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How Early Life Adversities Influence Later Life Family Interactions for Individuals with Schizophrenia in Outpatient Treatment: A Qualitative Analysis

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Abstract

Many individuals diagnosed with schizophrenia state that family relationships are a primary facilitator of their recovery. However, they also report higher rates of early life adversities, typically in their family environments. We used modified Grounded Theory on 20 semi-structured, in-depth interviews with adults (half ethnic minorities, half women) diagnosed with schizophrenia or schizoaffective disorder and receiving treatment at an urban psychiatric outpatient clinic to investigate how early life adversities influence later life family interactions. Approximately half of participants did not mention early life adversities and described positive family interactions and perceived supportive involvement in their illness. The other half of participants experienced abusive and/or unstable childhood homes that many explicitly linked to limited family interactions and perceived absence of support for their illness. These findings suggest that limited familial interactions following early life adversities may reflect resilient boundary setting, and indicate the value of considering these adversities before incorporating families in care.

Keywords Qualitative · Schizophrenia · Early life adversities · Family interactions · Social support

Introduction

Many individuals diagnosed with schizophrenia state that restoring social relationships and receiving social support—particularly with family—are primary facilitators of their recovery (Griffiths et al. 2019; McCarthy-Jones et al. 2013; Soundy et al. 2015; Wood and Alsawy 2018). Bolstering this, higher social functioning, stronger social connections,

and more perceived social support lead to better symptomatic and functional outcomes for individuals diagnosed with schizophrenia (Couture et al. 2006; Degnan et al. 2018; Sündermann et al. 2013).

Despite these personal priorities and positive benefits, individuals diagnosed with schizophrenia have fewer social connections and lower perceived social support than those without schizophrenia (Gayer-Anderson and Morgan 2013; Palumbo et al. 2015; Sündermann et al. 2013). These social limitations start early, due in part to poorer social functioning prior to onset of illness and to cognitive and social deficits related to the illness (Couture et al. 2006; Galderisi et al. 2018; Gayer-Anderson and Morgan 2013). These social limitations can be further exacerbated as a consequence of the illness (e.g., persecutory beliefs and distrust), its treatment (e.g., disruptive hospitalizations), and related social disadvantage (e.g., loss of employment) (Griffiths et al. 2019; McCarthy-Jones et al. 2013; Palumbo et al. 2015). It is also well-established that early life adversities are linked with the onset and course of schizophrenia including social and cognitive deficits (Bentall et al. 2014; Longden et al. 2016; Trauelsen et al. 2015; Varese et al. 2012).

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While social limitations are clearly a feature of schizophrenia, less has been discussed about how individuals diagnosed with schizophrenia may actively choose to limit their social interactions. Qualitative data indicate that individuals diagnosed with schizophrenia sometimes engage in self-imposed withdrawal and isolation as a protective mechanism from family and friends who do not understand what they are going through. This is due in part to perceived stigma and fear of being negatively evaluated by others (Griffiths et al. 2019; McCarthy-Jones et al. 2013; Palumbo et al. 2015; Wood and Alsawy 2018). More recently, it has been suggested that individuals diagnosed with schizophrenia might also withdraw and isolate themselves from their families due to early life adversities such as child abuse and neglect and parental loss and separation (Dickson et al. 2016; Jansen et al. 2016; Trauelsen et al. 2016). Given that individuals diagnosed with schizophrenia have higher rates of early life adversities than the general population (Matheson et al. 2013), this is an important factor to consider not only for risk of developing schizophrenia (Bentall et al. 2014; Longden et al. 2016; Varese et al. 2012) but also in the experiences of individual diagnosed with schizophrenia.

Previous research confirms that early life adversities can lead to reduced social functioning in psychiatric diagnoses including schizophrenia (Cotter et al. 2014; Rokita et al. 2018). However, it is not yet clear whether individuals diagnosed with schizophrenia also make explicit connections between these early life adversities and later life family interactions. In a qualitative study from the United Kingdom, individuals with persecutory delusions expressed that childhood difficulties with caregivers led to negative expectations and beliefs about others and reduced social functioning including avoidance and isolation (Dickson et al. 2016). However, in a qualitative study from Denmark, individuals with first-episode psychosis who reported traumatic childhood experiences still said they felt supported by their families (Jansen et al. 2016). While these are important preliminary findings, both countries differ from the U.S. context in terms of national healthcare systems, social services, and family structures, which would all influence the expectations and practices around involving family members in care.

The aim of this qualitative analysis is to investigate how individuals diagnosed with schizophrenia perceive the role of early life adversities on their later life family interactions, including perceived support for their illness, among a diverse sample of patients diagnosed with schizophrenia and receiving treatment at an outpatient psychiatry clinic in a large urban area in the United States. Study procedures were approved by the Partners HealthCare Human Research Committee (#2015P001274/MGH).

