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Finding the "Golden Moments": Strategies of Perseverance Among Parents and Siblings of Persons With Severe Mental Illness and Violent Tendencies

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Abstract

This article examines strategies family members identify as being helpful when challenged by stressors related to living with an aggressive child or sibling with severe mental illness. Data from in-depth, ethnographic interviews with 42 parents and siblings of violent children with severe mental illness were analyzed using a modified version of grounded theory. Our analysis identified three themes that represent helpful strategies: (a) gaining insight and knowledge, (b) joining peer support programs, and (c) identifying a silver lining. Giving attention to these strategies may prove beneficial for other family members confronted and confused by mental illness, violent, and the complex mental health system. We recommend mental health practitioners help family members locate and engage with these resources and strategies to minimize family members' sense of isolation and confusion, and to increase their knowledge of mental illness.

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Chronic and severe mental illness (SMI) presents a unique stressor situation for family members who are tasked with complex responsibilities, including the social, emotional, and financial well-being of the person with mental illness (P. L. Solomon, Cavanaugh, & Gelles, 2005). Some family members assume the role of advocate by attending treatment-related appointments or treatment team meetings, while others also oversee medication management and monitor or prepare for possible—and sometimes unpredictable—increases in symptoms that might lead to unsafe or aggressive behavior toward the self or others, including family members (Bernheim & Lehman, 1985; Karp, 2001; Labrum, Walk, & Solomon, 2016). Persons with SMI are often dependent on family members for housing, financial, and/or assistance with daily-living activities (Clark & Drake, 1994; Dixon et al., 2011; Onwumere, Zhou, & Kuipers, 2018); this type of dependence has been shown to predict, in part, increased aggression against family caregivers (Korbin et al., 1991; Labrum, Solomon, & Bressi, 2015).

Important to note is the majority of persons with mental illness are not violent. In fact, persons with mental illness are more likely to be the victim rather than the victimizer in a violent crime (Desmarais et al., 2014; Torrey et al., 2016). However, 12-month prevalence rates of violent behavior among persons with SMI vary between 11% and 52% (Arseneault, Moffitt, Caspi, Taylor, & Silva, 2000; Desmarais et al., 2014; Havassy & Mericle, 2013; Steadman et al., 1998; Swanson et al., 2006). Some researchers suggest persons with SMI are between two and eight times more likely than the general population to engage in violent behavior (Corrigan & Watson, 2005; Joyal, Dubreucq, Gendron, & Millaud, 2007).

For those who are violent, persons with mental illness are more likely to direct that violence toward family members than toward strangers (Labrum & Solomon, 2016; Onwumere et al., 2018). Earlier research found about half of all violence committed by persons with mental illness to be directed at family members (Estroff, Swanson, Lachicotte, Swartz, & Bolduc, 1998). More recent studies found similar results. For example, Labrum and Solomon (2017) surveyed 573 relatives of a person with mental illness to examine the rate of victimization of family members committed by a relative with mental illness. Nearly half of all respondents reported being the victim of their relative's violent outbursts since the onset of mental illness, and 22% reported being the victim of a violent outburst in the past 6 months. Other researchers investigated familial homicide in which the offender has a serious mental illness. For example, Torrey et al. (2016) estimated the offender had serious mental illness, such as schizophrenia or bipolar disorder, in at least two thirds of homicides that included the killing of a parent and in 15% of homicides that included the killing of a sibling. Important to note, compared with all other persons, mothers are the most at-risk for victimization among family members living with a relative with mental illness (Labrum & Solomon, 2016).

The current research adds to a growing body of literature that addresses the prevalence, risk, and experience of violence and victimization in a small yet important population of victims. While much research has addressed negative outcomes, this project complements and extends such work by examining expressions of positivity and perseverance among family members of violent persons with SMI. In particular, this research relies on in-depth interviews to better understand strategies parents and siblings of aggressive children with SMI employ to persevere despite the SMI- and care-related stressors in their lives. In the following section, we briefly summarize the extant literature on stress in families of persons with SMI. We then focus on resilience and positivity among family members of persons with SMI, which will later be used to organize our findings.

Background

Caregiving and Mental Illness

Research on individual-level outcomes related to caring for a child with SMI shows an increased risk of subjective burden, depression, grief, and stress (e.g., Karp, 2001). Parents of children with mental illness report fear of victimization for themselves and other family members (Labrum & Solomon, 2018), high levels of emotional burden and various feelings such as confusion, guilt, grief, anxiety, shame, and anger, and a sense of loss for themselves and their children (Harper & Hoopes, 1990; Sporer, 2016). Chen and Lukens (2011) examined archival data from 137 parents and siblings of persons with SMI to compare well-being, depressive symptoms, and burden. While both parents and siblings reported high levels of subjective burden and grief of their relative with mental illness, parents reported more depressive symptoms than siblings. For example, spouses reported moderate to severe levels of hardship and conflict in their marriages due to the stress of having a child with a chronic illness (Safer, 2002; Seligman & Darling, 1997). Parents struggled to balance caregiving responsibilities with roles associated with being a spouse and a parent of a healthy child (Safer, 2002; Seligman & Darling, 1997; Sporer, 2016). This struggle was exacerbated if one parent perceived a lack of spousal support (Atkin & Ahmad, 2009).

