ORIGINAL ARTICLE



Mothers of Violent Children with Mental Illness: How They Perceive Barriers to Effective Help

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Abstract The goal of the present study was to understand how mothers perceive and experience barriers to effective help for their violent child with mental illness. Data from ethnographic interviews with 26 self-identified mothers of violent children with mental illness were analyzed using grounded theory and focused coding. Our study identified three themes that represent barriers to help: (1) denial of mental illness and severity of violence by treatment providers, extended family, and non-family members; (2) limited access to quality treatment and supports; and (3) a recurring cycle from optimism to hopelessness. To inform policy makers and practitioners on how best to remove these barriers, we draw comparisons between the current sample and survivors of intimate partner violence. Our paper concludes with recommendations for mental health practitioners and family intervention specialists.

Keywords Child-to-parent abuse \cdot Mental illness \cdot Barriers to help \cdot Domestic violence \cdot Intimate partner violence

Since deinstitutionalization in the mid-twentieth century, parents have assumed a primary role in the caretaking of adolescent and adult children with mental illness. Recent estimates suggest that up to 65% of persons with mental illness live at home with family caregivers (Murray-Swank

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et al. 2007). There is considerable knowledge of the burden and stress related to caring for and living with a family member with mental illness (e.g., Hinojosa et al. 2015; Karp 2001; Sporer 2016). Of most significance to the current research, however, is the prevalence of and experience of violence committed by persons with mental illness toward family members. It is important to note that most persons with mental illness are not violent and will not exhibit violent behavior in their lifetime (Slate et al. 2013). Indeed, estimates of the lifetime prevalence of violent behavior among persons with mental illness range between 1% (McCampbell 2001) and 7% (Swanson et al. 1990).

Despite these low percentages, those who do become violent are more likely to direct that violence towards family members—particularly mothers—than towards strangers (Nordström and Kullgren 2003). Earlier research on this type of violence identified caregiving-related behaviors to be risk factors for increased aggression by persons with mental illness, like persuasive or coercive limit setting (Straznickas et al. 1993), over-involvement by family members (Bebbington and Kuipers 1994), and dependence on a family caregiver (Solomon et al. 2005). More recently, researchers have noted high rates of violent behavior towards family members by persons with mental illness. In one study, Philips et al. (2016) examined violent behavior among 135 children (ages 5-12) hospitalized in a psychiatric ward. These children had a history of directing harm towards their mothers, peers, and teachers; 76% of the children were perpetrators of sibling violence. In a second study, which drew from a national survey of 573 adults with an adult relative with psychiatric disorders, Labrum and Solomon (2015) found that almost half of the respondents (47%) reported being the victim of their relative's violent outbursts, and 22% of these family members were victimized in the past 6 months. These findings are



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consistent with earlier studies by Vaddadi and colleagues. In one study, Vaddadi et al. (1997) examined prevalence rates of abuse of relatives by patients in a psychiatric facility. They found 32% of the sample had been struck on at least one or two occasions. Fifty percent of the sample reported verbal abuse, threats, and temper outbursts. In a follow-up study of parents of 101 children with mental illness, Vaddadi et al. (2002) found in the past year 40% felt threatened by violence at some point, 40% were hit or struck at some point, and 17% had sustained a substantial injury.

Moving beyond prevalence studies, qualitative studies have helped us to better contextualize the lived experiences of family caregivers of violent children with mental illness (Holt 2013). Band-Winterstein et al. (2016) interviewed 16 parents of abusive adult children with mental illness to explore the perceptions they hold of their children's violent behavior, as well as understand how the parents' perceptions impacted their own emotional domains. The study findings revealed that many of the parents provided ongoing care to their child despite extensive violence and victimization, as it was their duty as a parent to do so. The results indicated that parents described a wide range of feelings towards their child, from love, commitment, and perseverance, to helplessness, misery, and lack of love. In a second study, Sporer (2016) interviewed 42 parents and siblings of a violent child with mental illness. The participants described their lives as being consumed by the stress of living with and caring for a child with mental illness, and that such stress was compounded by unpredictable yet frequent acute violence and victimization. The researcher suggests that families with a violent child with mental illness cannot live through episodes of violence without temporarily or permanently removing the child with mental illness from the home or suffering considerable damage to the family.

Our paper continues this line of qualitative research to better understand the families of violent children with mental illness. We rely on ethnographic interviews with 26 mothers of violent children with mental illness to understand the experience of mothers who seek help for their child. We focus particularly on the barriers that make it difficult to find effective help. With an end goal of informing policy makers and practitioners on how best to remove these barriers, we draw comparisons between our current sample and survivors of intimate partner violence. In the following section, we summarize the extant literature on child-to-parent abuse and intimate partner violence. We focus the latter half on barriers to effective help identified by survivors of intimate partner violence. We then use our understanding of these barriers to frame our findings regarding barriers to help encountered by mothers of violent children with mental illness.



Literature Review

Child-to-Parent Abuse

Researchers have discovered alarmingly high prevalence rates of child-to-parent abuse. Earlier estimates based on self-report data from young people range between 6.5 and 10.8% of respondents having hit one parent at least one time in the last 1 to 3 years (Agnew and Huguley 1989; Brezina 1999), with mothers being five times more likely than fathers to be victims (Gallagher 2008). Of these cases, 7.6% of the assault incidents caused physical injury (Agnew and Huguley 1989). In a national survey of 2,143 families, Ullman and Straus (2003) found 20.2% of mothers and 14% of fathers reported being hit by their child in the previous 12 months. Similarly, Pagani et al. (2009) analyzed self-report data from both young people and their parents. They found prevalence rates of aggression against mothers and fathers to be 13.8 and 11% respectively. When the definition of child-to-parent abuse is expanded to include verbal and psychological violence in the past year, prevalence rates jump to 34 and 64% (Pagani et al. 2009).

