

# Caregiving as Role Transition: Siblings' Experiences and Expectations when Caring for a Brother or Sister with Schizophrenia

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## ABSTRACT

Using a qualitative design, this study examines changes in the caregiving relationship in ten siblings caring for a brother or sister with severe schizophrenia. Siblings reported mourning the loss of a person they once knew and struggled to accept the brother or sister's dependency in day-to-day living. As the relationship progressed, siblings became closer to their ill brother or sister and learned to appreciate modest accomplishments as evidence of success. Siblings expressed ambivalence toward transitioning into a primary caregiving role as their parents aged. Including these siblings in community care planning is a necessary step in supporting them toward this transition later in life.

**Keywords:** siblings, schizophrenia, brothers, sisters, caregiving role, life course

## RÉSUMÉ

Les frères et sœurs peuvent être des sources de soutien pour les personnes atteintes de maladie mentale vivant dans la communauté. Néanmoins, la relation d'aide dans ce contexte demeure mal caractérisée. Utilisant la théorie des parcours de vie, cette étude rétrospective a examiné les expériences de dix personnes avec un frère ou une sœur atteints de schizophrénie. L'analyse des entretiens a révélé des points de transition

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clés dans la relation, y compris le deuil de la personnalité antérieure à la manifestation de la maladie et l'appréciation progressive des réalisations modestes comme marqueurs de succès. Les préoccupations de frères et sœurs tandis que leurs parents vieillissent sont également discutées.

**Mots clés :** schizophrénie, frères et sœurs, rôle d'aidant familial, parcours de vie

Beginning in the 1960s, the deinstitutionalization of people with severe mental illness in the United States and Canada shifted care for schizophrenic patients from state institutions to families and nonprofit organizations (Talbot, 1979). Since that period, baby boomer parents of adult children with schizophrenia have assumed a large portion of care due to insufficient community mental health services (Tausig, Fisher, & Tessler, 1992; Wright, Avirappattu, & Lafuze, 1999). As these parents are aging, their ability to provide care is decreasing and, in some cases ending, due to disability or death (Lefley & Hatfield, 1999). Consequently, the involvement of siblings without mental illness in primary caregiving is likely to grow over the coming two to three decades (Hatfield & Lefley, 2005; Stalberg, Ekerwald, & Hultman, 2004).

There is still limited research on how siblings become caregivers for a sister or brother with schizophrenia. In particular, more needs to be known about the experiences of sibling caregivers who have aging parents as primary caregivers. In this context, these siblings are likely to feel ambiguous about undertaking further responsibilities and concerned about the possible effects increased caregiving may have on their well-being later in life (Ewertzon, Cronqvist, Lützn, & Andershed, 2012).

To address this gap in knowledge, this study considers how siblings engage and redefine their relationship with a brother or sister with schizophrenia following diagnosis, what factors come into play in facilitating their engagement as caregivers, and their expectations for and concerns with the future once parents are no longer caregivers. Further understanding of this process is justified given the benefits sibling support brings, including increased quality of life for the relative with mental illness (Smith, Greenberg, & Seltzer, 2007) as well as enhanced recovery trajectory and overall prognosis (Bowman, Alvarez-Jimenez, Wade, McGorry, & Howie, 2014). This study is particularly relevant to mental health clinicians and practitioners who seek further information on this particular group of sibling caregivers. The study also offers evidence that could be useful for the development of family and sibling-centred services, which are scarce although greatly needed to manage community recovery for people with severe mental illness (Lukens, Thorning, & Lohrer, 2004; Sanders, Szymanski, & Fiori, 2014).