Siblings of persons with mental illness also experience negative social and psychological outcomes. For example, siblings report feeling abandoned, invisible, or forgotten by their parents; these feelings are compounded when the child perceives the parents as focused primarily on the child with mental illness (Lukens, Thorning, & Lohrer, 2004; Marsh & Dickens, 1997). Koocher and O'Malley (1981) identified a variety of negative emotions felt by siblings of persons with mental illness, such as feeling left out, jealousy, fear for one's own health, and resentment toward the sick sibling. Relatedly, Liegghio (2016) interviewed seven siblings, aged 7 to 21 years, of a brother or sister with mental illness to examine the experience of family stigma. The sibling participants described a variety of negative experiences. Primarily, they struggled to make sense of their sibling's and family's identity, which they perceived as grounded in mental illness and stress.

Mental Illness and Violence in the Family

Family members living with a relative with mental illness are at an increased risk of being a target of violent behavior. Risk of violence is related in part to the caregivers' accessibility (Labrum & Solomon, 2018), responsibility in managing disturbing and difficult behaviors (Hyde, 1997; Labrum et al., 2016), and financial oversight (Estroff et al., 1998; Kageyama et al., 2016). Fear or threat of harm compounds caregiving-related stressors, including those we summarized above.

Fear of victimization and exposure to violence by a relative with mental illness has a negative impact on individuals and family systems. In a recent systematic review, Onwumere et al. (2018) examined existing literature on the effects of violence exposure on caregivers of persons with psychosis. The researchers found correlations between patient violence and caregiver burden, the latter including financial burden, emotional distress, and carer trauma symptoms. Five of the 20 studies included in the review suggested fear was associated with a belief that the caregiver's life was in danger or that there would be a recurrence of violence in the future by the person with mental illness (Copeland & Heilemann, 2008; Friedrich et al., 1999; Hsu & Tu, 2013; Loughland et al., 2009; Nordström & Kullgren, 2003). Hsu and Tu (2013), who conducted in-depth interviews with 14 parent–child dyads in which the child was hospitalized for schizophrenia, found caregivers expressed feelings of powerlessness and frustration when unable either to control their child or to effect positive change.

Fear for the safety of one's self, other family members, and the person with mental illness is a common finding in the extant literature. For example, Labrum and Solomon (2018) examined data from a national survey conducted by the National Alliance for Caregiving to understand safety fears among 1,505 caregivers of adults with mental illness. While caregivers expressed fear that their family member would be hurt by others or die by suicide, 40% of the respondents also feared for their own safety and the safety of others. This fear was compounded by certain characteristics of the relatives with mental illness, such as history of alcohol and substance abuse, history of arrest, and refusal to take psychiatric medications as prescribed. Consistent with literature on caregiving more broadly, respondents reported their own health to be worsening, which they attributed to caregiving-related stress.

Recent qualitative studies have contextualized experiences of family members and family systems with violent persons with SMI. Sporer and Toller (2017) interviewed 20 parents and siblings of violent children with mental illness to examine how family members perceive their family life and family identity. The participants characterized their lives as abnormal and crumbling. Furthermore, each participant described their family member's mental illness and related caregiving needs as all-consuming, ongoing, and unlikely to dissipate. In a smaller study, Sporer (2016) interviewed 10 parents and siblings from four families who had an aggressive child with SMI to investigate how families adapt and respond to living with a violent child with SMI. The participants described their family lives as being consumed by stress they associated with living with a child with SMI, and that such stress was compounded by unpredictable yet frequent acute violence and victimization. In fact, the violence at home forced three of the families to remove the child with SMI from the home rather than endure continued violence and victimization. While findings from these small studies are ungeneralizable to a larger population of family caregivers, it is unsurprising that parents and siblings of violent persons with mental illness tend to be significantly more distressed than the general public (Martens & Addington, 2001).

Positive Outcomes

Although there is an extensive list of negative experiences, there is a small but growing body of literature on positive outcomes for family members of persons with SMI. Researchers have found the following positive outcomes: a reduction in stressors (Toohey, Muralidharan, Medoff, Lucksted, & Dixon, 2016), a heightened gratitude for their own lives, and an eagerness to live fully (Bayat, 2007; Kinsella, Anderson, & Anderson, 1996). In an earlier study, Johnson (2000) interviewed 180 family members of persons with SMI. Despite the frequent disruptions and time-consuming nature of caregiving, participants reported fondness and concern for the well-being of their child or sibling. For example, family members reported a greater sense of purpose, greater empathy, and greater closeness to their families (Aschbrenner, Greenberg, Allen, & Seltzer, 2010; Greenberg, Seltzer, & Judge, 2000; Koocher & O'Malley, 1981; Marsh, Lefley, Evans-Rhodes, Ansell, & Doerzbacher, 1996). In fact, Kinsella et al. (1996) found family caregivers of persons with mental illness reported increased feelings of empathy and compassion for others, resiliency in the face of adverse conditions, and overall assertiveness. They were likely to advocate for their family member with mental illness, particularly by seeking out mental health services, changing outsiders' views of mental illness, and increasing public awareness.