Researchers have identified numerous characteristics of perpetrators of child-to-parent abuse. Studies most often recognize males as more likely than females to perpetrate child-to-parent abuse (Walsh and Krienert 2007); however, other studies conclude males and females perpetrate similar amounts of abuse but in different forms. Girls are more likely to use psychological or verbal abuse, while males are more likely to engage in physical violence (Calvete et al. 2013). In comparison to other types of juvenile offenders, perpetrators of child-to-parent abuse tend to have more learning difficulties (Ibabe and Jaureguizar 2010), a history of substance abuse (Kethineni 2004), mental health problems (Rout and Anderson 2011), previous hospitalization for psychiatric reasons (Ibabe and Jaureguizar 2010), and previous suicide attempts (Kennedy et al. 2010). Non-intrapersonal characteristics for increased risk of child-to-parent abuse include a history of victimization by a family member (Kennedy et al. 2010), witnessed parental violence at home (Ullman and Straus 2003), single-parent households (Cottrell and Monk 2004), problematic parenting practices (Jablonski 2007), and peer groups that include aggressive friends (Deptula and Cohen 2004).

The impact of parent abuse can be extensive. Researchers have found that abuse by children on parents can exacerbate existing health problems or create new ones for the parent victims, including depression, clinical distress, anxiety, and drug or alcohol abuse (Cottrell 2001; Howard and Rottem 2008; Parentline Plus 2010; Paterson et al. 2002). Abused parents also report shame, social isolation, fear of stigma, and feelings of helplessness (Gelles 1997; Kennair and Mellor 2007; Routt and Anderson 2011). Not only do some

parents blame themselves for their child's violence (Kennair and Mellor 2007), their family relationships undergo stress and conflict, including disagreement on how to manage the violent child (Cottrell 2001) or issues related to attention being focused on the violent child rather than other family members (Kennair and Mellor 2007).

The emotional impact of this type of violence directly impedes a parent's likelihood to disclose victimization or to seek help. Parents are typically fearful of their child's aggression and are fearful the child will become even more violent when the parent does seek help (Cottrell and Monk 2004; Paterson et al. 2002). Relatedly, parents delay disclosure out of fear their child may become entangled with the criminal justice system (Cottrell and Monk 2004; Edenborough et al. 2008) or they might lose their relationship with the child (Paterson et al. 2002). Last, fear of shame and blame imposed by the community contribute to parents' delayed disclosure of victimization (Howard and Rottem 2008).

Nevertheless, parents who do seek formal or informal support encounter barriers to effective help. Parents who disclose victimization tend to confide in other family members or close friends, while few others confide in welfare professionals (Stewart et al. 2006). Some parents who disclose to nonprofessionals, like friends, family, or neighbors, are later blamed for the abuse (Howard and Rottem 2008). In one study, Sheehan (1997) found mothers were unlikely to openly disclose victimization at group therapeutic meetings out of fear their child would later retaliate. In fact, this is a valid fear. Pagani et al. (2003) found mothers to be at an increased risk of further victimization by their aggressive child after the mothers disclosed abusive behaviors.

Research on child-to-parent abuse, while limited in comparison to other types of family violence, continues to grow. And there is little doubt that more research is warranted given the general prevalence of such abuse. To further facilitate such research and identify effective social policies, Wilcox (2012) argued for researchers to integrate parent abuse into the broader field of domestic violence. As a step toward this integration, we next turn to the intimate partner violence literature, particularly how survivors of intimate partner violence (IPV) perceive and experience violence and the barriers to effective help. We later use the experiences of IPV survivors to frame our understanding of mothers of violent children with mental illness.

Intimate Partner Violence & Barriers to Effective Help

IPV is commonplace in many homes within the United States and takes many forms, including physical, sexual, and psychological violence (Catalano 2013). Findings from a 2010 national-level survey revealed roughly one in three women had experienced IPV (i.e., rape, stalking, and/or

physical assault) in her life-course (Black et al. 2011). Given the extent of IPV, many victimized women seek help to reduce or end the violence they experience, either by leaving their abusive relationship or by searching for ways to assist their partner in changing his violent behavior. However, in their pursuit of seeking help, IPV victims can encounter several challenges and barriers (Beaulaurier et al. 2007; Fugate et al. 2005).

Negative Reactions by Formal and Informal Support Systems

Women who seek help in addressing IPV face the decision of whether to disclose their victimization to others. Victims may choose to reveal their IPV experiences to family and friends, or to individuals within institutions where they seek services, such as religious organizations, healthcare clinics, or the criminal justice system (Fugate et al. 2005; Sylaska and Edwards 2014).

Victims encounter a range of reactions from individuals to whom they have disclosed, and such reactions can influence the victims' subsequent help-seeking behaviors. In their review of literature regarding victim disclosures to informal social supports (e.g., friends, family), Sylaska and Edwards (2014) reported that social reactions to disclosure vary between positive/helpful and negative/unhelpful. Negative and unhelpful reactions from informal social supports can include a host of unfavorable statements, actions, and advice, such as blaming the victim for the abuse, diminishing and minimizing the violence, not taking the victim seriously, ignoring and/or avoiding the victim, encouraging the victim to forgive and forget the abuser's actions, and expressing frustration towards the victim (McGee 2005; Sylaska and Edwards 2014).

IPV victims can also experience adverse reactions from institutions designed to assist them. For instance, in a study focused on older women victimized by their intimate partners, Beaulaurier et al. (2007) noted several barriers related to family, clergy members, the criminal justice system, and community resources and services. Additionally, in a study designed to examine help-seeking experiences of female IPV victims in the United Kingdom, Bacchus et al. (2003) found that some women have negative experiences (e.g., inadequate support, lack of knowledge) when disclosing their victimization to healthcare professionals.

Limited Access to Victim Services

A variety of barriers reduce the effectiveness or availability of domestic violence services: shortage of funding, paucity of staff members, lack of shelter and transitional housing availability, inadequate transportation for rural locations, limited legal services, language barriers, insufficient



availability of substance abuse and mental health counseling, little to no childcare services, and need for basic necessities (NNEDV 2007). Findings from the 2007 National Census of Domestic Violence Services revealed that roughly 7,700 requests by victims did not result in services being provided (NNEDV 2007). Similarly, the 2006 and 2007 censuses indicated that most unmet requests were related to inadequate availability of housing (Iyengar and Sabik 2009; NNEDV 2007). In a review of federal- and local-level housing policies and practices, Baker et al. (2010) explained how the unavailability of housing for IPV victims could also be related to other housing challenges, such as shelter-specific policies, which further inhibit IPV victims from receiving assistance in addressing their violent victimizations.

