

UNIVERSITY OF CALIFORNIA

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The Experience of Violence and Help-Seeking
Among Mothers of Adult Chronically Mentally Ill Individuals

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Nursing

by

Darcy Ann Copeland

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The dissertation of Darcy Ann Copeland is approved.



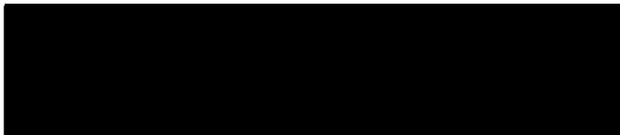
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I would like to dedicate my work to my partner, Leslie Hillen, our wonderful daughter
Skyla, and my Committee Chair, friend and mentor, Dr. MarySue Heilemann.

Without the support, guidance, patience, understanding, and encouragement of these
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ABSTRACT OF THE DISSERTATION

The Experience of Violence and Help-Seeking
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by

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Mothers of mentally ill adults are frequently primary caretakers. If mentally ill individuals become violent, mothers are most often victims. In their role as primary caretakers, mothers are knowledgeable regarding their children's illnesses. They are also familiar with the mental health system, including criteria for involuntary hospitalization. Mothers can identify signs of decompensation in their mentally ill children and recognize their need for hospitalization. They cannot, however, always access mental health treatment due to their children's refusal and/or not meeting legal criteria for involuntary hospitalization. This is problematic, particularly for mothers whose mentally ill, adult children have a history of violence.

This study used Grounded Theory methods to explore mothers' experiences of violence perpetrated by their mentally ill, adult children and the process used to seek help when violence occurred. Mothers described periods of living on high alert, characterized by waiting in frustration while their children decompensated but did not meet involuntary hold criteria. Mothers used distraction, isolation, and reality orientation to manage their fear and uncertainty. Once their fear and uncertainty outweighed their abilities to manage the chaos their children created, they called the police or psychiatric evaluation (PET) teams, who served as gatekeepers to mental health treatment, for assistance. Mothers then dealt with responses from their children and gatekeepers, and accepted the consequences of being responsible for their children's involuntary hospitalization or of being left home with their children if the gatekeepers did not initiate involuntary hospitalization.

Mothers discussed their children's limited housing options. For mothers, stable, long-term housing was a component of mental healthcare for their children. In the absence of conservatorship or a court order, long-term placement was not a possibility. Instead, mothers saw their homes, homelessness, or temporary board and care placement as the limited options available to their children. These three options were temporary and undesirable. Seven factors were identified as important to mothers in deciding which option they preferred for their children: concern for safety, children refusing/walking away from placements, advice from others, maternal obligation, imposing consequences for behavior, quality of available placements, and their inability to provide care.

Introduction to Dissertation Overall

In general, individuals who are mentally ill are no more likely to exhibit violent behavior than individuals who are not affected by a mental illness (Steadman, et al., 1998). However, some individuals with mental illnesses are at increased risk for becoming violent, especially those with psychosis or neurological impairments (American Psychiatric Association, 1996). If individuals who are mentally ill do become violent, family members are most likely to be victims of that violence (American Psychiatric Association, 1996; Nestor, Haycock, Doiron, Kelly & Kelly, 1995; Steadman et al., 1998). Parents are the victims of this violence the majority of the time (Binder & McNeil, 1986; Straznickas, McNeil & Binder, 1993).

Mothers in particular are most often the victims of violence perpetrated by individuals who are mentally ill (Estroff, Zimmer, Lachicotte & Benoit, 1994; Estroff, et al., 1998). Unfortunately, little is known about their experiences of victimization and their help-seeking efforts when this type of violence does occur. In addition to being the most likely victims of violence perpetrated by their mentally ill children, mothers are also frequently their mentally ill children's primary caretakers. Because mothers are responsible for providing support for their children who are mentally ill, mental health professionals often have the opportunity to interact with them. Mental health professionals need to be cognizant of mothers who may be at high risk of violent victimization in their role as primary caretaker for their mentally ill children. In order to facilitate the recovery process for mothers and their children, mental health professionals need to understand the timing and triggers for mothers seeking

assistance when their mentally ill children become violent, from whom that help is sought, and the effectiveness of the help received.

