt to preserve it in order to protect their other children. Society believes that siblings and other family members are contaminated by the disease.[31,32] Similarly, parents worry about their other children and other family members being able to get married or find jobs. [10] Investigating the factors related to hiding the disease and the effects and of hiding the disease on stigmatization may provide significant contributions to the experts in fighting stigmatization and supporting parents.

#### **Recommendations for Reducing Stigmatization**

The parents' recommendations in social terms were about informing society and providing people with an empathetic understanding. They also highlighted that changes should be made in the educational system, and that cooperation should be ensured. In the literature, the relatives of individu-

als with schizophrenia have also been reported to recommend that society should be informed about mental diseases. [2] In the present study, the parents attributed the negative beliefs they encounter to the unawareness of the public and negative depictions of mental diseases in the media. Similarly, the literature has also shown that family members experience misunderstandings about mental diseases, and the fact that the media divulges inaccurate information about mental diseases is associated with social stigmatization. [4,33]

#### **Study Limitations**

This study was conducted with the parents of patients at a single hospital in Western Turkey. Since women are mostly assigned with the role of caregivers in Turkish society, most of the parents who were providing care for individuals with schizophrenia followed up during data collection were mostly the patients' mothers. In addition, as a part of Turkish culture, the parents also focused on their children's experiences of stigmatization rather than their own experiences, which can be regarded as another limitation of the study.

#### Conclusion

The findings of this study provide important data for the development of policies regarding research, practice and the provision of mental health services. The results show that fighting against stigmatization is a primary issue that should also be considered in terms of parents. The fact that parents, who act as caregivers, are also affected by stigmatization and discrimination should be considered in structuring the mental health policies, and new models should be developed to support them.

Healthcare professionals should investigate parents' experiences of stigmatization. In this regard, parents' stigmatization experience, its emotional and social effects, and parents' efforts to cope with it should be investigated, and information and counseling should be provided to them. Since parents' social networks and resources for coping are reduced, interventions should be implemented to improve their coping skills. The fact that parents participate in support groups consisting of family members with similar experiences may help them to share their experiences and concerns and to cope with stigmatization. Education should be provided to change society's stereotypes toward parents, and events should be organized to promote interaction with individuals with mental diseases together and their parents. Campaigns and awareness studies aimed at changing society's negative beliefs about parents and patients should be conducted. Investigating the factors that affect the severity of the stigmatization experienced by the parents and are protective against stigmatization in future studies may help to guide intervention studies to be structured particularly for parents.

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