Current Study

Given the challenges associated with living with and caring for a person with SMI, understanding the lived experiences of family members warrants further investigation. The current research adds to the literature on positive outcomes by examining the strategies and behaviors family members identify as being helpful when challenged by stressors related to living with and caring for a violent child or sibling with mental illness. This article answers the following research question: What strategies do family members of violent children with mental illness employ to persevere despite their stressful lives?

Participants

Data used in this article are drawn from ethnographic, in-depth interviews with parents and siblings of violent persons with SMI.[1] The participants (n = 42) represent 29 of individuals who self-reported either currently or previously having lived with a sibling or child with SMI who has acted violently toward at least one family member. The family members with mental illness, who were not interviewed as part of the current project, ranged in age from 8 to 48 years old. Participants experienced or witnessed various forms of aggressive behavior, from destruction of inanimate objects (e.g., breaking mirrors, furniture, or windows) to physical and verbal abuse (e.g., punching, throwing knives, swearing and yelling, or pushing family members down stairs). Pseudonyms were used to ensure participant anonymity.

Participant recruitment began after receiving approval from the University of Nebraska Medical Center's Institutional Review Board (IRB; approval number 496-13-EP). Verbal consent was obtained from participants, as signed informed consent was waived by the IRB. We relied on nonprobabilistic sampling strategies for participant recruitment (Berg, 2009; Bernard, 1995; Guest, Bunce, & Johnson, 2006; Trotter & Schensul, 1998). Participants were recruited through social and professional networks in the Northeast and Midwest, as well as social media websites (e.g., Facebook), and a variety of community-based support programs and the National Alliance of Mental Illness. After each interview, participants were asked to refer other family members or acquaintances who might be willing to participate. The use of a third party (e.g., family member, treatment provider) gave potential participants the freedom to decline participation without revealing their identities.

The final sample included 26 mothers, 6 fathers, 8 sisters, and 2 brothers; the participants were from 17 different states. Their ages ranged from 16 to 83 years, and the median age was 45 years. One participant identified as Hispanic and the rest identified as Caucasian. The snowball and purposive sampling techniques inadvertently led to a greater representation of Caucasian participants who identified as middle or upper-middle class. It is important to note that different ethnic or racial populations and those with different financial means might have different levels of access to either formal or informal support groups, and they might have different perceptions of and reactions to mental illness.

Purposive and snowball sampling strategies are not without limitations, especially with regard to generalizability. However, these sampling techniques are sufficient for this research for three reasons. First, this study is explorative, qualitative, and descriptive. Our goal was to understand social processes in a very specific subpopulation (i.e., family members of violent persons with mental illness), rather than generate broad generalizations. Second, the rich data gathered through our interviews would otherwise be difficult, if not impossible, to obtain through more traditional research methodologies (e.g., household surveys; Snijders, 1992). Last, snowball and purposive sampling strategies are helpful in gaining access to hidden populations (Berg, 2009; Bernard, 1995; Guest et al., 2006; Trotter & Schensul, 1998) and many researchers have utilized these strategies to access families of persons with mental illness or disabilities who are otherwise unidentified and thus unreachable (e.g., Clarke & Winsor, 2010; Copeland & Heilemann, 2011; Cox et al., 2003; Huang et al., 2008; Leith & Stein, 2012; Moyson & Roeyers, 2012).

An important outcome of our sampling strategy was the inclusion of two or more family members from 7 of the 29 families. The multiple perspectives from within the same family unit allowed us to triangulate emerging themes and corroborate stories (Daley, 1992), which enhanced the validity of our findings (Berg, 2009; Rolland, 1994), and produced a comprehensive depiction of the participants' lived experiences.

Interview Procedure and Data Collection

Data were collected through in-depth, ethnographic interviews (Blumer, 1969; Spradley, 1979), which elicited rich data as a foundation for thick description (Charmaz, 2014; Geertz, 1973). Each participant selected the time and place of the interview and each interview lasted approximately 90 minutes. The interviews utilized open-ended questions to promote the emergence of unforeseen stories (Charmaz, 2014) and offered information that might not be available in written documents (Fontana & Frey, 1994).