Financial Restraints

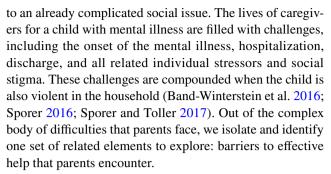
Several scholars have noted the importance of financial independence and an IPV victim's ability to leave her violent relationship (Fugate et al. 2005; Kim and Gray 2008). For example, Fugate et al. (2005) reported that 20% of the women who had reported not contacting an agency or counselor for help did so because of lack of money, insurance, or time. In essence, the cost associated with seeking help through the legal or healthcare systems can be taxing, especially when an IPV victim has low socioeconomic status, financial dependency on her abuser, or if she has inadequate health insurance.

Misguided Hope and Optimism

In some instances, domestically violent men are sanctioned or volunteer to attend batterer intervention programs (BIPs). Though the effectiveness of treatment has varied across studies, results from most BIP evaluations and meta-analytic reviews have generally revealed minimal effectiveness at reducing IPV recidivism (Eckhardt et al. 2013). As noted by McGee (2005), female IPV victims may place hope in the BIPs success at reducing their partner's violence without knowing BIPs general ineffectiveness. For instance, Gondolf (1998) reported that roughly 60% of the women felt very safe at the start of her partner's program intake, yet only 44% believed their partner would not hit them in the near future.

Current Study

There is a gap in the literature when it comes to abuse of parents by children with mental illness (Straus et al. 2006). Scholarship on child-to-parent abuse tends to identify mental illness as either a risk factor for violent behavior or as an outcome of victimization (Holt 2013; Hong et al. 2012). While this literature is significant, we believe it does not address the complexity that a child with mental illness adds



The primary goal of the present study is to understand how mothers perceive and experience barriers to effective help for their violent child with mental illness. The specific research question is: What barriers do mothers of violent children with mental illness identify as impediments to their ability to help their violent children with mental illness? The three kinds of barriers encountered by survivors of IPV outlined in the literature review helped us to arrive at our findings and to put into focus the similar barriers encountered by mothers of violent children with mental illness.

Methodology

Participants & Recruitment

Data used in this study were drawn from the first author's larger research project on individual- and family-level coping strategies among parents and siblings of violent children with mental illness. The participants in the current study are a sub-sample of that larger project and include 26 selfidentified mothers of a violent child with mental illness (see Table 1). The subjects' children included both young and adult children; their ages ranged from 8 to 44 at the time of the interview. Psychiatric diagnoses and disorders were identified by the participants, not from official medical records. The diagnoses fell under a variety categories outlined in the DSM-IV (American Psychiatric Association 2000), like mood, anxiety, schizophrenia or psychotic, and personality. Regarding violence, the participants reported persistent aggression and violence by their child, from physical and verbal abuse, such as punching, throwing knives, swearing and yelling, or being thrown down stairs; to destruction of inanimate objects, such as breaking mirrors, furniture, or windows. The participants lived in 16 different states across the United States and represented varying degrees of education, socioeconomic status, and employment. Pseudonyms were used to ensure participant anonymity.

Because family members of those with mental illness are generally fearful of stigma and hesitant to disclose their situation (Karp 2001), this study employed a nonprobabilistic sampling strategy as the primary source of recruitment (Berg 2009). Participants were recruited through both public and



Table 1 Participant demographics

Name	Age	Race	Marital status ^a	Education	Employment	SES ^b	Participants' child with mental illness	
							Gender	Age at first diagnosis; Diagnoses
Alicia	36	White	S	Masters	Social worker	M	Male ^e	15; BPD, ADHD
Carmen	34	White	M	Some college	Stay-at-home mom	UM	Male	8; ODD, Depression, BPD, ADHD, Traumatic Brain Injury
Casey	47	White	M	Masters	Vice President of retail chain	UM	Malee	8; Schizoaffective
Catelyn	55	White	D	College	Business owner	UM	Male	17; BPD, Depression, OCD
Dina	54	White	D	Masters	Substitute teacher	M	Male ^e	16; Depression, Anxiety, Schiz- ophrenia, PTSD, Agoraphobia, Reactive Attachment
Grace	57	White	M	Associates	Disabled/Unemployed	UM	Male	5; Schizoaffective, ODD
Jamie	38	White	M	Masters	Stay-at-home mom	UM	Female ^e	8; Conduct, Pre-psychopathic & callous emotional traits
Jane	65	White	M	College	Retired	UM	Male	20; Schizophrenia
Jessica	34	White	D^c	Some college	Stay-at-home mom	L	Male	9; Psychosis, ADHD
Julia	42	White	M	Unknown	Office work (part-time)	M	Male	14; Bipolar, Personality, ADHD
Kelley	31	White	D^c	Associates	Nurse practitioner	L	Female	10; Bipolar, PTSD, ADHD, ODD, IED
Korina	37	White	S^d	Masters	Accounting clerk	LM	Male	7; Bipolar, ASD
Laura	34	White	D^{c}	Doctoral candidate	Nurse	M	Male	9; Bipolar, IED, ADHD, ODD
Libby	63	White	M	Some college	Photographer/Artist	L	Male	8; Bipolar, Schizophrenia, ADHD
Lily	58	White	M	College	Disabled/Unemployed	M	$Female^e$	16; Bipolar, Depression
Linda	49	White	D	Some college	Executive assistant	LM	Male	7; Bipolar
Maggie	48	White	M	Some college	Stay-at-home mom	M	Male	12; Bipolar, ASD
Mary	34	White	M	Masters	Behavioral health manager	M	Male	7; ADHD, ODD
Sarah	70	White	M	College	Retired	UM	Male	20; Schizophrenia
Shannon	46	White	D^{c}	College	Business owner	UM	Male	24; Bipolar
Sue	51	White	M	Vocational	At-home daycare owner	UM	$Female^e$	13; Bipolar
Tammy	51	White	M	College	Unemployed	M	Male	5; Pervasive Developmental, ADHD, Bipolar, Psychotic
Tina	55	White	M	College	Paraprofessional	M	Male	10; OCD
Tori	40	White	M	JD	Stay-at-home mom	UM	Male	5; ADHD, Bipolar, Anxiety
Winona	48	White	M	College	Data coordinator	UM	Male	12; Schizophrenia, ASD
Yvette	54	Hispanic	D	Some masters	Medical transcriber	L	Male	12; Bipolar, Depression, ODD, Impulse control