## LITERATURE REVIEW

Since the 1960s, the deinstitutionalization of people with mental illness in Canada and the United States resulted in the vast majority of people with schizophrenia living in the community where they require extensive follow-up (Lamb & Bachrach, 2001). Parents of adult children with schizophrenia have historically assumed the primary responsibility of community care due to the absence of adequate services (Tausig et al., 1992). Demographically, parents in the baby boomer generation constitute the largest group of caregivers; many are also entering the later stages of their lives and experiencing diminished caregiving capacity due to health problems (Awad & Voruganti, 2008). An American community survey of 697 caregivers of people

with schizophrenia found that 70% of mothers were 60 years of age or older and 33% were older than 70 years (Awad & Wallace, 1999).

Against this backdrop, a growing number of siblings caring for a brother or sister with schizophrenia have to confront the prospect of transitioning into a primary caregiver role (Stalberg et al., 2004). To our knowledge, there are no specific estimates of how many siblings have transitioned into primary caregiving. However, we know aging parents express a preference to have their other children take on increased caregiving responsibilities instead of relying on mental health professionals or advocacy groups for support (Hatfield & Lefley, 2000; Smith, Hatfield, & Miller, 2000). Also, sibling caregivers themselves can be ambivalent about such a transition. For example, Greenberg, Seltzer, Orsmond, and Krauss (1999) found that only one third of siblings of people with severe mental illness expected to become primary caregivers in the future. Similarly, in a survey of 60 siblings, Hatfield and Lefley (2005) noted that most siblings indicated they would offer more emotional support but felt less committed toward increasing instrumental care.

Such ambivalence can be situated in relation to the siblings' current or prior experiences with caregiving alongside their parents. Research points to several factors that either "push" siblings toward caregiving or "pull" them away, such as felt obligation toward parents, perceived need of the sibling with schizophrenia, geographic proximity, early socialization within the family, severity of illness symptoms, and quality of the sibling-family relationship (Greenberg et al., 1999; Jewell & Stein, 2002; Smith & Greenberg, 2008). Parental requests for assistance also positively influence siblings' caregiving involvement (Lohrer, Lukens, & Thorning, 2007) along with willingness on the part of the ill brother or sister to help with chores, being affectionate, and exchanging gifts (Horwitz, Reinhard, & Howell-White, 1996). Beliefs about the uncontrollability of symptoms can discourage siblings from considering deeper involvement in caregiving (Smith & Greenberg, 2007, 2008) as well as the extent to which they experience stress and burden as a result of managing their brother's or sister's symptoms (Barnable, Gaudine, Bennett, & Meadus, 2006; Friedrich, Lively, & Buckwalter, 1999; Lively, Friedrich, & Rubenstein, 2004). Having persistent feelings of guilt, anger, shame, jealousy, grief, and anxiety are also discouraging (Bowman, Alvarez-Jimenez, Howie, McGorry, & Wade, 2015; Stalberg, et al., 2004; Stein & Wemmerus, 2001; Titelman & Psyk, 1991).

Sibling's involvement in caregiving is thus a complex process which is far from assured. There is still limited research specifically addressing the evolution of the sibling relationship over time and the impact of this process on the views of siblings about caregiving in a primary capacity once aging parents are no longer able to provide care (Barnable et al., 2006; Ewertzon, et al., 2012; Gerace, Camilleri, & Ayres, 1993; Lively, Friedrich, & Buckwalter, 1995; Lively et al., 2004; Sanders et al., 2014). As Lukens and colleagues (2004) note, only "a few investigators have used qualitative approaches, particularly in-depth interviewing techniques, to study the relationship between adult siblings when one or more is affected by mental illness" (p. 490). In light of this assessment, this study focuses on investigating siblings who care for a brother or sister with schizophrenia in relation to changes in the sibling relationship following diagnosis, the process of becoming a caregiver over time, and their views on future caregiving as their parents grow older.