Specifically, narration and interviews allowed participants to both "tap into the complexity of [their] experiences and beliefs" (Blee, 1993, p. 599) and interpret their experiences (Denzin, 1978). Ethnographic and in-depth interviews have advantages for both the interviewer and the interviewee (Charmaz, 2014). First, ethnographic interviewing is a holistic research methodology that, in particular, allows the researcher to enter the private sphere and observe firsthand how family members interpret, understand, and experience family interactions (Spradley, 1979; Tracy, 2013). Second, the interviewer is able to shift the conversation and follow hunches, ask for clarification, come back to an earlier point, go beneath the surface of the described experience(s), and slow or quicken the pace. Third, the interviewee is able to tell his or her own story, be the expert, choose what to tell and how to tell it, share significant experiences, and teach the interviewer how to interpret them. Last, qualitative researchers are able to corroborate stories (Daley, 1992) and triangulate findings (Berg, 2009) after interviewing or observing multiple family members, thus producing a more solid depiction of the family's reality.

Spradley (1979) and others (e.g., DiCicco-Bloom & Crabtree, 2006) note that traditional ethnographic research methodologies allow rapport to develop naturally over time; however, it was critical that rapport was established rather quickly because the interviewer had only a couple hours with each participant (during initial interviews). The first author conducted all of the interviews using a participatory approach (Lyons & Chipperfield, 2000), which minimized apprehension and established rapport at the start of each interview. This approach involved the researcher offering self-disclosures about how the current research was inspired by their time working in the mental health field and how those experiences led them to the current research. Participants were then asked descriptive questions to initiate the conversation and allow the informants to speak freely (Spradley, 1979; e.g., “Can you describe to me when you first started to think John might have mental illness?”). Open-ended follow-up questions were also posed, which evoked clarification without leading the participant (e.g., “You mentioned your son could ‘fly off the handle.’ Can you explain how you prepare for that during dinner time?”).

Participants were asked questions to yield a complete family narrative, including opening and contextual questions (e.g., “I don’t have a brother who has mental illness and is aggressive, could you tell me what it is like for you?”), relationship-related questions (e.g., “Can you tell me how your relationship with your father has changed over time?”), and clarification and concluding questions (e.g., “After having these experiences, what advice would you give to someone who is in the same position?”). Additional topics and conversation points were reflected on as participants discussed issues not previously considered.

While most participants were interviewed individually, four participants asked to be interviewed with their spouse (i.e., two interviews were conducted with both a husband and wife). Interviews were conducted in the participants’ homes, at coffee shops and restaurants, and the first author’s apartment. However, some participants preferred telephone interviews. Telephone interviews presented additional barriers to rapport building, primarily because of the loss of face-to-face nonverbal cues (Berg, 2009). However, it has been argued that rapport might be no different in telephone interviews from in-person interviews. Furthermore, the telephone offers immediate anonymity (Berg, 2009), which allow participants to feel relaxed and more apt to disclose sensitive information (Novick, 2008). Throughout the data analysis, there was little to no difference in quality or quantity in the interview content when comparing telephone and in-person interviews.

Data Analysis

Data were analyzed using a modified version of grounded theory. Grounded theory is a flexible, nonlinear methodology that allows themes and ideas to emerge during analysis through the process of creating, comparing, and contrasting categories identified in the data (Charmaz, 2014). Traditional grounded theorists suggest data analysis begin soon after the first interview, and that all interviews and analyses are completed prior to reading the extant literature (Glaser & Straus, 1967). While we implemented core principles and strategies of traditional grounded theory, our approach differed in that we began the data analysis after most of the interviews were completed, and we read the extant literature before, during, and after analysis.

Our data analysis consisted of five steps but started with reading entire interview transcripts to generate provisional codes. Initial codes were provisional in that we remained open to other directions the data analysis may take. In general, initial coding included word-by-word and line-by-line coding. As data analysis progressed, various codes were compared, modified, and combined to help move them into broader categories. Codes related to positive coping were identified during this initial line-by-line coding process and initial memo writing. Memo writing, in general, is a means of brainstorming and organizing concepts in a free-flowing and spontaneous manner (Charmaz, 2014). Early in this stage, it became apparent that all participants reflected on positivity in some way despite their stressful home lives. With this in mind, the second step took a more focused approach in which larger segments of data were synthesized and analyzed to develop more salient categories and to integrate theoretical ideas related to positivity codes identified in the first stage. The third analytical step included advancing the memos and refining conceptual categories. The first two authors met at this stage of the data analysis to interpret the emergent conceptual framework, during which time themes were compared within and across the interview transcripts. Three of the more prominent themes were selected for the present research project.

The fourth stage of the data analysis elaborated and refined the final three themes until they reached theoretical saturation. Theoretical saturation is the process in which data are elaborated and refined until no new properties emerge (Charmaz, 2014). This was imperative as we moved into the fifth stage of data analysis, which included sorting and integrating memos and diagraming concepts of the emerging theory. These analysis techniques allowed categories to reach a higher level of conceptualization, which improved the subsequent theory development. The data analysis was conducted using both pen and paper and MAXQDA (Version 12).

Results

Each participant was asked to reflect on how they coped with living with and caring for a violent child or sibling with SMI. In spite of negative consequences at both the individual and family level, participants exhibited perseverance, resilience, and hope. This article focuses on three strategies participants identified as helpful when coping with SMI and violence-related stressors: (a) gaining insight and knowledge, (b) joining peer support programs, and (c) identifying a silver lining.