This dissertation is comprised of three separate manuscripts. Each manuscript will be submitted for publication independent of the others. The three manuscripts include a literature review and two data-based papers articulating the study's findings. Results of the study were broken into two separate data-based papers because analysis of the interviews indicated two distinct decisions made by the mothers: to seek immediate assistance when their children became violent and deciding whether or not to allow their children to live with them after a violent event had occurred. Because the data-based papers are intended to stand on their own, there is some redundancy in the descriptions of the study's methods and sample characteristics presented in chapters two and three.

The first manuscript (Chapter One) utilizes the Vulnerable Populations Conceptual Model (Flaskerud & Winslow, 1998) as an organizing framework to present a review of literature concerning familial violence and mental illness. The Vulnerable Populations Conceptual Model (VPCM) is a population based model and was used to structure the literature review in an effort to associate violence perpetrated by a mentally ill relative under the rubric of familial violence, rather than as violence among a clinical population. Violence perpetrated by mentally ill individuals is rarely investigated as a form of familial violence, even though relatives are most likely to be victims. Rather, the bulk of literature addressing violent behavior among individuals

who are mentally ill falls under one of two investigative umbrellas: clinical studies of violence among psychiatric patients or studies of mental illness among violent criminals. Given the increased risk of violent victimization among family members, a shift away from a clinical or criminal justice focus and onto family seems prudent.

The VPCM utilizes the concepts of resource availability, relative risk, and health status to frame specific populations as vulnerable, that is at increased risk of adverse health outcomes as a result of limited resource availability (Flaskerud & Winslow, 1998). In the present case, family members of individuals who are mentally ill are at increased risk of violent victimization if their relatives become violent. In their role as primary caretakers they receive little support from the mental health system (Biegel, et al., 1994; Saunders, 2003). Family members of individuals who are mentally ill also experience limited resource availability as a result of their own social stigmatization (Phelan, Bromet, Link, 1998) and isolation (Veltman, et al., 2002). For these reasons, family members of violent mentally ill individuals were identified as a vulnerable population within the VPCM.

The literature review revealed a gap with respect to the experiences of family members who have been victims of violence perpetrated by a relative who is mentally ill. Specifically, there is an absence of literature addressing how, when and from whom family members seek help when a mentally ill relative becomes violent and if any help received is perceived as effective. For this reason, a study was designed to examine the experiences of violence and help-seeking among mothers who are victims

of violence perpetrated by a mentally ill, adult child and their help-seeking behaviors in relation to these experiences.

Grounded theory methods were used to investigate the meanings that mothers who have been victims of violence by adult children with a mental illness attach to their experiences and the social and situational factors influencing their help-seeking behaviors. Grounded Theory methodology is useful in understanding social processes and in learning the ways in which individuals understand and manage their lives in ever-changing environments (Streubert Speziale & Rinaldi Carpenter, 2003). It recognizes the multidimensionality of human existence and our ability to make sense of our lives and world (Charmaz, 2003). The concepts of active participation in the world, meaning derived from such action, and truth as contextual are critical in the conduct of research employing Grounded Theory as a methodology (Clarke, 2005). In order to generate a theory of a social phenomenon, both meaning and action must be understood from the perspective of the actor and placed within a social/political/environmental context.

Grounded Theory is a valuable research design to employ in areas that have been understudied or in areas where empirical research has been conducted, but has resulted in the simplification of concepts relevant to a phenomenon, and a lack of deep understanding of characteristics of the phenomenon (Stern, 1980; Streubert Speziale & Rinaldi Carpenter, 2003). There is a lack of scientific literature addressing violence by adult mentally ill individuals towards their mothers as a form of family violence, the aid family member victims perceive as available and useful to them, and the

effects of any intervention received by victims. The majority of research with parents of mentally ill individuals has been quantitatively oriented and has focused on issues such as burden and risk factors for violent victimization. Little attention has been paid to understanding the perspectives of these family members and how they navigate through various formal and informal sources of help.

The sociological theory of Symbolic Interactionism forms the foundation of Grounded Theory. Sociologist Herbert Blumer suggested that meaning is ascribed to social situations through the use of symbols and language (1969). The Grounded Theory methodology used in this study drew heavily from three fundamental Symbolic Interactionist assertions proposed by Blumer. First, people act towards objects (i.e. situations, people, possessions) on the basis of the meanings of those objects in their world. Second, the meaning of an object arises out of social interaction. Third, the meanings of objects are modified through an interpretive process in which an individual notes, interprets and assesses a situation. Through social interaction and interpretation of those actions, people create meaning in their world (Blumer). For the purpose of this study, the social interaction of interest was a violent interaction between a mother and her mentally ill, adult child. Consistent with these tenets of Symbolic Interactionism, in order to understand the action taken by a mother in response to the violence she experienced, it was necessary to understand the meaning that interaction had for her. In order to understand the meaning the violent interaction had for her it was also necessary to know how she understood her child's illness and what options she perceived as available in terms of assistance.