Methods

Study Participants and Setting

Twenty study participants were recruited between September 2015 and January 2016 at an outpatient psychiatry clinic specializing in schizophrenia and serving patients on both public and private insurance in a large urban area in the United States. Recruitment was conducted at the clinic via fliers targeting both providers and patients and describing a project about how culture and gender influence experiences of schizophrenia. Inclusion criteria were English speakers, at least 18 years old, with a diagnosis of schizophrenia or schizoaffective disorder, who were not actively psychotic. Purposive sampling was used to recruit an ethnically and gender diverse sample in which approximately half the participants were white and half were ethnic minorities, and approximately half were men and half were women. Written informed consent was obtained from all participants.

Data Collection and Procedures

Individual face-to-face interviews were conducted at the clinic by a trained research assistant (LP), audio recorded with permission of the participant, and lasted up to 90 min. The semi-structured interview guide was developed via a thorough literature review and input from the research team (e.g., Bresnahan et al. 2007; March et al. 2009; Sham et al. 1994), and used a list of open-ended questions and topics to stimulate and facilitate discussion about the influence of culture and gender on the course and outcome of the participant's illness (see Online Appendix). It began with background information that included their family history and if they were ever a victim of violence, then included 25 guided questions across four major sections: (1) their early/current illness and pathways to treatment (e.g., "describe what it was like when you first got sick?"); (2) the impact on their family relationships (e.g., "how has your family been involved in your treatment?"); (3) their perception of cultural influences on their illness (e.g., "are there any aspects of your culture that you feel have helped you with your illness"); and (4) their perceptions of gender influences on their illness (e.g., "are there any aspects of being a man/woman that you feel have helped with your illness?"). The interviewer did not introduce any new topics, but did probe further for topics introduced by the participant. All study participants were compensated $20 for their time.

Data Analysis

The 20 audio recorded interviews were anonymized, transcribed verbatim, and imported into Nvivo 12 (QSR International Pty Ltd. 2018). Qualitative analysis was conducted using a modified Grounded Theory approach (Charmaz 2014; Strauss and Corbin 1990) that combined inductive and deductive coding (Fereday and Muir-Cochrane 2006; Vaismoradi et al. 2013). This approach included open, focused, and axial coding to identify main concepts, group the concepts into themes, and assess how the themes related to each other (Maxwell 2005).

For open coding, each transcript was reviewed line by line and coded for descriptive categories. Two coders (SM, KJ) created initial codebooks, consolidated them into one, and tested inter-coder reliability ($\kappa \geq 0.80$). One coder (SM) continued line-by-line coding, and the second coder (KJ) double-coded 20% of transcripts to confirm on-going inter-coder reliability (κ's ≥ 0.80). While the primary research question was about the role of culture and gender, this open coding process also led to emerging patterns related to early life adversities and family interactions. For the analysis reported here, focused and axial coding were then restricted to early life adversities and family interactions. The most significant and/or frequent descriptive concepts were identified, similar or related codes were merged into more inclusive themes and subthemes, and the themes and subthemes were assessed for how they related to each other (Maxwell 2005). Constant comparison was used to identify trends and patterns across themes, including within-case comparison for each participant, cross-case comparison between pairs of participants, and matrix tables by groups that were both deductive (e.g., ethnicity, gender) and inductive (e.g., early life adversities, social deficits) (Ayres et al. 2003; Huberman and Miles 2002). Data analysis was considered complete when no new insights were being reached.

Results

All 20 participants had a diagnosis of schizophrenia (80%) or schizoaffective disorder (20%), and were currently receiving treatment at the outpatient psychiatric clinic (Table 1). The median age was 49.5 years (range, 23–69 years). Half identified as male (50%), almost half as female (45%), and one as transgender (5%). Participants came from a range of self-identified racial and ethnic groups but were broadly categorized as White (45%), Black (30%), Asian (20%), and Multiracial (5%). The majority of the sample was single (85%), living alone (80%), did not have a college degree (65%), and did not currently have full-time employment (100%).

Table 1 Sociodemographic characteristics of qualitative study sample (N = 20)

Characteristic	N	%
Age in years, *median (range)*: 49.5 (23–69)		
Psychiatric diagnosis		
Schizophrenia	16	80
Schizoaffective disorder	4	20
Family history of mental illness		
Yes	10	50
No	8	40
Unknown	2	10
Gender identity		
Male	10	50
Female	9	45
Transgender	1	5
Racial/ethnic categorization		
White	9	45
Black	6	30
Asian	4	20
Multiracial	1	5
Relationship status		
Single	17	85
Married	1	5
Divorced	2	10
Housing status		
Live alone	16	80
Live with roommate or spouse	2	10
Live in group home or shelter	2	10
Educational attainment		
Some high school or less	2	10
High school diploma or GED	3	15
Some college	8	40
2-Year degree	2	10
4-Year degree	4	20
Master's degree	1	5
Employment status		
Part-time student	2	10
Part-time employment	6	30
Unemployment	11	55
Retired	1	5