Diagnoses and disorders were reported by participants

ADHD Attention deficit, ASD Autism spectrum, BPD Bipolar, OCDObsessive compulsive, ODD Oppositional defiant, PTSD Posttraumatic stress, IED Intermittent explosive

online forums. The first author attended numerous community-based meetings and other venues for families of persons with mental illness and handed out recruitment flyers in both a Northeast state and a Midwest state. Concurrently, study information was posted in various online forums (e.g.,

Facebook) to expand recruitment across the country. Participants themselves became recruiters in that they were asked after their interview to refer other family members or acquaintances that might be interested in participating in the study. These sampling strategies gave family caregivers



^aM = Married, D = Divorced, S = Single

 $^{^{}b}$ SES = Socioeconomic Status, MU = Upper Middle, M = Middle, LM = Lower Middle; L = Lower Middle, LM =

^cRemarried

^dEngaged

^eAdopted

and potential participants both anonymity and the freedom to decline participation. Further, the resulting snowball sampling strategy and use of multiple recruiters assured potential participants of the project's legitimacy (Berg 2009).

Interviews & Data Collection

Stigma, social isolation, and parental denial are primary challenges for researchers to overcome when investigating parent abuse (Holt 2013). These challenges are further exacerbated by the presence of mental illness (Karp 2001). Given that the family is universally accepted as a private institution, one that is prone to conceal and/or deny violence, victimization, and mental illness, it is understandable why such families choose to keep their stories untold. To combat this challenge, Holt (2013) suggests researchers provide a space that will promote open dialogue so that individuals are more likely to discuss their experiences. The ethnographic interview provides such a space.

Ethnographic interviewing is a holistic methodology that produces rich accounts and close approximations of the family experience by accommodating multiple perspectives (Tracy 2013). It allows the researcher to enter the private sphere and observe firsthand how individuals interpret, understand, and experience family interactions (Spradley 1979). Ethnographic interviewing also promotes rapport, an important variable for fostering open dialogue with an otherwise difficult-to-reach population. Traditional ethnographic research methodologies allow rapport to develop naturally over time (DiCicco-Bloom and Crabtree 2006; Spradley 1979); however, for the current project, it was critical that the interviewer establish rapport rather quickly because she had only a few hours with each participant. Thus, the interviewer relied on a participatory approach (Lyons and Chipperfield 2000) that minimized apprehension at the start of the interviews. Specifically, the interviewer offered selfdisclosures about her time working in the mental health field and the experiences she had that led to the current research.

Questions included three categories that generated a complete family narrative, including opening and contextual questions (e.g., "I don't have a child who is mentally ill and 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 child with mental illness 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.

Each participant selected the time and place of the interview. Most often participants preferred to meet in their own homes or at coffee shops and restaurants, while others requested telephone interviews. Telephone interviews

present potential methodological barriers related to rapport building and the inability to see nonverbal cues (Berg 2009). However, telephone interviews can also improve content by adding immediate anonymity (Berg 2009). Indeed, increased anonymity has been shown to relax interviewees, making them more likely to disclose sensitive information (Novick 2008). Comparably, in the current study, the in-person and telephone-based interviews had no substantial differences regarding rapport, disclosure, or overall quality of the interview process and content. The interviews differed in length, ranging from 41 to 130 min; most interviews averaged 90 min. Most participants were interviewed individually, except two mothers who were interviewed with their husbands and a second mother who was interviewed with her husband and daughter. No interview was conducted in which the child with mental illness was present.

Data Analysis

Data were analyzed with a modified version of grounded theory. Grounded theory is a flexible, non-linear 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 and 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 extent literature before, during, and after analysis.

At the start of the larger project, the first author began initial coding by reading entire interview transcripts to obtain analytic ideas to pursue as part of additional data collection and to generate memos that would move the codes into broader categories. During this brainstorming phase, we discussed the larger research project and preliminary findings. While we covered many talking points, the second author noted similarities between the parents in the larger project with survivors of intimate partner violence. For example, both populations rationalized how and why they delayed disclosure of the violence. The second author described the broader IPV literature, particularly the literature on female survivors, their help-seeking behaviors, and barriers to effective help. The authors soon recognized how the mothers' narratives in the larger study included stories similar to those described in the IPV literature. The authors concluded that such commonalities across victim/survivor populations warranted an empirical analysis.

After collaboration and brainstorming between the two authors, the data analysis took a more focused approach. Specifically, the first author returned to the data to develop



more salient categories and integrate theoretical ideas related to the IPV literature. Emerging themes were advanced, compared, and further explored with memo writing. Next, the authors met again to determine if the emerging themes remained consistent with the IPV literature. This was an important stage in terms of reliability. Reliability in qualitative research can be attained by scrutinizing themes and features in the data multiple times, and by constant shifting between the data, literature, and memo writing (Silverman 2009). We compared our data—including data in the original transcripts, excerpts, and memos—between and within participants, allowing us to compare and contrast the narratives and to confirm the consistency of each participant's story within each interview. We also returned to the extent literature to determine how our emerging themes compared to those made by other scholars. After identifying what we believed to be the primary themes, we purposefully selected data (theoretical sampling) to refine the categories and to reach a higher level of conceptualization (Charmaz 2014). The data analysis was conducted using both pen and paper and MaxQDA, professional software for qualitative data analysis.

Qualitative studies, which are primarily geared toward small-N samples, have inherent limitations and generally should not be generalized to a larger population (see Mahoney 2000). Romney et al. (1986), however, argue that smaller samples could render reliable information provided the participants are culturally competent. In fact, Romney et al. (1986) claim that a reliable cultural description can be illustrated with as few as four participants if the participants share in-depth knowledge of and experiences with the phenomenon of interest. Indeed, the participants represented in the current paper share the common experience of being a mother of a violent child with mental illness. Their knowledge, experience, and perception make up the social reality of living with a violent family member with mental illness. Furthermore, our small sample size offered us the opportunity to scrutinize and analyze very rich interview data that might not otherwise be possible with alternative methodologies. In short, the rich accounts provided by each participant were scrutinized and analyzed in such a way that our findings can be used to not only shed light on an otherwise hidden problem, but also be used to inform program and policymakers and treatment providers.