Social workers and nurses on two adult, inpatient locked psychiatric units were responsible for identifying patients with a psychotic, mood or anxiety disorder without a co-occurring substance abuse or personality disorder who had been violent towards their mothers. The social workers and nurses contacted these women, explained the study and invited them to contact me if they were interested in participating. I screened the women for eligibility which included biological, step or adoptive mothers under age 65 who were able to participate in an interview conducted in English.

After obtaining informed consent, semi-structured interviews were audio-taped in a private location chosen by the woman. Probes were used to elicit the mothers' understanding and experiences of their children's illnesses, the violence they experienced, decisions they made with respect to their children's illness and violent behavior, and what assistance was perceived as helpful to them. The audio tapes were transcribed verbatim.

Data analysis and interpretation revealed two major decision points for the mothers. The first was the decision to seek immediate assistance when their children became violent towards them. The second was deciding whether or not their mentally ill, adult children could live with them after the mothers had been violently victimized.

The second manuscript (Chapter Two) describes how the mothers understood their children's mental illness and the violent behavior they exhibited as well as articulating the process mothers used to seek immediate assistance when their children became violent towards them. The themes identified with respect to the mothers' understanding of their children's illness included the origin of the illness, the

symptoms of the illness and their children's prognosis. In terms of the violence they experienced, the mothers described its origin and its onset in addition to the perception that violent behavior was a key to getting their children needed mental health treatment. The process of getting immediate assistance when their children were violent involved a period of living on high alert. Living on high alert was characterized by a period of waiting in frustration until their children met involuntary hold criteria. During this period mothers attempted to manage the fear and uncertainty of their living environments by utilizing techniques such as distraction, isolation, and reality orientation. Once the mothers reached a point where they did not know what more to do in order to manage their children's behavior or were too fearful to continue to be near their children, they called either the police or a psychiatric evaluation team (PET) for assistance. Once that call was made, the mothers dealt with responses from both the police or PET team and their children and accepted the consequences of making that call.

The third manuscript (Chapter Three) describes the limited housing options the women's children had and the factors the mothers considered when deciding which of those housing options they preferred for their children. All of the mothers wanted their children in long-term, stable placement of some kind. Because the mothers did not have conservatorship of their children, the children had the right to refuse or walk away from any residential placements. So, while ideally they would have chosen stable, long-term placement for their children, instead they were forced to choose between their children's homelessness, temporary board and care placement, or their

own home. They perceived each of these three options as undesirable. None of these options were permanent and most of the children routinely moved between these three housing situations. Seven factors which were important in how the mothers decided which option they felt was best for their children were identified: concern for safety, their children's refusing or walking away from placements, advice from others, maternal obligation, imposing consequences for their children's behavior, the quality of available placement facilities, and their own inability to provide care for their children.

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Chapter One

Conceptualizing Family Members of Violent Mentally Ill Individuals as a Vulnerable Population

Mental health providers tend to focus on the primary psychiatric patient as the only person in need of services; but doing so may inadvertently invalidate, underestimate, or ignore the needs of family members who often serve as caregivers for that patient. Caregivers, specifically family members, of mentally ill individuals face a multitude of challenges. For some family members one of these challenges may include exposure to their relative's violent behavior. While it is acknowledged that mentally ill individuals can be victims of violence or abuse perpetrated by family members, many researchers investigating assaultive psychiatric patients report that family members are the victims of a mentally ill relative's violent acts more than 50% of the time (APA, 1996; Nestor, Haycock, Doiron, Kelly & Kelly, 1995; Steadman et al., 1998). In general, the most common family member targeted is a parent (Binder & McNeil, 1986; Straznickas, McNeil & Binder, 1993).