Gaining Insight and Knowledge

Participants in this study described being caught off guard with the onset or diagnosis of mental illness. Despite warning signs of mental illness, they were unprepared for the management of their child's mental illness and violent outbursts. Many participants reported poor communication from treatment providers, including therapists and psychiatrists, regarding available resources and education. Participants felt confused, lost, vulnerable, and ignored. For example, Gail, whose son was diagnosed with schizoaffective disorder and oppositional disorder at 5 years old, described not knowing whom to call for help when her son was symptomatic:

> As time went on, he didn't just become psychotic, he became aggressively psychotic. We were terrified of him. We were calling the police constantly because there was no one else to call. There's no road map, there's no manual, for parents like us who were desperately trying to stay married and keep a job.

Gail's sense of not having the information or a guidebook on how to navigate the mental health system or her child's mental illness and violent behavior was present in each participant's narrative. They reported inadequate or unavailable resources that left them uncertain as how to best take care of their family member. Some participants took it on themselves to self-educate and to find meaningful support through reading books, doing research, and attending seminars. They would not only use these resources to support themselves and their child but also to help others in similar situations. In the following excerpt, Winona summarized her journey of self-help and self-education:

> Well for me, getting all the information that you can. I just educated myself. And I read, "Your Difficult Child." Eventually it went like, "Your Bi-Polar Child." I kept on reading, "Your Quirky Child." . . . I went to conferences. I just had to learn everything I could. . . . That was just how I managed to make connections and meet other people in the community . . . so I pretty much went to any parent group that was available to me. I found that to be a real support. . . . But definitely for me, educating myself, and just talking it through. It's like keep on getting another opinion.

Self-help groups make for an important reference point for evaluating the care provided by mental health providers. Participants can compare and contrast their own experiences with those of their peers and the stories told, for example, in online forums. Also, as Winona stated above, talking to peers and sharing information was like "getting another opinion."

Educating themselves about their family member's symptoms, triggers, and behaviors not only helped participants better establish a sense of understanding and preparedness for any type of behavioral episode they may experience but it also helped them become informed advocates. Many participants identified themselves as the primary advocate of their child or sibling and described how advocacy occurred in numerous locations, such as doctor offices, schools, protests, or online. In the next excerpt, Laura described how being informed better prepared her for advocacy:

> The way I coped was to research, to learn everything I could about mental illness, in order to take an active role in managing it, and just really [be] involved in and advocating for him in school. . . . Part of the way I coped was to try to really learn everything I could, and really . . . take an active role in helping him.

Gaining insight and knowledge had important benefits for participants coping with their family member's mental illness. It allowed them to better understand and anticipate symptoms and behaviors and it offered them a sense of utility in managing their family members' care.

Joining Peer Support Programs

While online forums, community support groups, and local, state, and national conferences provide information about mental illness and the mental health field, they also bring together individuals who share a common bond: caring for a loved one with SMI. Indeed, each forum provides participants with access to an otherwise unknown peer support system. For the participants in this study, a peer community provided them with the tools and encouragement needed to confront such adversity. Casey, whose son was diagnosed with schizoaffective disorder at 8 years old, suggested all parents of persons with SMI find "other parents because you will learn 100% more from those parents than you will ever learn from a teacher or a doctor." Similarly, Tina, whose son was diagnosed with obsessive compulsive disorder at 10 years old, encouraged other caregivers to "do everything you can to help your child" and to "seek support from others who have been in a similar situation" because they "are the only people that will understand."

Positive social support, whether online or in person, was a central element of caregiver perseverance for the participants. Social support platforms allowed participants to share their own experiences or to hear stories from their peers. Shannon, whose son was diagnosed with bipolar disorder in his early 20s, described how stories shared in her online support group helped reduce feelings of isolation:

> People write in all the time and they share their story. "This is my experience with bipolar disorder." It's just page after page of all these people writing in, which is really tangible . . . and then you know you're not alone. You can share your story and if you're involved in a community like that, just by knowing that you are not alone, I think it just lifts your spirits.

The benefits of "knowing you are not alone" was a common sentiment among participants who reported having a strong social network.

Many participants who participated in a support group identified their peers as sympathetic and understanding, primarily because they faced similar challenges. For example, Dina described her peer support group as her "only true friends because they were the only people who really get it, because everybody was dealing with really extreme behavior." Like Dina, Linda could "not express how much relief it gives a person to find out that they're not alone; that what they're going through is normal." On tough days when her son was symptomatic and aggressive, Linda vented to peers to relieve stress, saying, "It was the one place where I could actually go on there and say, 'I literally wanted to kill my child today' and have other people know; and get the kind of support that I needed at the time." Like Diane and Linda, participants described how support groups reduced their feelings of isolation and provided an opportunity for creating a community in which personal narratives could be shared. It was also important for these participants to be able to tell their stories among a group of people without fear of judgment or negative reprisal.