Results

This paper focuses on three main themes that represent the barriers to help experienced by mothers of violent children with mental illness: (1) denial of mental illness and severity of violence by treatment providers, extended family, and non-family members; (2) limited access to quality treatment

and supports; and (3) a recurring cycle from optimism to hopelessness.

Denial by Treatment Providers, Extended Family, & Non-family Members

Participants described experiencing negative reactions from formal and informal sources of support. Treatment providers, extended family, and teachers denied problems or suggested things would get better for the mothers. According to their narratives, participants did not believe they were "blamed" for the child's mental illness. Rather, they described how others denied the reality of or the extent of the problem—both the aggressive behaviors and the mental illness—in such a way that they second guessed themselves, isolated themselves, or further delayed psychiatric help. For example, Sarah knew her son's behavior was not just teenage rebellion. She described numerous events she believed warranted professional or psychiatric intervention before her son was in high school. Sarah explained how she and her husband considered such intervention but continued to delay after her son's high school guidance counselor and teacher downplayed her concerns.

I used to call his guidance counselor his senior year in tears...His guidance counselor would always say to me, "Oh Jack will be all right." One teacher that I talked to, "He'll be all right, he's just so bright..." In high school they were telling me, "He'll be all right." In my heart I knew they were wrong, but they were telling me that so it sounded good to me. That summer after his senior year was when all hell broke loose. (10/14/13)

Some mothers also indicated that friends and extended family members would attribute disruptive behavior and aggression to poor parenting. Linda explained how friends and extended family blamed her son's behavior on her parenting and a general lack of discipline: "I felt like I was dealing with nothing but skeptics" (5/4/14). Her family and friends often told her, "Maybe you are not disciplining him appropriately" or "Maybe you're not spanking him enough." It took witnessing the aggression and his first psychiatric hospitalization for others to acknowledge her son's behavioral problems were manifestations of mental illness. She reflected on the events that led to her son's first hospitalization and how that led to sympathy and acceptance.

I don't remember exactly what triggered it, but he became violent...Somehow I was able to push him out on the patio and lock the doors. He really had no place to go. My daughter and I were protected...He decided to rip off the fence line and start beating at the door, yelling that he wanted to kill me. (5/4/14)



Linda managed to call the police who restrained Jacob and transported him to the hospital. While being evaluated in the emergency room, Jacob "proceeded to very calmly walk over to the blinds in the room and wrap the cord around his neck. That got him hospitalized." He was 7 years old at the time. Linda explained how after this event, her family "suddenly went, 'You weren't kidding. There's really something wrong with him.' I got more sympathy, and nobody really accused me of bad parenting anymore" (5/4/14).

Mothers also described a certain "mother's intuition" that something was remiss; despite their pleas for help, various professionals—including pediatricians—denied there was an authentic problem or suggested the abnormal behavior was "typical" childhood behavior. For example, some parents were told their child would grow out of it, characterizing the behavior as "typical boy or girl stuff," while other participants were told they were ineffective parents. There was denial by non-family members despite the mothers' reports of concerns or their disclosure of abnormal to violent episodes. In the following narrative, Laura explains how her 14-year-old son's tantrums were different from those of a typical young child, which dated back to kindergarten.

Like so many families we didn't know for many years what he had ... They're little and they have tantrums but it's not just tantrums. You talk to your pediatrician and she says, "Oh, he's just a boy. He'll outgrow it." You say, "No really." They don't outgrow it and then you start interfacing the school. My son, when he was 5 years old in kindergarten, they already had a clear-the-room plan in place for his kindergarten class. (6/6/14)

Like Laura, Tammy was confident that her son was atypical as young as one or 2 years old even though he reached important developmental milestones.

Tammy: I sensed there was something off when he was young, 1, 2, because I started dragging him to different doctors. I went into the children's hospital. I'll never forget this woman I met with this doctor. She said, "Oh it's because he's a boy. That's why he's aggressive and that's why he doesn't talk." Everyone thought I was crazy...I know you're not supposed to compare your kids but I guess it was mom's intuition. I felt like there was just something amiss. I could not put in words because then they would go through the whole developmental thing with me. Yes, he crawled in time. Yes he did this on time. Yes, yes, yes. Obviously it wasn't matching up to their standards, but I just knew there was something wrong. I knew they were not buying it. (10/17/13)

To combat denial by non-family members, participants would document their child's aggressive behavior, whether

through journaling and note taking or taking pictures and videos. Sometimes their documentation would be the only evidence of the child's mental illness or extreme behavioral issues. Grace, for example, explained how she tape-recorded her son's unpredictable behavior to ensure that treatment providers would believe her. She explained how her son, who is now in his twenties, presented with concerning symptoms "literally from birth." She called his behaviors "meltdowns" that seemed like "an out-of-body experience."

Limited Access to Quality Treatment and Supports

Many of the mothers who were victimized by their child reported difficulty in obtaining support from treatment and social services. Mothers were asked, "If you could pick one program or service that would help you and your family, what would it be?" In response, they typically paused, sighed, rubbed their temples, shook their heads, threw their hands in the air, or cursed; some cried in despair. Many participants reflected on a tiresome effort to gain access to services, find a hospital bed, advocate for better providers, and pay for treatment. Their answers were diverse. Some talked about possible programs that, if available, would help their child with mental illness; other participants focused on programs that might help themselves and their entire family. Participants also reflected on broader social issues related to stigma, a poorly informed public, the lack of informal support, or negative media attention. The struggle families experienced across the life course, however, was consistent across each narrative: Their struggles persisted despite professional intervention.

Each participant perceived the mental health system as disorganized and ill equipped to help those for whom it was created. One mother, Mary, explained how she could not pick one thing that could help her and her son.