There is an abundance of scientific literature addressing the relationship between violent behavior and mental illness, but the majority of these studies address the issue from an individualistic perspective. It is largely addressed with respect to the violent mentally ill individual's demographic, clinical, psychosocial, or historical/criminal characteristics (Estroff et al., 1994; Estroff et al., 1998; Estroff & Zimmer, 1994; Nestor et al., 1995; Steadman et al., 1998; Straznickas, McNeil &

Binder, 1993; Stuart & Arboleda-Florez, 2001; Swanson, Holzer, Ganju & Jono, 1990; Swanson et al., 2000; Swanson et al., 2002; Tardiff, Marzuk, Leon & Portera, 1997). Violence in families that is perpetrated by an individual who is mentally ill is rarely conceptualized under the broad umbrella of family violence.

In order to make the wealth of information regarding violence and mental illness, emphasizing familial violence, more accessible, a literature review of the current state of knowledge on familial violence perpetrated by a mentally ill individual is presented. The Vulnerable Populations Conceptual Model developed by Flaskerud & Winslow (1998) is a population-based model used as the organizing framework to review the literature about this unique form of family violence from a social rather than an individual perspective. The use of this model allows the review of literature to focus on specific concepts relevant to this phenomenon and provides the opportunity to increase coverage of issues that have lacked attention in the past.

The Vulnerable Populations Conceptual Model and Family Members of Violent Mentally Ill Individuals

Vulnerable populations are those social groups who experience increased relative risk or susceptibility to adverse health outcomes as a result of limited resource availability (Flaskerud & Winslow, 1998). Vulnerable populations may also be described as those groups in society who experience health disparities, defined by the National Institutes of Health (NIH) as “differences in the incidence, prevalence,

mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States” (NIH, n.d, ¶ 6).

The Vulnerable Populations Conceptual Model (VPCM) emphasizes community health and therefore stresses opportunities and resources available in the community that help its members achieve and maintain optimal health (Flaskerud & Winslow, 1998). The conceptual model (see Figure 1) proposes four relationships among the concepts of resource availability, relative risk, and health status. Model concepts are defined in Table 1. The four proposed relationships are: 1. lack of resources increases relative risk, 2. increased exposure to risk factors leads to increases in morbidity and mortality, 3. at the same time, compromises in health status may intensify ongoing exposure to risk factors, and 4. patterns of morbidity and mortality in a community may deplete existing resources further compromising their availability. Practice and education issues, research, and ethical and policy analysis may be directed at any of the concepts directly or the relationships among them in the VPCM (Flaskerud & Winslow). Analysis of these concepts may help illuminate the factors contributing to a specific social group’s health disparity and give direction to primary, secondary, or tertiary interventions to be utilized in practice to alleviate those disparities. Because family members of mentally ill individuals have been shown to be at increased risk of victimization if their relative becomes violent (Arboleda-Florez, 1998; Nestor, Haycock, Doiron, Kelly & Kelly, 1995; Steadman et al., 1998) and also encounter stigmatization in our society (Phelan, Bromet & Link, 1998; Veltman et al., 2002), they are conceptualized in this review as a vulnerable population.