## Theoretical Framework

A lifecourse perspective guided the study's design and implementation. Lifecourse is defined as "the age-graded, socially-embedded sequence of roles that connect the phases of life" (Mortimer & Shanahan, 2003, p. xi). A central tenet of this perspective is that acquisition of new roles in any period of life should be understood in relation to people's prior experiences and their expectations for the future. In health research, this perspective emphasizes the importance of taking into account contextual factors when researching people's life trajectories, including familial and work responsibilities (Pailhé, Robette, & Solaz, 2013), prior history with the care recipient (Wheaton, 1990), the cultural meanings of caregiving (Burton, 1996), and the involvement of other siblings and/or parents in a caregiving capacity (Horowitz, 1985).

While lifecourse research initially relied on quantitative longitudinal data analyses, recent efforts have used cross-sectional biographical methods such as life stories, in-depth interviews, and personal narratives (Verd & Lopez, 2011). This shift recognizes the value of retrospectively examining transitions in people's lives in relation to important events, constraints, and personal experiences (Jovchelovitch & Bauer, 2000). With this development in mind, we used in-depth interviews to retrace the life stories of siblings acting as caregivers to an ill brother or sister following a diagnosis of schizophrenia. We designed the interview questions and conducted analysis and interpretation of the data to articulate the lived experience of caregiving at key stages in the sibling's relationship with the affected brother or sister. We asked siblings to speak about their experiences of assuming a caregiving role over time and how this process unfolded in relation to handling schizophrenia symptoms and their familial and social contexts. Finally, we asked them to express thoughts on their future as caregivers in relation to these previous experiences and in the context of having aging parents as primary caregivers.

## METHODS

We drew on narrative methods to elicit personal stories from participants. This approach seeks to uncover "the constellation of procedures, conditions and resources through which reality is apprehended, understood, organized and represented in the course of everyday life" (Holstein & Gubrium, 2000, p. 94). We specifically sought to gain insight into the siblings' day-to-day engagement in caregiving and the meanings they attributed to their relationship with the ill brother or sister. The study received ethical approval from the University of Victoria's Human Research Ethics Board and informed consent was obtained from all participants.

### Recruitment and Sample

Recruitment occurred with assistance from a mental health advocate who maintained an online support network for parents and siblings of people with schizophrenia, providing them advice and information via an email list. She was selected because of her trusted profile within the community of families of people with schizophrenia and the extensiveness of her contacts. Although not involved as an investigator in the study, she agreed to distribute the study's invitation poster to her email list. The poster specified four recruitment criteria: (1) have a brother or sister diagnosed with schizophrenia according to DSM criteria (APA, 1994); (2) have at least monthly contact with the brother or sister face-to-face and/or by telephone; (3) be 19 years

of age or older; and (4) reside in Greater Vancouver, British Columbia. We used monthly personal contact with the sibling with schizophrenia as a proxy for significant caregiving engagement. We defined caregiving as a role involving consistent provision of emotional and/or instrumental support through a range of activities such as having supportive conversations, accompanying the sibling to recreational activities, monitoring medication, and assisting in daily tasks (Archbold et al., 1990).

A total of 10 participants replied to the poster and volunteered for the study. The sample consisted of five males and five females who ranged in age from 21 to 56 years (mean = 32.2 years; see Table 1 on the next page). On average, each participant had two siblings (range = 1–4 siblings). Four of the participants were older and six were younger than the sibling with schizophrenia. The average age difference between the participants and their sibling was 3.1 years (range = 1–10 years). With one exception, no participants lived with their sibling. However, seven had resided with their sibling for extended periods of time in the past depending on circumstance and care recipients' needs. At the time of the sibling's diagnosis, the participants ranged in age from 8 to 29 years (mean = 19.9 years). Most of the participants' parents were in the later stages of the life cycle, with mothers' ages ranging from 56 to 69 years (mean = 61.6 years) and fathers' ages ranging from 62 to 86 years (mean = 67.7 years). One parent, a mother, was deceased. All other parents were involved in the care of their son or daughter in a primary capacity.