It's hard to say that there's one thing since [the mental health system is] so completely discombobulated and broken. There is so much that you need. I want the people to pay attention, "oh look there is a problem" and it's not a "bad kid" or "bad parent" situation. I don't know if there is a service...that is actually what he needs right now. (12/11/14)

Mary's quote summarizes many of the concerns noted by the mothers: the systemic problems are vast and hard to pinpoint; the mental health system in general is disorganized; parents are blamed for issues associated with mental illness; and programs that could help do not actually exist.

Libby explained how her son needed access to services beyond his psychiatrist. She believed her son would have benefitted from different types of services, including therapy and vocational training. She questioned how and why those services were not available in one program or under one



roof. In the following narrative, Libby reflected on what she thought people with mental illness need and also the difficulty she and her son faced when looking for nurturing and qualified service providers.

They need to get jobs. They need training...They have to have access to people that are going to be kind and nurturing...Even when we go to some of the doctors' here, people are so rude to us. Maybe it's because they're underpaid and they're for non-profit. I don't know why. They're having a bad day. They're human beings. But it's like it makes you like you don't want to go there again. You don't feel like they care about you. (12/22/14)

Libby said that if she could focus on "one thing for the future" it would include access to many kinds of services and alternative treatments, but in a place where they are "treated in a way, not like a child. They want to be treated like they have a choice in the matter...That would be really cool" (12/22/14).

Libby and Mary reflected on the general problem of finding quality care with service providers that are empathetic and willing to help. Other participants identified more specific barriers to quality care, which can be grouped under the categories of hospital-related barriers and financial barriers.

Hospital-Related Barriers

For the mothers in this study, three primary barriers to quality treatment for their child in the hospital included: (1) lack of hospital beds, (2) refusal to admit the child with mental illness, and (3) premature discharge. Participants reflected on how minimal access to beds was a source of frustration, particularly when the children with mental illness were in crisis. In the following quote, Lily reflected on how she wanted a better "time frame to how you get help." She explained how her daughter waited for both admission and a psychiatrist, despite her daughter reporting suicidal ideation.

The only answer for a parent going through that is to go sit in the emergency room, sometimes for days while they find a bed. Then you get a bed and the facility is useless. The kids are running wild. They just release them after a couple days...Then to wait for a psychiatrist, we were on the waiting list for 8 months before. This is all the while that we're in and out of the hospital. Cutting and doing all this stuff and I had to take her home...We couldn't get in to see a psychiatrist for 8 months. I think that they need to make more services available for the amount of people they're serving and realize that these are urgent issues, not issues that can wait 8 months. (12/14/14)

Even when long-term hospitalization was an option, the services received were viewed as inadequate, or patients were prematurely discharged. Grace described the system as "insane." She said, "That's why I'm an advocate. It's got to change. It's going to take a lot of people making that happen" (12/5/14). Grace described an event in which she transported her son to the hospital during a psychotic episode. After waiting 4 h for an evaluation, her son did not meet admission criteria and they were told to go home. It took her another 2 months to have him officially admitted to an inpatient psychiatric facility.

Financial Barriers

Participants also discussed the financial barriers to treatment they experienced while seeking help. Such financial barriers reported by the mothers included issues with out-of-pocket expenses, health insurance, and government funding. When asked what she would ask for if she could receive any one service, Dina answered, "Affordable treatment that works" (12/15/14). She explained how affordable care "just doesn't exist" in her state and that quality care "is out there" but "it's hard to find and really expensive." She had been battling the health insurance company to help pay for her daughter's many medical bills.

Linda also had a hard time paying for her son's mental health treatment. She explained how her income put her in a bracket too high to receive state-sponsored services, thus forcing a decision between work with high health care costs and unemployment with financial assistance.

The hard part is I have worked through all this... I was making a few thousand dollars over the limit for getting any sort of public assistance. Programs that offered care, income counseling, and support were out there, but not for someone who works for a living. You have to actually find a group and pay for it, which unless you're at a level making a whole lot of money, it's not affordable...Really, I paid a pretty heavy price for being a working parent. It would be really, really nice to figure out a way to fix that. (5/4/14)

In addition to treatment-related expenses, family caregivers are often responsible for paying adult children's housing costs, especially when government income (e.g., social security disability, SNAP benefits) is unable to cover living expenses, including housing, food, and transportation. Casey, for example, applied for a state-sponsored individual care grant designed to pay for either intensive outpatient community-based services or residential treatment for children with severe mental illness. In the following narrative, she explained the difficulty in the application process.



When Tim was 12 we applied and were denied, which we thought was weird since he was just diagnosed with schizophrenia. When he was 14, I managed to find some people who had gotten the grant for their kids before. They helped us with our application; we applied and were denied again. We appealed and then he was accepted...With all of the violence we had at home and how many times we had to send him to the hospital for his own safety and everyone else's. (1/12/14)

A Recurring Cycle from Optimism to Hopelessness

Many of the participants were hopeful that their child would improve, whether because of advancements in treatment and medications or with maturation and time. They believe medication and treatment would help "fix" or "manage" their child to the point that s/he could remain at home. However, participants explained how this hope and optimism was short lived. In most cases, what the mothers hoped for (e.g., medication will improve the child's mental health) did not happen at all and they soon felt a sense of loss or hopelessness for the future. For others, they describe their hope as fleeting and they speculated on how their child will inevitably become symptomatic in the future. In the first example, Catelyn described her son's metamorphosis after undergoing electroconvulsive therapy (ECT) on two separate occasions.

Catelyn: I took [my son] home for a few days and then he said "I'm ready to start ECT" and we did. Within four treatments, he was back, bright eyes, bushy tailed. Interviewer: How does Kurt seem with you when he's like that?

Catelyn: Not normal because ECT does not affect OCD...He was still under his OCD crazy stuff, but his personality came back...He had two major psychotic breaks and came back to live with me to start ECT, shock therapy...He was in such horrible, horrible, total breakdown state that he had to come home...By the fourth session, he was back. He was normal. It brings him back. It's miraculous. It's miraculous... (4/13/14)

She described her son's recovery as "miraculous" but that he predictably quits treatment and will decompensate.