In addition to reducing feelings of isolation, support groups offered participants a way to better manage their emotions. Tammy's son is diagnosed with bipolar disorder, psychotic disorder, attention-deficit/hyperactivity disorder, and pervasive developmental disorder; he also has a history of substance abuse. Tammy reflected on a particularly difficult time in her life. She said, "I was worrying all the time, anxious all the time. I was a basket case, then I lost both my parents. I was coming undone." Tammy made the decision to attend a local peer support group for family members of persons with substance abuse and mental health issues. She described the positive effect the group had on her:

> It has really helped me. I realized I'm powerless over my son. It was amazing . . . I've made that shift that I'm not going to fix him and I can't enable him. I have to take care of me. It has really, really helped me a lot.

By utilizing peer support, whether online or in person, participants were able to build relationships and learn strategies to help them better cope with the stressors related to caring for their family members with mental illness.

Identifying a Silver Lining

All participants in this study described their lives as rife with turmoil and concern for the safety of themselves and their family members. They also described caregiving as comparable to a full-time job that, for some, consumed their daily lives. Despite what may be best described as the burden of sympathy (Karp, 2001), some participants recognized a silver lining.

Expressions and stories of positivity ranged from brief interactions with the child with mental illness to a broader worldview grounded in “not sweating the small stuff.” Some participants described daily positive interactions with the child with mental illness, while others struggled to put a positive spin on their lives, which they found to be acutely disrupted by mental illness and violence. Each participant was intent on *enjoying the moment* regardless of frequency. Libby, whose son was diagnosed with schizophrenia and adolescent-onset bipolar disorder at 8 years old, described her son as “really violent when he’s feeling psychotic.” Libby’s mornings were harbingers for the type of day to come. Depending on her son’s morning disposition, she could predict whether the day would include a trip to the beach or a trip to the emergency room. For example, she knew her day would be relatively easy if her son was calm and quietly took a shower; in contrast, she knew the day would be challenging when her son was “laughing hysterically . . . [or] talking to himself in the shower.” Libby provided the following narrative when asked to describe a typical, beach-going day:

> I’m usually up first. I like to get up early and have some quiet time. I hang out with my cat, and drink some tea, and write, and do whatever. Then I’ll hear some stirring on the other side of the house, it’s usually [my son]. Usually he’ll come in, and his eyes are all sleepy, and he’ll come in my room and he’ll smile at me, just to look at me. He wants to. He really has a thing about it. He wants to see me first thing in the morning. I’ll say, “Good morning,” and he’ll smile. Then he’ll go get a drink of water, and he might go back to bed.

This is a “good” day for Libby and her son, when they could do things together like grocery shop, visit the library, or walk on the beach. Libby viewed these “good” days with her son, as well as his morning ritual of saying hello and her seeing his “sleepy eyes,” as part of a silver lining in their life.

Other participants recounted infrequent good days. Carmen, for example, said, “I do appreciate the good days [but] they’re few and far between.” Her son is diagnosed with oppositional defiant disorder, depression, and attention-deficit/hyperactivity disorder. He also suffered a traumatic brain injury while in third grade. Carmen said most days were difficult, but she tried "to find the silver lining because when you have a child with any type of physical, mental, or health issues, it's so easy to focus on everything that's wrong." Her son had a history of hitting his siblings, and there were "several instances that involved [her] being pushed down stairs, being thrown on a table, or being pushed up against a wall." If she were to focus only on these moments, Carmen explained, she "would always be depressed, which doesn't do anyone any good." In the following quote, Carmen explained how her son's aggression and mental illness made other potential problems seem trivial:

> A good day, it gets marked on the calendar. Some people are out there worried about how are they going to save for a trip to Hawaii. It puts our priorities in perspective. We're not worried about the next family vacation. We don't worry about our cars, or our house. For us, a lot of it is, "Do we have enough money in the bank to pay for his therapy? Do we have money to pay for an emergency, in-patient hospitalization?" If we need that.

For Carmen, marking good days on the calendar and redefining priorities helped her identify a silver lining and reconstruct her family narrative.

Similar to Carmen, Gordon reflected on sporadic good days that "sprinkle throughout the year." Gordon was married with two children, aged 16 and 18 years. His oldest son exhibited behavioral problems and aggressive behavior before his second birthday, around the time Gordon's younger daughter was born. His son's first psychiatric hospitalization was at age 13 after assaulting his mother at a local café. Gordon spent time reflecting on his life before children and how the stress and unpredictability of his son's mental illness made him a "less easy-going, a more stressed-out person." Gordon looked to "golden moments" for his silver lining:

> I think I've learned a lot, you know? I've come to appreciate those moments that things are going well. . . . Those feel like those golden moments that sprinkle throughout the year like, "Ah yes, we are able to get along together." Like yesterday, like today so far. . . . We've been watching movies with the kids. We watched *Sharknado*. . . . It's ridiculous. Ah, but the kids loved it and they loved it the way it was meant to be loved. The two of them sitting there laughing their heads off recognizing how stupid it was. . . . We live for those moments. They're few and far between, though. I assume that people who always have those moments must not recognize how special they are.