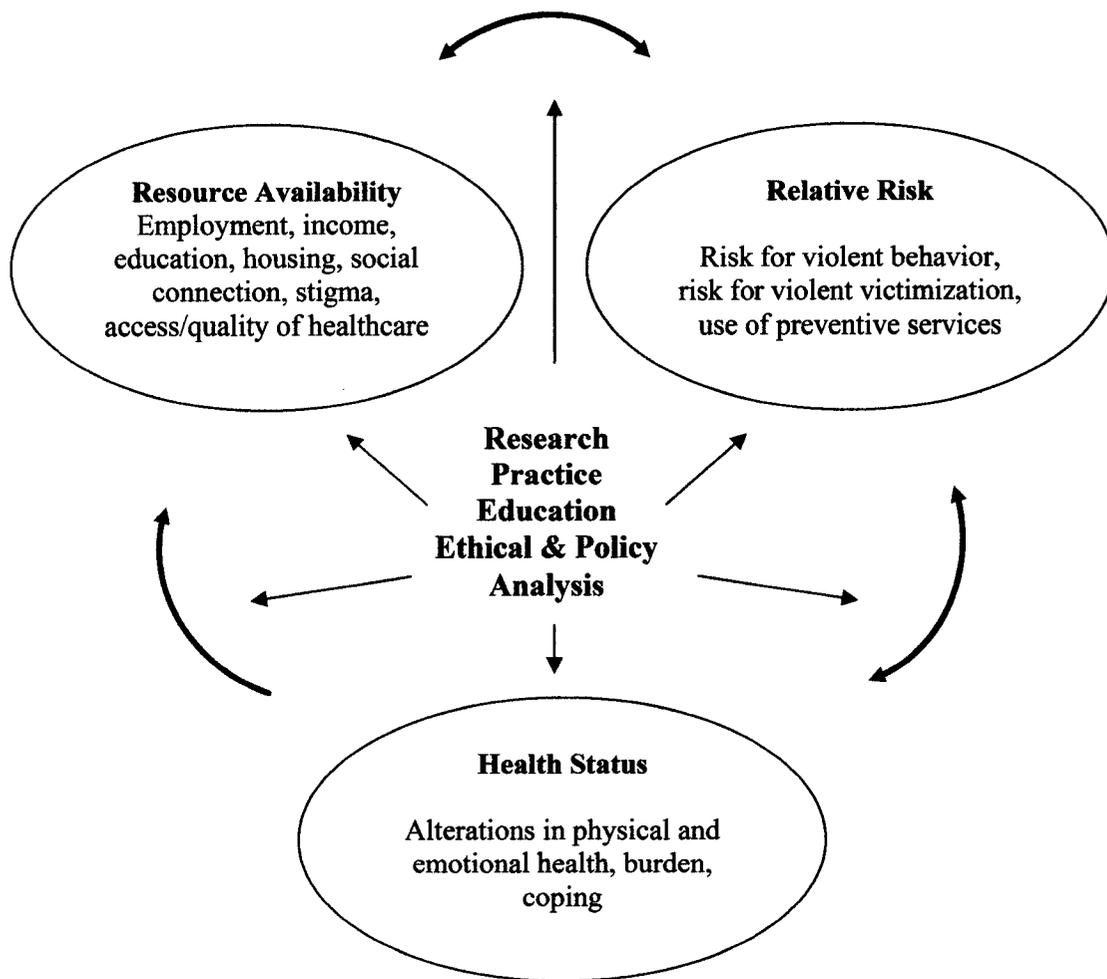


Figure 1. Vulnerable Populations Conceptual Model Applied to Family Members of Mentally Ill Individuals. From "Conceptualizing Vulnerable Populations Health-Related Research," by J.H. Flaskerud and B.J. Winslow, 1998, *Nursing Research*, 47(2), p. 70. Copyright 1998 by Lippincott Williams & Wilkins. Adapted with permission.

Table 1. *Vulnerable Populations Conceptual Model Concepts Defined*

Model Concept	Definition
Resource Availability	Socio-economic and environmental resources including human capital such as employment, income, education, and housing. Social disconnection, or the degree to which a social group experiences marginalization, stigmatization or discrimination is a characteristic of resource availability. Social status and access to and quality of healthcare, are also aspects of resource availability.
Relative Risk	Exposure to various risk factors including lifestyles, behaviors, and choices. Use of health promotion services, which mitigate risk factors, and exposure to and/or participation in stressful events such as violence, firearm use, unintentional and intentional injury, and suicide also fall under the umbrella of relative risk.
Health Status	Patterns of morbidity and mortality. In this review, alterations in physical and emotional health will be used to describe the health status of family members and caretakers of mentally ill individuals.

Note. From "Conceptualizing Vulnerable Populations Health-Related Research," by J.H. Flaskerud & B.J. Winslow, 1998, *Nursing Research*, 47(2), 69-78.

Methods

Three electronic data bases, PsychINFO, CINAHL, and PubMed were searched for relevant literature using the search terms mental illness, family, violence and their respective mesh terms in the abstracts, titles, or keywords. From the results of these searches, only original research articles that addressed resource availability, risk, and/or health status of a family member of a mentally ill individual were used in this review. Additionally, only studies in which the relationship between a person with a mental illness and their family member was articulated and described as a relationship other than intimate or married partners were included. With the exception of risk, the direct examination of violence directed towards family members of mentally ill individuals has been largely overlooked. Therefore, a wide net was cast with respect to inclusion of relevant literature. Time was taken to comb through articles addressing the concepts of interest (resource availability, risk, and/or health status) as related to family members from as early as the 1980's, some of which are included in this review because they are among the only works available addressing these concepts.

Resource Availability for Family Members of Mentally Ill Individuals

As described below, family members of mentally ill individuals are affected by the resource needs, such as employment and housing, of their relatives. They face stigmatization and diminished social connection themselves, and express concern about access to and the quality of health care their relatives receive.