He just stopped [ECT treatment] and so...He relapsed terrible and we started all over, ECT again and so, he came back to live with me again and, again, would not do the weaning off. I think he had 10 or 12 the second time and just stopped abruptly, but has stayed living with me because he knows he needs the moral support, although I'm not much moral support to him because I'm his major OCD trigger. (4/13/14)

This recurring cycle from optimism to hopelessness became a predictable pattern for Catelyn's son. Yet she continued to believe that her son—if he were to follow treatment recommendations—could be "normal" and that they might someday have a healthy and reliable mother-son relationship.

Korina described a comparable cycle in which her son is admitted to a psychiatric unit, discharged with little improvement in his functioning, then readmitted within a few days. At the time of her interview, her son showed some improvement with a new antipsychotic prescription.

When he has to go to the hospital they usually send him home before they're ready. It's a horrible, horrible feeling because I want to help my child and I don't know what else to do other than take him to the hospital, but every time he's never received what he needed. Sometimes they mess it up more. He had two hospitalizations back to back. He was manic. They did not want to consider bipolar. All they did was take him off all his medications, send him home to go through withdrawals, which was just super fantastic. We were right back in the hospital. Then I got lucky and found a doctor willing to try lithium. He is almost normal now. It fixed all kinds of stuff. It was amazing. (12/8/14)

Other mothers focused on how time and maturation would improve their child's functioning. For example, Casey believed that a change in environment might help her son be both independent and safe.

Well, I hope that he [gets] more independent...I know he wants it. He is talking about when he turns 21 and move out, and we are like, "yeah, sure you are," it is not that long away...Todd is never going to be 100% independent...We have this plan, we have this place up in Maine, it is an island, and my husband grew up there. It is a very small population, we know everybody up there and our plan is to, hopefully in the next 5 or 6 years, move up there full time so that Todd can have some independence...from us, but...also be in a place where he is isolated enough that he cannot get in a whole lot of trouble...I am hoping the relationship is going to be him a little more independent, him feeling a little more like an adult; I can assume that for helping him manage his illness, it is not going to be a whole lot different than it is now. (1/12/14)

Discussion

The current paper contributes to a growing body of research on child-to-parent abuse by offering a rich account and analysis of a population that is often behind closed doors. The participants in this study described a persistent and



frustrating struggle to increase awareness of and belief that they and their children need help. They discussed how both formal and informal support systems denied there was a problem; other participants explained how denial was compounded when they were blamed for their own victimization and the child's aggressive behavior. This skepticism led participants to experience overwhelming feelings of aloneness and resignation. To further complicate their ability to help themselves and their children, they described an exhausting effort to find quality and affordable psychiatric treatment for their child. Even when mothers could bring their child to an emergency room, for example, oftentimes the child would be discharged prematurely or would be refused overnight admission. Consequently, mothers would find themselves driving their child back home even if the child was a safety risk. At the same time, the participants described a sense of optimism that despite these struggles their children might someday improve. They speculated on how future advances in treatment and medications could help their children. Indeed, some mothers did see their child improve with various treatments and medications. For some, however, their optimism shifted to hopelessness as they saw their child decompensate or disregard treatment recommendations. These situations left parents desperate for help, but help is difficult to attain.

In brief, our findings highlight how mothers perceive barriers to effective help for their violent children with mental illness. Using a modified version of grounded theory, we focused on three barriers: (1) Denial of mental illness and severity of violence by treatment providers, extended family, and non-family members; (2) limited access to quality treatment and supports; and (3) a recurring cycle from optimism to hopelessness.

As we indicated earlier, there are close parallels between these three barriers and those encountered by IPV survivors. The first barrier experienced by our participants was denial from informal and formal social supports. IPV victims who disclose their victimizations to others can be met with a variety of social reactions ranging from positive and helpful to negative and unhelpful (McGee 2005; Sylaska and Edwards 2014). Unfavorable, negative reactions given by informal social supports (e.g., family members, friends) and serviceproviding institutions (e.g., religious organizations, healthcare systems) can prevent or delay victims from further seeking and/or receiving help in the future (Beaulaurier et al. 2007; Sylaska and Edwards 2014). In view of the literature on parent blaming, it is unsurprising that—like survivors of intimate partner violence—our participants identified denial by others to be a barrier to effective help. Researchers have long suggested that parent or mother blaming (Caplan and Hall-McCorquodale 1985) is a result of the socially constructed notion of the ideal family. Generally speaking, an ideal family is represented as a middle-class, heterosexual couple with children in a self-contained, well-functioning family unit (Thorne 1993). Families with a violent child with mental illness deviate from this norm. Mothers have been blamed for a child's mental illness for decades, and early explanations of the etiology of a child's mental illness often blamed the mother (see Bateson et al. 1956; Lidz et al. 1965). In a content analysis of literature on mother blaming, Caplan and Hall-McCorguodale (1985) identified many instances of mother blaming. The researchers revealed how mothers of children with mental illness were overrepresented as targets of blame and were described as themselves having mental health problems or being neglectful and manipulative. Last, mothers were five times more likely than fathers to be cited as part of the child's problem.

The second barrier identified by our participants was limited access to quality treatment and supports. This is not unlike IPV victims who experience various challenges when seeking help from social services. These challenges can, in part, be attributed to the reality that demand far exceeds the availability of victim resources (Iyengar and Sabik 2009; NNEDV 2007). Relatedly, our participants reflected on broader social problems related to deinstitutionalization and health care coverage and costs. Evaluations on mental health care in the United States present a dismal reality. The Bureau of Labor Statistics estimated that 89.3 million Americans live in geographic locations designated as mental health professional shortage areas (Kliff 2012). Similarly, the U.S. Department of Health and Human Services (2015) suggests an additional 2,800 psychiatrists are needed for underserved areas and populations. Data from the National Comorbidity Survey showed that only 15.3% of persons with serious mental illness received "minimally adequate treatment" (Wang et al. 2002, p. 92). The issue associated with inpatient psychiatric hospital beds has been a significant barrier to treatment for years. Between 1954 and 1996, the United States saw the number of state and county psychiatric beds drop from 553,979 to 61,722 (Geller 2000). In 1955, there were 340 inpatient psychiatric hospital beds per 100,000 persons, by 2005 that number dropped to 17 beds per 100,000 persons (Torrey et al. 2008). The need for easier access to mental health treatment and services in the United States is critical and expanding.