The participants identified eight brothers and two sisters diagnosed with schizophrenia who ranged in age from 26 to 46 years (mean = 32.5 years) and were diagnosed at an average age of 20.5 years (range = 14–27 years). They had been ill for an average of 11.9 years (range = 4–31 years). At the time of the study, none of the siblings with schizophrenia were involved in a romantic relationship, had ever been married, or had been employed. Three of the siblings with schizophrenia lived with their mother, two with both parents, two were in a group home, two were renting an apartment, and one was hospitalized in a psychiatric facility.

### **Data Collection**

The first author conducted in-depth, semi-structured interviews with the participants. The interviews lasted one hour on average and took place at the participants' residence or at their workplace. Questions were open-ended and allowed participants to develop their own narrative about their relationship with the brother or sister with schizophrenia. Due to the sensitive nature of the topic, the interviews started with non-threatening questions about family living arrangements and caregiver background. This phase enabled participants to become comfortable in the interview setting and with the researcher. Once a rapport was established, the interview focused on the participants' evolving relationships, their experiences with caregiving, and their views on future caregiving responsibilities.

### **Data Analysis**

All interviews were audio-recorded with participants' permission and transcribed verbatim. Both authors read and thematically analyzed the transcripts and identified themes using grounded theory coding procedures (open coding, axial coding, and selective coding; Charmaz, 2006). The constant comparative method was used to verify the themes against the data and refine their dimensions and properties. Disagreements on identified themes were resolved by further discussion and rereading of relevant transcripts when necessary.

**Table 1**  
**Characteristics of Sibling Participants**

Participant	Pseudonym	Age	Gender	Other well siblings by gender and age	Current occupation	Education	Marital/Relationship status	Age when sibling diagnosed	Age of father	Age of mother
1	Troy	24	m	f/29, f/21	Manager	College diploma	Single	17	65	59
2	Ethan	37	m	n/a	Nurse	Undergraduate degree	Common law	18	67	65
3	Tyler	56	m	m/54, f/52	Radio producer	Undergraduate degree	Married	23	86	Dead
4	Corry	31	m	n/a	Teacher	Undergraduate degree	In a relationship	25	65	62
5	Holden	26	m	n/a	Graduate student	Graduate degree	Single	22	65	61
6	Claire	34	f	f/37	Website editor	High school diploma	Separated/ in a relationship	27	67	65
7	Jen	21	f	m/24, f/29	Undergraduate student	Undergraduate degree	Single	15	65	59
8	Amy	29	f	m/24, f/21	Trainee/teacher	Undergraduate student	Single	25	65	59
9	Sienna	30	f	n/a	Marketing coordinator	Undergraduate degree	Common law	12	62	56
10	Mia	34	f	n/a	Doctoral student	Graduate degree	Married	8	70s	60s



The techniques of member-checking, reflexivity, and thick rich description were employed to enhance credibility (Creswell & Miller, 2000). In member-checking, the first author conducted follow-up interviews of 30 to 45 minutes in duration with all participants to verify analytical interpretations of the data and gain further insights into their experiences. He also gave participants a summary of the findings specific to their interview and asked them to comment on its accuracy in reflecting their views and experiences. All participants felt the summaries represented their views and experiences accurately. With regard to reflexivity, the authors kept a journal in which they recorded methodological decisions and the reasons for them and the beliefs and opinions they felt could undermine their interpretations of the data. Thick rich description is used as much as possible in relating the findings and to underline the participants' range of experiences.

## FINDINGS

The evolution of the siblings' caregiving relationships is summarized with the following three themes: (1) Diagnosis and Changing Sibling Relationship; (2) Adopting the Caregiving Role; and (3) Caregiving Challenges and Expectations for the Future.

### Diagnosis and Changing Sibling Relationship

In this section, we discuss the trauma siblings experienced when schizophrenia transformed their relationship with the brother or sister as well as the process by which they adapted to this change and began to consider adopting a role as caregiver.