Employment/income/education/housing. In a qualitative study with 20 caregiving family members of chronically mentally ill individuals, Veltman and colleagues (2002) identified “Systems Issues”, including the inability to find affordable housing for their relative and their desire for respite care from their caretaking role, as a primary theme. Participants also discussed financial strains associated with both caring for a family member who is unable to find employment and being unable to work more themselves due to their caretaking responsibilities.

Financial characteristics have been associated with both violence and increased burden among family members of mentally ill individuals. Estroff and colleagues (1994) found that individuals with major psychiatric disorders who were financially dependent on family members were significantly more likely to threaten others or exhibit violent behavior than those who were not financially dependent on their families.

Social connection. It can be difficult for family members to provide support to a mentally ill family member when they perceive it as ineffective or one-sided (Hogarty et al., 1997). The National Institute of Mental Health (NIMH) National Advisory Mental Health Council (1995) reported that the most highly distressed individuals, those in most need of support, may be the least likely to receive it because their distress drives away potential supporters. At the same time, research with individuals with schizophrenia and alcoholism indicate that high levels of social support are instrumental in decreasing relapse and the need for hospitalization as well as increasing the successful maintenance of effective treatment (NIMH, 1995). While

the social environment extends beyond the family structure, individuals with major mental illnesses often do not have extensive social support networks outside of this unit and nuclear families provide a majority of the instrumental and affective support they need (Estroff & Zimmer, 1994).

The size and composition of a mentally ill individual's social network have been associated with violent behavior. Estroff and colleagues (1994) investigated social functioning and social networks among individuals with major mental illnesses. They found that individuals with larger social networks and those with higher numbers of family members in their social networks had increased odds of threatening others.

Perhaps not surprisingly, perceived threat and hostility from significant others have been linked to violent behavior among mentally ill individuals (Estroff & Zimmer, 1994). The Structural Analysis of Social Behavior scale has been used to investigate perceptions of hostility by both mentally ill perpetrators of violence and their targets (Estroff et al., 1994; Estroff & Zimmer, 1994). This scale requires individuals to identify their most significant other and rate that person's behavior in relation to their own behavior. Mentally ill respondents who engaged in violent acts rated their identified significant others as more hostile than those who were not violent, but perceived themselves as more friendly and less hostile than participants who were not violent. The more threatened a mentally ill respondent felt by a significant other, the higher the odds of making threats and vice versa (Estroff & Zimmer, 1994).

Stigma. In addition to the challenges of providing financial and social support for mentally ill individuals, family members and caregivers frequently report changes in their own perceptions of social connectedness and stigmatization. Phelan, Bromet and Link (1998) investigated stigma among 156 individuals identified as significant others of patients admitted to psychiatric units for the first time. Half of the participants in this study reportedly made attempts to conceal the hospitalization of their family member from others. Participants also perceived that other people avoided them. The perception of avoidance was significantly associated with high psychotic symptomology in their ill family member (Phelan, Bromet & Link).

Additional issues of familial stigmatization were described by Veltman and colleagues (2002). In their study, caretakers described experiencing stigma from the public as well as within their own families. For example, children did not invite friends to their house because they were ashamed of their parents who had schizophrenia. One caretaker did not share “details” with extended family beyond letting them know her husband was “not well.” The wife of an individual with bipolar disorder felt that, “It’s a secret you keep to yourself. I have no friends” (p.110). Some of the caretakers also described how people did not understand why their relative needed to be cared for because “his disability is not visible” and “you can’t see it the way you see chicken pox” (p.111). Interviewees shared feelings of being unappreciated, blamed, and misunderstood by the general public, but also by mental health professionals (Veltman et al.).

The perception of feeling judged negatively by others is not uncommon among family members of mentally ill individuals. Struening et al. (2001) studied caregivers of consumers of mental health services. Roughly 70% of their respondents believed that most people would devalue a mental health consumer with a serious mental illness and 43% believed that most people also devalued the families of consumers of mental healthcare (Struening et al., 2001). Richardson (2001) reported similar findings in a study of 235 parents of children between the ages of 5 and 19. In her study, 29% of parents reported that other family members would not approve if they took their child for mental health services. Roughly 28% of these parents reported that they would be concerned if somebody found out that their child was receiving mental health services, and 12% expected to feel embarrassed when taking their child to a mental health professional (Richardson).