In this analysis, our main finding was that family interactions and perceived support for illness varied by whether or not participants mentioned early life adversities. Figure 1 presents a simplified model as a framework for these findings. Key themes that emerged among the approximately half of participants with *no mentioned early life adversities* were (1) *perceived positive family interactions* including regular interactions and space for conflict, and (2) *perceived supportive involvement in their illness* including emotional and instrumental support despite families'
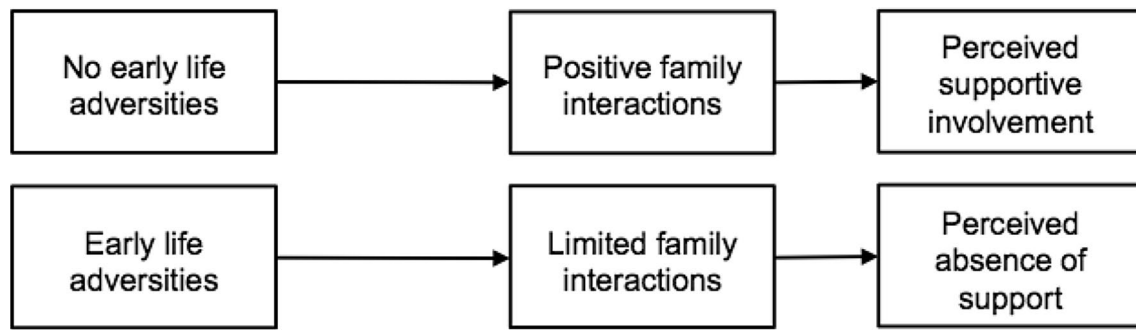
Fig. 1 Simplified model of connections between early life adversities, later life family interations, and perceived support for illness

variable understanding of their illness that necessitated finding the right balance. In contrast, key themes among the approximately half of participants who described *early life adversities* of childhood abuse and unstable childhood homes were (1) *Perceived limited family interactions* due to deliberate distance and limited sense of family, and (2) *Perceived absence of support in their illness* due to lack of communication and lack of contact (Table 2).

Part 1. Absence of Early Life Adversities Lead to Perceived Positive Family Interactions and Perceived Supportive Involvement in Illness

About half of participants had *no mentioned early life adversities*, but otherwise did not describe a common profile of their early family life. This was in part because many did not go into details about life before their illness; the few who did described it briefly as fine, typical or uneventful. Importantly, this does not mean their early family life felt perfect. A few participants also described aspects that were challenging such as high expectations to succeed or pressures to provide parents with support. Although participants did not highlight this themselves, the questions about the impact on their family relationships revealed that the majority of these participants grew up knowing their biological mother and/ or father, even if sometimes their parents were separated, divorced, or had passed away.

Perceived Positive Family Interactions

Despite limited details and potential variability in early family life, the majority of these participants still shared the commonality of *perceived positive family interactions* including regular interactions and space for conflict.

Regular Interactions Regular interactions with parents and siblings encompass a set of positive family interactions that occurred outside the context of the illness such as spending time together and being in consistent contact, which some

participants described as important and valuable to them. One participant, a Black man in his 50 s, described how it was most important to him to focus on his family relationships over other social relationships:

> Right now, it's like […] I'm also in the middle of an affair with my family. And, I gotta make sure my mom's all right, I gotta make sure my brother's all right, before I even, like, decide to have a girlfriend.

Another participant, a White man in his 30 s, described the value he experienced by being in consistent contact with his sister:

> It's funny, like, we don't speak every day. We speak, like, y'know, maybe once—twice—once every two weeks, or once in like a week and a half, or twice in a week and a half at most. So yeah, I mean, she understands. And she gives me good advice, y'know, and she knows, y'know, certain things that I say or whatever… she'll tell me, like, what she thinks is the right thing to do, and so I follow what she says.

Space for Conflict These positive family interactions did not preclude participants from being in conflict with family members, including both short-term frustration and long-term disconnection. Sometimes positive and negative interactions were with different family members, sometimes with the same one. This highlights the complexity of these family interactions, which were often not ideal or perfect with everyone but could still offer meaning and connection with some. For example, a White woman in her 50 s described the pain of one sister ceasing to communicate while still retaining a connection with another sister:

> Well, my sister [NAME] don't talk to me no more cause she's real mad my mother had to help me. And she felt she didn't get help from my mother. […] I talk to my other sister. We exchange Christmas gifts, she lives in [STATE] and she's a cardiac nurse. I get her 9…about 9 presents every year, cause she's got a