Siblings reminisced about the fun times they had had with their brother or sister prior to the onset of schizophrenia—they also felt keeping these memories alive helped them maintain a caring relationship. Several siblings closer in age to the sibling with schizophrenia spoke of entering their teen years together expecting to share adult life milestones like marriage and raising a family. They characterized the disclosure of the diagnosis of schizophrenia as a traumatic event marked by the realization that their relationship with the diagnosed sibling would never be the same.

The initial stages of the caregiving relationship were defined by mourning the loss of the sibling they once knew and adjusting to illness-related personality and behavioural changes and the side effects from antipsychotic medications (e.g., flat affect, slurred speech, lethargy). Siblings talked about feeling angry at an illness that “attacked,” “consumed,” and “overtaken” their sibling. They bemoaned the brother or sister's abandonment of activities they once enjoyed like a sport or playing a musical instrument in favour of passive pursuits like watching TV, smoking cigarettes, and listening to music. Siblings found these changes disheartening, especially when common friends who had participated with them in these activities distanced themselves.

Siblings spoke about how caregiving really begins with learning to accept the brother or sister as they are now rather than as a person with a “past healthy self” and a current “sick self,” as illustrated by this quote:

So, there are only a very few occasions where I can actually be fulfilled on a really good level and see her true self or identity of who she is now and learn to accept that. And I think that is another hard thing to do, to accept who she is now and is different from who she was, and she will never be the same and try to go on. (Holden)

Early in the caregiving relationship, siblings often hoped that a cure for schizophrenia would soon be found but eventually came to accept that recovery from schizophrenia would be slow and gradual, a process one participant described as “two steps forward, one step back.” A particularly difficult challenge for many siblings was to accept that the chronic and severe nature of schizophrenia would prevent their brother or sister from completing university and securing gainful employment. Siblings found it frustrating whenever their brother or sister made plans to go to school or look for some type of employment and later became disappointed when such plans went unrealized. For example, Claire told of how her brother wanted to become a matador, but believed that this was a “grandiose thought.” She went on to explain, “I guess it’s like anyone with a new idea. You get excited about it and then as the kind of reality of what’s involved in doing it sets in. I know Luke’s like that—he’ll get excited about something and then it’s not practical for him to do it.”

### Adopting the Caregiving Role

As the relationship progressed, siblings spoke of gradually adopting a caregiving role. In particular, they mentioned taking the initiative of setting attainable goals for their brother or sister and learning when to put “pressure” on the sibling and when to “back off.” Siblings also mentioned how, over time, they developed greater appreciation of their brother or sister’s limited competencies and modest accomplishments. This even became a source of pride for many as illustrated by this quote:

Carter is doing beading, bracelets and stuff like that. I think that’s something that they’ve given him to do at the hospital. This last birthday, he gave me a bracelet. He’s never really given me anything because he never had any money or cared about it. I just felt when he made me this bracelet [that] I almost wanted to cry, you know. I just couldn’t believe it. And it had a little card on it and he wrote my name on it and it was just amazing. (Sienna)

A key feature in this process was the siblings’ willingness to accept and manage their brother or sister’s state of dependency brought on by schizophrenia. Siblings spoke of their relationship as taking on a “parent–child-like quality,” as exemplified by this comment: “So in that sense, my role has become more of a provider rather than a peer. That’s what I mean when I say the relationship remains not sort of equal. It’s not the same as having a buddy chat with my sister” (Ethan). At this stage of the relationship, siblings mentioned more readily doing tasks such as preparing nutritious meals, overseeing payment of the rent, or buying clothes. They also monitored medication and interacted with mental health professionals.

Over time, they came to view these caregiving tasks as opportunities to further develop their relationship with the sibling with schizophrenia. Although these accomplishments were modest, participants said they fostered a more intimate engagement. They saw this time as a way to nurture the sibling bond and reaffirm the strength of their relationship. Yet, they singled out the sibling’s frequent failure to reciprocate socially as a challenge. Siblings described their brother or sister as being often “stuck in their own minds or preoccupied with their thoughts” and “oblivious to the needs of others around them.” As one sibling observed, “It’s all about her now... she likes to talk about herself... [and] the topics centre around her” (Ethan).