Gordon's daughter, Carrie, was affectionate toward her older brother despite fearing potential escalation. She had memories of her brother, who was diagnosed with bipolar disorder and autism, yelling and throwing things at her.

She described being afraid of her brother after he threatened her and her family with a knife. Despite the aggression and fear, Carrie assumed the role of loving sister and protector of her brother, which is described in the following excerpt:

> He will come up to me and he'll tell me, "There's this girl I like." It was the cutest thing he did the other day. I had to figure out how I deal with this, him having a first crush. Like these little situations are just happiness, you obviously handle them differently than [if] he is slamming doors. He remembers little things, which is really nice because it seems like he's remembering stuff about me when he doesn't remember stuff about other people. I think we have a really special relationship and bond.

Carrie, Gordon, Carmen, and Libby have all witnessed aggression and victimization at the hands of a loved one with mental illness. They described dangerous interactions that, for some, resulted in bruises, broken bones, and trips to the hospital. However, they also saw golden moments and a silver lining that helped them stay positive in an otherwise stressful life. These moments are deeply personal and important for these participants to persevere as both caregiver and family member.

Discussion

This article identified three strategies family members employ to persevere despite their stressful lives: (a) gaining insight and knowledge, (b) joining peer support programs, and (c) identifying a silver lining. First, participants gained insight and knowledge about mental illness and the mental health system by reading self-help books, doing research, and attending seminars, trainings, and conferences. These family members often felt unprepared for the demands of caring for a person with SMI. Self-education helped them fill this void, which many participants attributed to a lack of information provided by mental health practitioners. Second, participants also relied on peer support as resources for guidance and encouragement. Joining with others for peer support, whether online or in person, reduced feelings of isolation and helped them manage their emotions by introducing participants to a community whose members faced comparable adversities. Third, challenged by acute and unpredictable aggression by their child or sibling with mental illness, participants identified a silver lining and told stories of positivity and resilience. It was through these silver linings that participants attributed, in part, their ability to persevere. Interesting to note is these *golden moments* are often *ordinary moments* for most families. In other words, watching a movie as a family or seeing your child smile in the morning are ordinary events for many families. For family members of aggressive persons with SMI, however, they attribute the meaning of these moments as being rare, making ordinary moments extraordinary.

Our findings complement the work of other scholars and help inform policy and practice. Regarding the first theme, family members of persons with mental illness often self-educate about mental illness and the mental health system by reading books, doing research, and attending seminars and conferences. This is an especially important finding as researchers continue to identify poor relationships with and a negative perception of mental health staff by family members of persons with mental illness (e.g., Clarke & Winsor, 2010; P. Solomon & Marcenko, 1992; Sporer, 2016; Sporer & Radatz, 2017). For example, Clarke and Winsor (2010) found unsupportive hospital staff and exclusion from the treatment team or discharge meetings to be particularly concerning for parents, especially because they felt unprepared to manage and care for their child with mental illness. Similarly, participants in a second study reported a lack of education at the time of discharge (e.g., information about mental illness), and felt unprepared for crisis intervention, medication management, or to cope with caregiving responsibilities (P. Solomon & Marcenko, 1992). However, seeking help, attending self-help groups, and acquiring knowledge can help caregivers reduce feelings of insecurity, loneliness, and shame and, instead, help them become more knowledgeable of available resources (Hill, 1994; Passa & Giovazolias, 2015; M. Solomon, Pistrang, & Barker, 2001). Parents, siblings, and other caregivers would benefit from trainings and formal support. Treatment providers, within their legal constraints, can provide family members with information about educational resources, including books, seminars, and conferences that are uniquely appropriate for each family member.

There is a growing demand for the inclusion of informal caregivers in treatment planning for persons with mental illness (Hsu & Tu, 2013; Onwumere et al., 2018; Sporer & Radatz, 2017). For example, Onwumere et al. (2018) suggested clinicians employ a caregiver-centered intervention (e.g., community treatment model) to help reduce the risk of patient violence and potential negative psychological and physical outcomes for caregivers. This approach allows for clinicians and family members to recognize which family settings violence is likely to occur and to understand the unique needs of informal caregivers. In general, the inclusion of informal caregivers in treatment planning can be an important step for increasing education about the realities of and treatment of SMI, which will better prepare the family members for care-related responsibilities.

Regarding the second theme, our participants identified peer support and meeting people who shared similar challenges related to violence and mental illness to be especially valuable. Past research has found individuals engaged in peer support to express less burden and stress than persons without peer support. For example, Cook, Heller, and Pickett-Schenk (1999) administered a survey and conducted telephone interviews with family caregivers of individuals with SMI to better understand the effect support groups had on caregiver burden. The researchers compared participants who attended National Alliance on Mental Illness (NAMI)-affiliated support groups with participants who did not attend support groups. They found family members who participated in NAMI-affiliated support groups expressed significantly lower levels of caregiver burden compared with family members not participating in any type of support groups. Although unnecessary or unwanted by some family members, easy access to peer support locally or online might offer needed social and emotional support. Again, this provides an opportunity for treatment providers and mental health practitioners to direct family members to appropriate and available peer support groups available in the local community or online.