Table 2 Main themes and subthemes from modified grounded theory analysis

Part 1. No adversities → Positive interactions → Supportive involvement		
No mentioned early life adversities	Perceived positive family interactions	Perceived supportive involvement in illness
No single profile for early family life among those who did not describe early life adversities Many did not go into details about their early family life, but those who did tended to describe their early family life as fine, typical or uneventful although not perfect; they still could describe aspects they liked less than others. Also tended to describe growing up knowing their biological mother and/or father, although sometimes their parents were separated, divorced, or one or both had passed away	**Regular interactions** Nuanced set of positive family interactions such as spending time with parents and siblings, talking regularly with them, and feeling close to them, both in context of their illness but also more generally **Space for conflict** Did not preclude conflict with other family members, including both short-term frustration and longer-term disconnection. Sometimes positive and negative interactions were from different family members, sometimes from the same one	**Emotional/instrumental support** Emotional and instrumental support such as helping enter treatment and navigate the system, hospital visits, appointment and medication reminders, regular contact, and financial support **Variable understanding of illness** In some cases, family members already knew about mental illness or were willing to learn more. In other cases, support was provided even when family members lacked understanding or were not provided many details **Finding the right balance** Even if the type or level of support had not been optimal at prior moments, often a sense of improvement in finding the right balance whether it was becoming closer or interacting less often

Part 2. Early adversities → Limited interactions → Absence of support		
Early life adversities	Perceived limited family interactions	Perceived absence of support in illness
Childhood abuse Experiencing or witnessing sexual, physical, and/or verbal abuse as a child, directed from parents toward the participant or between parents at each other (includes biological, step, adoptive, foster parents) **Unstable childhood homes** Moving between families, most commonly due to experiences of abuse in biological families although sometimes for other reasons such as parent mental illness or substance use	**Deliberate distance** In limited contact with family members as adults. Some described this distance passively, while many described proactive efforts to create this distance **Limited sense of family** Instabilities in family structure as adults. For participants who moved multiple times, this often precluded having a family with whom they stayed in contact or a clear sense of family at all	**Lack of communication** Often did not tell family members much about their illness. Even if family members knew about their diagnosis, felt like family members did not really understand the illness and how it manifested in their lives **Lack of contact** For participants who did not feel like they had a family, it was impossible for them to be in contact with any family members or feel like they could receive support for their illness from them

family and a — her daughter, she's got 2 kids, and a son. One of hers, he has 2 boys and a son. And, um, the—her daughter and one of the sons have 2 kids each. And her other son has one child.

Another participant, an Asian woman in her 40 s, described appreciating her mother's care at the onset of her illness in college even though she could sense her mother's simultaneous frustration:

Well… she criticized me. I didn't like that. But actually… she noticed that I wasn't happy about it, so… So, actually, she acted as a really good nurse, taking care of me. That was really nice.

Overall, these perceived positive family interactions show that individuals diagnosed with schizophrenia can achieve regular interactions that are meaningful to them, even when there are some conflicts, which enabled supportive involvement in their illness.

Perceived Supportive Involvement in Illness

The majority of participants with *no mentioned early life adversities* and *positive family interactions* also described *perceived supportive involvement for their illness* starting from onset of symptoms to ongoing treatment and care, particularly emotional and instrumental support. Significantly, this support occurred despite family members having variable understanding about their illness and relied on finding the right balance for each person.

Emotional and Instrumental Support Emotional and instrumental support included a range of activities such as helping the participant enter care and navigate the system, visiting the participant in the hospital, offering reminders about appointments and medications, and providing financial support. One participant, a White man in his 40 s, described how much he benefited from regular visits and small gestures from his parents when he was feeling particularly low during some hard hospitalizations:

That was probably the lowest of the low right there. The 2003–2004 [hospitalizations]. […] My mom, of course, would faithfully visit me. My dad would visit me… he was very good when in '94 when I was in [HOSPITAL]. He always brought me two things. He brought me a vanilla milkshake and a copy of Newsweek. [Laughs loudly] I remember that. But mom and [FRIEND] especially in my 2003 and 2004 hospitalizations.

Another participant, a multiracial woman in her 50 s, said that her whole family was very supportive and actively involved in her care, including speaking with her psychiatrists in the past. She also offered a specific example of support in researching anti-psychotic medications:

Yeah, I was taking, I was taking [MEDICATION 1] when my niece read up on it, and she told her grandmother, which is my sister, and they told me next time I go see my psychiatrist tell him, have him take me off that and he did, and that's when I started taking [MEDICATION 2].

Another participant, a Black woman in her 30 s, stated that she did not have consistent familial involvement in her care but felt like she had a good relationship with her father because of the verbal and financial support he did periodically provide when she was having particularly tough times due to her illness such as hospitalizations:

Oh, we have a good relationship. My father's good to me. […] Oh, well I know I was in the hospital, he sent me $500, he told me to take my medication and maybe I wouldn't have to be in the hospital if I took my medicine. He told me, he just give me money a lot, you know what I mean. When I was in the young adult program, he gave me money. You know, my dad is not rich, but you know, he helps out, you know what I mean.