The management of dependency also became a focal point in the participants’ interactions with family members. There were discussions about strategies to improve functioning but, on occasion, family members just “gossiped” about the inabilities of the sibling with schizophrenia. Siblings reported these interactions as “draining,” particularly when disagreements surfaced about how to manage problem behaviours. A source of



tension was a perceived leniency on the part of parents who allowed their son or daughter to “do whatever they want.” A number of siblings denounced their brother or sister as “manipulative” and tugging at their parents’ “heart strings” for money or favours. They felt parents “gave in” because of feelings of guilt or exhaustion, as illustrated by this comment from a sister:

If you say “no we can’t go to the mall right now!” he’ll start crying, right? And it’s fake crying and you know it’s fake crying and you can just go “It’s not going to work on me.” Then he stops and I think what else is he going to do? And he leaves and then he comes back and he’s like “Mom just told me that you have to take me to the mall,” and I am like “Well, when did you talk to her?” (Sienna)

Siblings “saw through these acts” and felt strongly about placing limits on their brother or sister’s behaviour. Several siblings mentioned having to handle “child-like” behaviours like “yelling,” “stomping around,” “moping,” and “whining,” which forced them to take on a disciplinarian role and show “tough love.”

### Caregiving Challenges and Expectations for the Future

While siblings were deeply committed to caregiving, they also identified several challenges that mediated their ability to care. Many struggled with balancing the competing obligations of caring for the brother or sister and their own family needs. Involvement also fluctuated with the severity of their sibling’s illness and the support they required. For example, one sister talked about the impact of caring for a brother who was frequently hospitalized:

Whenever he’s having more problems—like if he’s in the hospital—then of course it affects me because it has to become a daily part of my day-to-visit with him, which is fine—like I don’t mind spending the time, but it’s disruptive emotionally to go every day through that experience. (Claire)

Most siblings talked of overextending themselves, most often when the brother or sister’s symptoms worsened or when their parents needed respite. After these times, they felt a strong need to disengage from the caregiving relationship to “recharge the batteries” and reconnect with their own life pursuits.

Siblings spoke of learning to handle these challenges over time in part because of a strong sense of familial duty. They made statements such as “If I did not help, who would?” (Holden) when lamenting about the lack of involvement of other siblings, which they attributed to age and personality differences and the stigma of being related to a person with mental illness. In families with only two siblings, these siblings also expressed guilt at being the one not affected by schizophrenia and felt pressure from parents to succeed. As one sister remarked: “I have more pressure to succeed because there is only the two of us. My mom is like, ‘Well I lost one so all my hope is in you’” (Sienna).

Nine siblings had aging parents providing primary caregiving and one sibling became a primary caregiver following his mother’s death from cancer. This sibling talked of falling into the role because of his father’s inability to manage his ill son’s erratic behaviours and addiction to crack cocaine. The father had directly appealed to him to become the “point person” for his brother with schizophrenia. In discussing future prospects, all other siblings said they were fearful of the time when their parents’ diminished health or death would force them to consider engaging more extensively in caregiving. Based on their own experiences and those of their parents, siblings portrayed primary caregiving as an all-consuming task which would interfere with their well-being, as exemplified by this quote:

I think I worry about it more for future stuff, for when my parents die. Like I said, Joe has always done his own thing and my sister, their relationship, is not always the greatest. So, I think it would fall up to me and I am just trying to figure out how that would work. How that would work out in terms of me having a life. (Jen)

Siblings' concerns thus appeared in part rooted in their own lack of experience with primary caregiving, which they had engaged in only when their parents were "in need of a break." Sibling caregiving also differed from parental caregiving. Sibling support was more sporadic and less comprehensive than the care parents provided. They also reported being unwilling to provide the same amount of support in the future as what their parents currently provide. Distressingly, none of the siblings had made clear plans for transitioning as primary caregivers despite the advancing age of their parents.