IPV survivors also report various financial challenges, wherein they are unable to afford services that will help them when leaving violent relationships (McGee 2005; Fugate et al. 2005; Kim and Gray 2008). While mothers of a violent child with mental illness face expenses for different kinds of services, expenses for things like hospitalization and medication would be of at least a comparable magnitude to the IPV victims' expenses for services, housing, and food. In general, mental health treatment is expensive and out-of-pocket expenses can cost up to \$5000 (Kliff 2012). A recent TIME magazine investigation on America's mental



health system found that the United States lost approximately \$4 billion in mental health funding between 2009 and 2012 (Szalavtiz 2012). In fact, the National Alliance on Mental Illness asserted that long-term, impatient psychiatric facilities were the primary victims of budget cuts during the recession (Kliff 2012). Because of these cuts, we can speculate that even more of the financial burden for the child falls on parents.

The third barrier as described by the mothers was a recurring cycle from optimism to hopelessness. A similar cycle affects IPV survivors who sometimes have optimistic views of their abusive partner's involvement in a batterer intervention program (Gondolf 1998). Yet batterer programming evaluations and meta-analytic reviews have reported small treatment effect sizes (Eckhardt et al. 2013). Thus, this quandary can create a misguided sense of optimism in a victim's trust in treatment. The optimistic belief that mental illness will be cured by innovations in treatment was also present in our participants' narratives. For example, participants reflected on times in which they saw a new medication or treatment strategy help their child, only to see it fail down the road. Researchers have investigated how parents are poorly educated about mental illness and related caregiving demands. For example, Solomon and Maracenko (1992), who interviewed 57 family members of patients discharged from a psychiatric facility, found that hospital and mental health staff did not provide parents emotional support, nor did they offer information on crisis intervention techniques and medication management. Parents were neither educated on how to cope with having a child with mental illness nor how to motivate their child to engage in treatment. In a similar study, Johnson (2000) interviewed families of 180 people with severe mental illness. The parents often felt dismissed or disregarded by hospital staff, especially when they tried to inform the staff of their child's warning signs or stages of decompensation (Johnson 2000). These studies highlight the importance of educating family caregivers on realistic expectations for caregiving and for an understanding of how mental illness is often chronic and episodic in nature (George 1999). With heightened awareness of the ups-anddowns of mental illness, parents may be less likely to experience extreme changes in emotion as seen in the recurring cycle from optimism to hopelessness.

Our confidence in these findings must be qualified by certain limitations. Our sampling strategies inadvertently led to a greater representation of Caucasian participants who identified as either middle- or upper-middle class. It is broadly accepted that individuals of a different race, ethnicity, and socioeconomic status will experience stigma differently; also, they often have different levels of access to both formal and informal supports and services. We believe this issue does not minimize our results or recommendations as there is no reason to expect that the barriers our participants

identified would be less of a problem for persons of a different race or with different financial resources. Regardless, future research would benefit from a larger sample size with varying demographics to better represent a larger population.

Conclusions and Recommendations

Our aim in this research was to answer the question: What barriers do mothers of violent children with mental illness identify as impediments to their ability to help their violent children with mental illness? Our focus on the barriers encountered by help-seeking mothers provides insight on a complex problem that often remains behind closed doors. Our findings highlight three barriers to treatment and support as identified by the participants: denial by informal and formal social supports, limited access to services, and a recurring cycle from optimism to hopelessness. Investigating barriers and how mothers experience them helps to expand the scope of domestic violence literature and provides a richer understanding of the complex body of difficulties that parents face when seeking help for themselves and their children with mental illness. Following Wilcox's (2012) argument, this paper acknowledges the importance of integrating child-to-parent abuse into the broader field of domestic violence.

In the process of exploring the issue of barriers to effective help, we recognized parallels between the experiences reported by our participants with those found in the larger intimate partner violence literature. It is important to note that unlike mothers who are victimized by their child with mental illness—whom we presume are not trying to leave their violent child—some IPV survivors encounter barriers when trying to leave their abuser and not just when they are trying to reduce the violence in their relationship. We maintain that regardless of whether an IPV victim is trying to leave the relationship, her goal is to reduce or eliminate the violence she is experiencing from her abusive partner just as a mother is trying to reduce or eliminate the violence from her child. With that said, the relevance of looking to the IPV literature is less about understanding the similarities of these two populations, and more about understanding how those similarities can be used to inform policy and social services.

Given the similarities noted above, another outcome of this study is our ability to identify programs and policies that have been effective for IPV survivors that might also be beneficial for parents of violent children with mental illness. This applies especially to programs that have been found to aid IPV survivors in overcoming barriers to help, by providing an informed support system and access to positive, helpful, and affordable care. For example, many IPV agencies work within a widely-recognized approach known as a Coordinated Community Response (CCR; Shorey et al.



2014), wherein multiple agencies and service providers (e.g., law enforcement, advocacy, health care, counseling) in an area work collaboratively to focus on the needs of IPV victims. A similar program might be helpful for parents of violent children with mental illness to address the complexities of their victimization and to enhance the effectiveness of a community's response.

Any CCR organized for parents of violent children with mental illness will be tasked with a wide range of responsibilities, including support for persons with mental illness and their caregivers. We argue that education is a crucial need for parents and that education will help parents to overcome the barriers identified in this research. For example, mental health practitioners or other family intervention specialists can engage parents in an open and honest dialogue about the realities of mental illness and related caregiving expectations. Open dialogue will not only combat denialrelated barriers, but will help parents be realistic about their child's mental illness and the complexities of caregiving. As with IPV survivors, it is dangerous for parents of children with mental illness not to protect themselves and to simply have faith that treatment might always work or might work someday. Practitioners can help parents to navigate across the life-course of mental illness and to learn how caregiving can be utilized most effectively, so that parents can avoid extreme cycles from optimism to hopelessness.

We recommend that researchers continue to explore the victimization experiences and help-seeking behaviors of mothers who have a violent child with mental illness. This will help researchers and practitioners alike better understand what programs and policies will assist parents in such a difficult situation. In short, our ability to keep families healthy and safe depends on access to quality and reliable mental health services. At present, however, our mental health system seems incapable of providing adequate support to persons with mental illness and their family caregivers, and this, of course, raises a host of questions about societal priorities.

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