Variable Understanding of Illness This supportive involvement occurred across family members' variable understanding of the illness—some family members already knew about mental illness or were willing to learn more while others did not appear to ever fully understand it. Across this variable understanding, the majority of participants still perceived supportive involvement in their illness. Unsurprisingly, family members who had a better understanding of mental illness could often provide more specific and concrete support. For example, a White woman in her 50 s described how her uncle's strong understanding due to prior family history of mental illness helped her first get into treatment, where she ended up seeing the same psychiatrist as her mother:

Yeah, actually, it was from my uncle, who got my mother the help she needed, and he got me the help—it happened to be the same doctor.

But even when family members did not fully understand the illness, they could still provide support if they understood the participant was suffering or sick. For example, another White woman in her 50 s was unsure if her sister truly understood her experience but that did not prevent her from reconnecting with her sister when she was feeling better:

I was able to take my sister's calls and kind of patch that up a little bit and say, "Yeah, I've been really sick. That's why I haven't been taking your calls." But it's hard because, I don't know, you know, if you've never experienced these things, it's hard to understand what's going on. So how much my sister understands, I don't know.

Finding the Right Balance In most cases, participants described needing to find what worked for them. Even if the type or level of support had not been optimal at prior moments, participants frequently described a sense of improvement in finding the right balance—whether becoming closer or creating some separation. One participant, a White man in his 30 s, described how his family members did not completely understand what he was going through at first but learning more about his illness helped their family become closer over time:

I think we got closure, like, I think my family is kinda close, and y'know, they understand a little bit more about how I think, and they understand, y'know, I have—I have schizophrenia. […] Well, y'know, ok, so, I think in the beginning my dad wasn't as involved with the therapy. After that, though, y'know, as it got better, as I have been going on with life, he understands more about the… about my mental health.

On the other hand, another participant, an Asian woman in her 30 s, said family support was important to her and the most helpful aspect of her recovery but that she also wanted to maintain distance from them:

It's pretty, it's good, I mean, I don't go into details about my personal life with her [mother] but we have a good relationship. […] I hardly communicate with my dad. I mean, he knows what's going on, kind of like the general aspects of things, but I don't, I don't, he doesn't know much about what's, like, the details of my day-to-day life or anything like that. […] I—I remember like when I came back from the hos what's, like, the details of my day-to the night that I was in the emergency room, I remember we came back and I was so scared that we all slept in the same room. My dad took out, like, a folding bed and came out, and, you know, basically was sleeping with us.

Overall, this perceived supportive involvement in illness is significant because it shows the importance and value that individuals diagnosed with schizophrenia ascribe to a range of emotional and instrumental support they receive from their family, even as it is also unique to each person's experience depending on whether their family understands their illness and whether or not the right balance for them will be more or less interaction with their family.

Part 2. Early Life Adversities Lead to Perceived Limited Family Interactions and Perceived Absence of Support for Illness

About half of participants described *early life adversities*. When we reviewed the examples included in this category, we identified two major subcategories: childhood abuse and/or unstable childhood homes. While these were not the only difficult or negative early life experiences that participants described, they were the ones that most consistently emerged. The two types, childhood abuse and unstable childhood homes, were also integrally linked since almost half experienced both; childhood abuse was a major reason participants moved between families (e.g., adopted or entered foster care) and unstable childhood homes could also be places where abuse sometimes occurred (e.g., in adoptive and foster families).

Childhood Abuse

The majority of participants with early life adversities included some form of childhood abuse, including experiencing or witnessing sexual, physical, and/or verbal abuse directed from parents toward the participant or between parents at each other. This included biological parents, stepparents, adoptive parents, and foster parents. When participants voluntarily mentioned childhood abuse, most provided minimal details. These brief descriptions typically stated that they had experienced physical and/or verbal abuse without describing the nature of that abuse. The participants who offered more details described being beaten by hand and with objects, burned with cigarettes, screamed and yelled at, and insulted repeatedly. Two female participants described childhood sexual abuse from non-family members: inappropriate touching as a child and sexual assault as an adolescent. Two participants described witnessing violence between parents; in both cases, their father beat their mother and also them as a baby. As one example of these minimal details, a White man in his 40 s briefly described physical and verbal abuse from his adoptive parents:

I was abused from 5 to 15. By my stepmom. My father. […] [It was] Physical and emotional. […] Like every day, she'd come up to me and be like, "You've been bad," and then I would have to take off my clothes and she would just beat me.

Unstable Childhood Homes

About half of participants who experienced early life adversities described unstable childhood homes that entailed

moving between multiple families, most commonly due to childhood abuse but sometimes for other reasons such as parent mental illness or substance use. As one example, a White man in his 40 s described how abuse and neglect by his birth parents led him into the foster care system:

> I had another mom and dad up to the age of 7, and they were abusive. They burned me with cigarettes and stuff. … Yeah, it was mostly just physical abuse. Not—not a whole lot, but a little bit, yeah. They just… they-they couldn't take care of themselves, never mind two kids.

Another participant, a Black woman in her 50 s, described how her biological mother also had schizophrenia and had not been able to take care of her children, which led her into the foster care system:

> Well, because my mom got schizophrenia, and our homemaker took care of us, her name was [NAME], and she kind of half raised us, too, and moved and then I went into the foster care system.