Consistent with our third theme, identifying a silver lining, researchers have found some family members of persons with mental illness report a greater sense of purpose, greater empathy and compassion, resiliency and assertiveness, and a sense of closeness with their families (e.g., Aschbrenner et al., 2010; Johnson, 2000). Maintaining a positive outlook and using positive attributions during stressful periods, for example, are associated with posttraumatic growth, life meaningfulness, improved well-being, and improved quality of life (Park, Edmondson, Fenster, & Blank, 2008; Roesch et al., 2005; Tedeschi & Calhoun, 2004). Furthermore, positive coping among family caregivers is associated with improved emotional well-being (Bayat, 2007; Carver, Scheier, & Weintraub, 1989; Stanton et al., 2000).

While it is probably ineffective, or perhaps insensitive, for practitioners to bluntly suggest family members find a silver lining, these interviews show that family members can be led indirectly to a more positive outlook by attending support groups and engaging with peer support. Certain interventions and community-support programs can be useful in helping foster positivity among family members and caregivers. For example, Toohey et al. (2016) conducted a randomized controlled study to understand the influence of Family-to-Family on caregivers' appraisal of their caregiving experience(s). Family-to-Family is a free 12-week community-based program run by peers and sponsored by NAMI that aims to increase informal caregivers' well-being and capacity for coping, and to better understand their family members' mental illness, including the experience and treatment of mental illness. The researchers found participation in the program increased caregiver endorsement of positive caregiving appraisals compared with the control group. Overall, the researchers found education had an important and positive affect on caregiver well-being that had a spillover effect on their interactions with their loved one with mental illness. If neglecting informal caregivers has a negative effect on both the caregivers and their loved ones, Champlin (2009) argued we can then assume that providing care, attention, and education to these caregivers will in all likelihood enhance the relationships between caregiver and patient and treatment provider.

Limitations and Future Research

Qualitative studies, which are primarily geared toward small sample sizes, are not without limitations. The findings generated from our sample size can neither determine causal inferences nor be generalized to a larger population (see Mahoney, 2000). Our aim in this study is not to generalize from the findings but rather to identify strategies family members utilize to persevere and survive an otherwise stressful life. Given the complexities of mental illness and violence, and their combined effects on the family, our study gave us the opportunity to examine very rich interview data that might otherwise not be possible with alternative methodologies (e.g., household surveys; Snijders, 1992). Relatedly, our purposive and snowball sampling strategies led to mostly Caucasian participants who identified as middle or upper-middle class. Different populations with varying demographic characteristics might have different perceptions of and experiences with mental illness and the mental health system. Furthermore, individuals from different economic, racial, and ethnic backgrounds might likely have different perspectives on “golden moments.” Future research will benefit from the inclusion of different populations to better understand such differences in experience and perception. We also did not scrutinize differences in our data by the age of participant or by the age of the child/sibling with SMI. A family member’s understanding of mental illness and, in this case, aggressive behavior, is most likely dependent on age and the passage of time (i.e., time since the onset of mental illness). Future research will benefit from the inclusion of maturity and cognitive functioning among participants and their family members with SMI, as well as an understanding of how family members cope over time. As such, we cannot be certain our findings and policy recommendations are appropriate for all family members of persons with SMI. In summation, future research would benefit from a larger sample that includes of a variety of persons with different backgrounds, social experiences, and financial means, and an examination of differences across age and time.

Conclusion

This research explored how family members of violent persons with SMI persevere despite an otherwise stressful life. We focused on three primary strategies family members attribute to their ability to persevere: (a) gaining insight and knowledge, (b) joining peer support programs, and (c) identifying a silver lining. In brief, these findings highlight the importance of positivity, education, and community for family members of violent persons with SMI. Giving attention to these strategies may prove beneficial for other family members and caregivers confronted by mental illness, violence, and the complex mental health system. We recommend mental health practitioners help identify, locate, and engage with these strategies to minimize family members' sense of isolation and confusion, and improve family members' knowledge about mental illness.

Authors' Note

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Note

1. Psychiatric diagnoses were disclosed by participants and not from official records. SMI was conceptualized as any *Diagnostic and Statistical Manual–Fourth edition* (*DSM-IV*; American Psychiatric Association, 2000) diagnosis or other traits consistent with a diagnosable serious or SMI (as reported by the participant). This research used the most recent legal definition of SMI, which generally includes adults aged 18 or older who are diagnosed with affective disorders, anxiety disorders, bipolar disorders, disruptive anxiety disorders, major

depressive disorders, and psychotic disorders. These disorders vary in degree of impairment and duration, but substantially interfere with or limit one or more major life activities. The current legal definition is more flexible than earlier definitions in that it includes room for state-by-state variation, an inclusion of childhood diagnoses, and exclusion of necessary functional impairment (Center for Behavioral Health Statistics and Quality, 2016).

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