Most siblings expressed deep concern about the impact such a transition would have on those close to them. They valued how current caregiving had given them a deeper appreciation of their brother or sister but worried that, as primary caregivers, they would come to neglect relationships with members of their own family as well as friends. Perhaps as a means to cope with these concerns, siblings voiced the hope that their brother or sister would improve in functioning by the time they transitioned to a primary caregiving role.

### Limitations

This study has several limitations. First, the sample size is small ( $n = 10$ ) and oversamples for siblings caregiving for brothers. Therefore, participants may not be representative of the population of siblings caring for an adult with schizophrenia. However, other qualitative studies in this field have similar sample sizes (e.g., Barnable et al., 2006). Secondly, ethnic diversity was limited in the sample. Therefore, the findings may not readily apply to siblings from other cultural backgrounds who might have different experiences caring for a brother or sister with schizophrenia. Third, we purposively sampled for siblings consistently involved in caregiving. Yet, in some families, other siblings were also providing care, albeit inconsistently. Further research is thus needed to capture the range of familial support which is available to siblings with schizophrenia. Finally, we asked siblings to remember becoming involved as caregivers and speak of the changing nature of this role over their years of involvement. Given the limitation of memory recall, participants may have identified some but not necessarily all factors which account for the evolution of their caregiving involvement.

### Implications for Practice and Directions for Future Research.

The findings have several implications for mental health practice. There is a need to integrate siblings in care decisions as they play an important role in supporting their brothers or sisters with schizophrenia in the community. We also found that siblings became more implicated as caregivers once they accepted the limitations brought on by schizophrenia. This finding suggests siblings need to be informed early on about their sibling's mental illness symptoms and treatment. As Smith et al. (2007) note, psychoeducation programs could help siblings "reframe their relative's condition as an illness, beyond the individual's control" (p. 31).

One concern is that mental health professionals may lack knowledge about how best to support siblings who deeply engage in caregiving (Nechmad et al., 2000). In this regard, further research is needed to

identify and evaluate interventions that help siblings acquire effective problem-solving skills and techniques for managing the symptoms of schizophrenia over the long term (Bowman et al., 2014; Sin, Henderson, Pinfold, & Norman, 2013). Such interventions would assist siblings as they consider transitioning to a primary caregiving role and enhance the prospects of a brother or sister successfully remaining in the community.

## DISCUSSION AND CONCLUSION

This study documented siblings' gradual and ambivalent engagement in a caregiving relationship with a brother or sister with schizophrenia. Following the diagnosis, these siblings reported mourning the loss of a person they once knew and many initially saw the sibling with schizophrenia as a "healthy self" overtaken by the illness. Participants spoke of beginning the caregiving relationship in an instrumental manner, mostly attending to the tasks of managing shelter, nutrition, and medications, but also addressing their sibling's unrealistic plans and expectations as they themselves adjusted to the illness. As the caregiving relationship progressed, siblings spoke of becoming closer to their ill brother or sister and learning to appreciate modest accomplishments as evidence of independence and success.

Siblings identified balancing responsibilities toward the brother or sister with their own family obligations as a key factor in mediating their level of caregiving engagement. One participant was already a primary caregiver while the other nine all expected having to consider providing primary caregiving in the future as their parents aged. Using current caregiving experiences as an indicator, siblings feared the compromises they would have to make in their own lives if they chose to accept greater caregiving responsibilities. They also expressed a lack of confidence in their ability to care to such an extent while a few hoped that possible improvement in the brother or sister's functioning in the future would make caregiving less of a burden. Our findings suggest that siblings approach the prospect of future engagement as a primary caregiver with ambiguity based on their previous experiences, which speaks to the need for developing effective interventions and services to educate and support them in this process.

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