These experiences most commonly led into the foster care system, which then led to multiple moves within the system: while a few participants described one primary foster family, most described several different foster families that led to a limited sense of family.

Perceived Limited Family Interactions and Perceived Absence of Support

The majority of participants who experienced early life adversities also *perceived limited family interactions* and *perceived absence of support for their illness*. We present these two themes together given the close interconnections in two distinct but related patterns: First, those who experienced *childhood abuse* described limited family interactions due to deliberate distance and absence of support due to lack of communication about their illness. Second, those who experienced *unstable childhood homes* described limited family interactions due to limited sense of family and absence of support due to lack of contact with anyone to consider family.

Deliberate Distance and Lack of Communication Participants who experienced childhood abuse often stated that they did not have positive memories of their families and were now in limited contact with them, sometimes for passive reasons but more often due to creating deliberate distance following the abuse. For example, a Black woman in her 50 s said she chose not to talk to foster mother due to prior abuse:

> Well, basically, because of the abuse and stuff, like, that I went through, it's, like, I did find my foster mom, but it's like, okay, I know where she's at, if I really want to talk to her, but it's like, I don't want to talk to her because of the abuse I was in with her.

Even when participants provided minimal details, they still described this deliberate distance. For example, a White man in his 40 s who said he was no longer in contact with his adoptive family succinctly explained that his relationship with them was not good due to prior abuse:

> Well [the relationship is] not very good. My stepmom abused me every day and my dad didn't do nothing about it.

For participants who experienced milder forms of abuse and might have been in some communication with their families as adults, there could be delays in creating deliberate distance if discord after their diagnosis pushed them further apart. One participant, an Asian man in his 20 s who described a turbulent childhood with verbal abuse and physical punishment from his biological parents, said he was too distrusting of his mother for her to stay involved in his care:

> I think my mom tried, she participated in the interview with the [CLINIC], I mean, but then I got suspicious of her, like, they were understanding it, and she can't participate anymore, and so… 'cause of my, they had to respect my confidentiality, they terminated the communication with my mom.

The only exception to these patterns appears to be the two instances where participants witnessed their father being abusive toward their mother, in which case they simultaneously described deliberate distance from their fathers and positive relationships with their mothers.

This deliberate distance led directly to lack of communication with family members about their illness, which precluded the ability for them to provide support. Importantly, many participants described this limited communication as a protective mechanism based on initial responses from family members or anticipation of how family members would respond. Even when family members knew about their diagnosis, participants often felt that their family members did not really understand the illness and how it manifested in their lives. One participant, a Black woman in her 30 s who experienced sexual abuse as an adolescent and was later kicked out of her home, described negative reactions from her parents following her diagnosis. Her mother ceased communication and her father started treating her differently:

> My mother stopped talking to me. My father looked at me different. My father understand[s] it now, but he

just wished that I didn't have it, you know? He said why did you take the medicine when you went in the first time? You shoulda said no, you know? Tell them to take you home, you know what I mean?

Another participant, a White man in his 40 s who was physically and emotionally abused by his adoptive parents, described how he had mentioned his illness to his adoptive parents but did not go into any details because he anticipated a negative reaction based on their religious beliefs:

No, they wouldn't believe me. 'Cause they're like over fanatical religious. […] Where they think demons are in you, and stuff. So I mean, any illness you have, it's not an illness, it's a demon. […] Like, they don't believe in taking medicine and stuff.

Overall, participants who experienced *childhood abuse* chose to maintain deliberate distance from their families as a protective mechanism, even as this distance led to a lack of communication about their illness that precluded any support they could receive from them.

Limited Sense of Family and Lack of Contact Most participants who experienced unstable childhood homes also described instabilities in family structure as adults, regardless of whether participants were still in contact with their biological families, only had one primary foster family, or had moved between multiple foster families. The majority had moved multiple times, which prevented them from staying in contact with family members or having a clear sense of family at all. In turn, this made it impossible for them to identify any family members to whom they could turn for support in the first place. Importantly, participants tended to describe these limitations in a factual matter and not as something they could change. For example, a White woman in her 50 s who had been in the foster care system described not being in touch with the majority of her biological family or any of her foster families, maintaining limited contact with one sibling, and never telling any of them about her illness; however, she did not appear to have negative concerns about this:

Well, I never knew my father and I only seen my mother, like, maybe ten times in my life. I have one sister, she's older than me. And my brother, he just recently passed away. I didn't know him very well. Uh, some reason I managed to keep in contact with my sister. But she lives out in [U.S. STATE]. So it's [pause] last time I seen her she visit me it be two years in June since she came up here, this way. And I keep contact with her, I usually call, like, every weekend or so. Just, I don't know, just to talk.

Another participant, a Black man in his 50 s who had moved between multiple group homes and foster families, simply stated there was no one he would consider family and therefore no one he could turn to for familial support:

Well I don't really know my family. I think I was in foster homes and stuff. Like group homes, and foster homes, and… foster homes, group homes.

One exception was a White man in his 40 s who felt his foster family rejected him after the onset of his illness only because he was not their biological child, and that they might have treated him differently otherwise:

They didn't care to help. It turns out, I thought they were good people, but it turns out that they were, they weren't my family, they were just my foster family, some place I had to go. […] Then the family didn't want to have anything to do with me, with a foster boy who has schizophrenia, so they got rid of me. […] I think if I was a blood member of the family, it would have been different.

Overall, most participants who experienced *unstable childhood homes* had a limited sense of family with whom to stay in contact, and this lack of contact prevented them from having expectations of relying on familial support in the first place.

Discussion

In this qualitative study, we interviewed individuals diagnosed with schizophrenia and schizoaffective disorder who were currently stable and in long-term care at an outpatient clinic specializing in schizophrenia. The sample was diverse in terms of economic background, ethnicity, and gender. The majority described onset of symptoms in adolescence and young adulthood and were over the age of forty at the time of interview, suggesting ample time to reflect on their social interactions and perceived support within the context of their illness. No participants described currently living with family member, and descriptions about the presence of absence of familial involvement in their illness could include both the past and the present.

All but one participant expressed positive feelings about their current life, most commonly due to a sense of improvement rather than to achieving their idealized life. While some expressed desire for more or deeper social connections, most focused on what seemed realistic and attainable to them. Many also self-identified as sensitive and reclusive and recognized that social interactions could be challenging, and that they sometimes chose to withdraw and maintain social distance. Within this context of individuals diagnosed with schizophrenia who were actively in treatment

and mostly accepted their current social circumstances, there were still notable differences in perceived family interactions and perceived support for their illness depending on whether or not they mentioned early life adversities. We emphasize *perceived* here; it is possible similar actions felt supportive to one person and unsupportive to another but these findings illuminate how participants interpreted and experienced these actions.

About half of participants reported early life adversities, which aligns with prior estimates of child abuse in other clinical samples of individuals diagnosed with schizophrenia (Morgan and Fisher 2007). The half of participants who did not mention early life adversities were able to achieve regular family interactions that were meaningful to them, even if they sometimes had conflict. Further, these positive family interactions fostered perceived supportive involvement in their illness including emotional and instrumental support. These experiences align with prior meta-syntheses of interviews with individuals diagnosed with schizophrenia that indicated the most valuable qualities for support are consistency, emotional and practical support, a positive attitude toward their mental illness, and people that would listen, accept, value and understand them and their experiences (McCarthy-Jones et al. 2013; Soundy et al. 2015; Wood and Alsawy 2018). Together, these findings corroborate the robust qualitative evidence that family relationships are meaningful to individuals diagnosed with schizophrenia both in of itself and as an important source of support (Griffiths et al. 2019; McCarthy-Jones et al. 2013; Soundy et al. 2015; Wood and Alsawy 2018), and also provide optimistic evidence that attaining meaningful family interactions and support can be possible even if not perfect.

However, these findings also complicate our understanding of when individuals diagnosed with schizophrenia might seek family interaction and support. The other half of participants who voluntarily described early life adversities in the family environment often explicitly connected those experiences to perceived limited family interactions and perceived absence of support for their illness. Those who experienced childhood abuse chose to maintain deliberate distance and limit communication with their families, even if it precluded receiving support. Meanwhile, those who experienced unstable childhood homes lacked a clear sense of family to turn to for support in the first place. These findings are corroborated by quantitative evidence that early life adversities impact social functioning later in life (Cotter et al. 2014; Rokita et al. 2018). In a study from Denmark, more early life adversities were associated with less face-to-face contact, but not telephone contact, with family members; qualitative interviews with some participants with early life adversities suggested they still felt supported by their families even if some felt bad when they spent time with them (Jansen et al. 2016; Trauelsen et al. 2016). This seems similar to the deliberate distance identified in our findings. Within the context of promoting family relationships for individuals diagnosed with schizophrenia, it will be vital to consider early life adversities in the family environment and to remember that sometimes lack of family connection may be intentional and protective.

Limitations

This qualitative study relied on a small, purposive sample of ethnically and gender diverse patients on a mix of public and private insurance receiving long-term outpatient treatment at a specialized clinic for schizophrenia in a single urban area in the United States. It does not reflect individuals diagnosed or undiagnosed with schizophrenia with other backgrounds including those who were unable to or chose not to obtain or maintain treatment. We note that not everyone who experiences symptoms associated with the diagnosis of schizophrenia such as hearing voices would identify it as an illness; here we focused on those individuals for whom medicalization has been helpful. In recent years, qualitative studies of individuals diagnosed with schizophrenia often focus on first-episode psychosis and capture those who are newer to their illness; our sample ended up including older participants who have been in treatment for longer and may have had more time to reflect on their recovery process. For example, their insight in connecting early life adversities with later life family interactions might be in part a result of receiving therapy that has helped them process these life experiences. We consider this an asset as it helps capture the meaning and connections that individuals diagnosed with schizophrenia make for themselves and reflect what matters most to them.

This study also relied on data that had already been collected; although participants were asked a series of questions about their family relationships, they were not explicitly asked about early life adversities. We cannot be sure those who did not mention early life adversities did not experience them. Individuals often do not mention traumatic experiences unless asked explicitly, and underreporting of early life adversities is common (e.g., Fisher et al. 2011; Jansen et al. 2016). Our findings likely also include underreporting since we did not explicitly ask about childhood abuse, unstable childhood homes, or other common types of early life adversities, including those that occur outside the family environment. Further, current symptoms and mood can also influence retrospective recall of earlier life experiences (Dohrenwend 2006). In this case, some participants may be feeling more negative in general, and thus tend to recall both negative early life experiences and negative family interactions. This would imply a stronger pattern in the responses than there may be in actuality.

Nonetheless, those who voluntarily mentioned early life adversities probably experience the consequences differently than those who choose not to mention them. For example, individuals who currently have poor family relationships may be attempting to make meaning by connecting their current relationships to earlier experiences, while those who currently have positive family relationships may not want to remember discordant earlier experiences. Understanding the experiences of individuals who do explicitly link their early life experiences to later life family interactions still offers important insights for these individuals. A major strength of not asking the question explicitly is that we identified these findings inductively and without a priori hypotheses while we were exploring potential patterns underlying fraught family relationships, making it particularly noteworthy that about half of participants voluntarily connected their early life adversities with later life family interactions on their own.

Conclusions

Given the abundance of evidence indicating the pivotal role of family to the recovery process—both subjectively and objectively—it is essential to broaden the clinical care lens to incorporate personal recovery goals and what matters most to individuals diagnosed with schizophrenia such as restoring family relationships and receiving support. However, it is equally important to understand that these goals are complex and might come laden with contradictions given the complicated history of some of these family relationships. It is well-established that there is a higher prevalence of early life adversities among individuals diagnosed with schizophrenia (Matheson et al. 2013), that the majority of these adversities occur in the family environment (Jansen et al. 2016; Trauelsen et al. 2016), and that these early life adversities influence the risk of schizophrenia symptoms (Bentall et al. 2014; Longden et al. 2016; Varese et al. 2012) including later social functioning (Cotter et al. 2014; Rokita et al. 2018). The findings of this qualitative analysis suggest that limited familial interactions could also be intentional and reflect resilient boundary setting. However, this could still lead to negative consequences since the social networks of individuals diagnosed with schizophrenia are predominantly comprised of family (Gayer-Anderson and Morgan 2013) and engaging in protective social withdrawal can still lead to feelings of distress and loneliness (Sündermann et al. 2013).

These preliminary findings indicate the value of considering early life adversities before incorporating family members into care. A guiding principle for psychosocial interventions for schizophrenia has been to involve family members as collaborators (Ahmed et al. 2016; O'Donnell and Schnakenberg Martin 2016). Family interventions are considered one of the most effective psychosocial treatments for schizophrenia and included as an evidence-based practice in clinical guidelines (McFarlane 2016; O'Donnell and Schnakenberg Martin 2016; Onwumere and Kuipers 2018). These guidelines do not expressly mention the role of early life adversities (Silverstein and Bellack 2008). It has been suggested that the emphasis on family members as collaborators may make clinicians reluctant to incorporate traumatic childhood environments into treatment plans (Jansen et al. 2016). However, proponents of family interventions have indicated that they may not be suitable for everyone. It has been suggested that family interventions should be used when patients and families are already in close contact but that friends or para-professionals can be substituted if preferred (McFarlane, 2016; O'Donnell and Schnakenberg Martin 2016; Onwumere and Kuipers 2018). While families may be critical for recovery, it is important to expand the definition of family beyond biological and early family caregivers and consider how to incorporate other significant individuals in a person's life.

Additional qualitative research is needed with more systematic questions related to the research question and in larger and more diverse samples. Future studies should explicitly ask about early life adversities, the connections that individuals diagnosed with schizophrenia make between those early adverse experiences and later life family interactions, their suggestions for adapting psychosocial interventions appropriately, and any insights they may have for reconciling the potentially competing goals of building connections and maintaining distance that might occur following experiences of early life adversities. Future research could also expand to look at the influence of early life adversities on other types of social relationships. For example, other early life adversities such as peer bullying could lead to protective self-withdrawal from peer relationships and sexual violence could lead to protective self-withdrawal in romantic relationships. However, for some individuals diagnosed with schizophrenia, other types of relationships also offer additional avenues for supportive involvement in illness for those who are unable to receive that support from their families. A deeper understanding of the potential influences of all types of early life adversities on all types of social relationships will enable better tailoring of psychosocial interventions to align best with each person's own recovery goals.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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