Access to and quality of healthcare. Few studies were found that addressed access to and quality of mental healthcare from the perspective of a family member or caregiver. In terms of anticipated access to mental healthcare, parents in Richardson's (2001) study anticipated difficulty getting an appointment for their minor child with a mental health professional (33%), not knowing where to go for services (24%), and being dissatisfied with what services were available (21%). A number of parents (32%) also reported a lack of understanding regarding the role of mental health professionals. Parents also had concerns about the capability of mental healthcare professionals to provide services for their children. Forty-one percent of these parents anticipated wondering if they could trust the mental health professional, 19% were

concerned that the professional would not care about their child, 15% expected the professional to be disrespectful and 14% expected the professional to be unfriendly to their child (Richardson, 2001).

Many family members and caregivers of mentally ill individuals are dissatisfied with the treatment they receive from mental health professionals. Veltman and colleagues' (2002) found that family members felt they received differential treatment by healthcare professionals compared to families of physically ill individuals. Lack of attention paid to caregivers by the healthcare system was also described. One participant stated, "as a caregiver, you're always fighting the system" (Veltman et al., 2002, p.111). Other participants also felt that their caretaking efforts were taken for granted; specifically that mental healthcare providers operated under the assumption that these family members were willing and able to care for their ill relative (Veltman et al., 2002). In interviews with 22 parents of individuals with schizophrenia, Ferriter and Huband (2003) reported that many parents perceived the information received from mental health professionals regarding their child's diagnosis or prognosis as insufficient or inaccurate.

While access to and quality of healthcare have been the topic of more current research, these studies have focused primarily on the perceptions of parents of minor children with mental disorders, thus the needs of parents of adult children remain largely unexamined. Table 2 includes descriptions of studies relevant to resource availability for family members of mentally ill individuals. Taken together these

Table 2. Resource Availability and Family Members of Mentally Ill Individuals

Author/Year Location	Purpose/Aim	Sample Characteristics	Findings: Resource Availability
Binder & McNeil, 1986 U.S.	Examine who are likely victims when psychiatric patients are violent prior to hospitalization; situational and interpersonal factors related to this violence	300 unduplicated medical records: 55% male; 68% Caucasian, 14% black, 11% Asian, 7% other ethnicity; mean age = 37; 57% resided with family; 15% assaulted a person within 2 weeks of admission	Patients who assaulted family were significantly more likely to live with them
Estroff et al., 1994 U.S.	Examine the relationships between violent acts/threats by people with a serious mental illness, characteristics of their social networks, and characteristics of their social support	169 people with a serious mental illness: 70% lived with family; 80% employed; 41% white women, 30% white men, 19% African-American men, 10% African-American women; mean age = 28; and 59 of their most significant others	63% of people in respondents' social networks were family members; Family members provided 57% of instrumental support; Individuals with mental health professionals in their social networks were less likely to be violent; 54% of respondents identified their mother as their most significant other
Ferriter & Huband, 2003 United Kingdom	Examine participant views on causes of schizophrenia, their emotional burden, and the helpfulness of others when seeking support	Parents of 22 patients diagnosed with schizophrenia receiving care in a secure forensic facility; all white; mean age = 60	Mean time from noticing something was wrong to date of first treatment = 2.7 years; Family, self-help groups and police were perceived as most helpful in providing support, psychologists, social workers, and psychiatrists as least helpful
Ostman & Kjellin, 2002 Sweden	Investigate psychological factors of stigma by association	162 relatives of hospitalized (voluntary and committed) psychiatric patients; 52% female, 27% parents, 38% cohabitated	83% of family members experienced burden related to stigma by association; Among parents, 72% reported having support from someone in carrying burden of being a family member of a person with a mental illness, only 28% felt that staff of psychiatric services were supportive and 26% felt inferior to staff in conversations; 33% believed that their child's illness affected their ability to have company

<p>Perlick et al., 1999</p> <p>U.S.</p>	<p>Assess impact of problem behaviors, role dysfunction, and adverse effects on burden among family caregivers of individuals with bipolar disorder</p>	<p>266 in or outpatients diagnosed with Bipolar I, II, or schizoaffective disorder manic type and their primary family caregivers</p> <p>Patients: 58% female, mean age = 39; 54% lived with caregiver</p> <p>Caregivers: 66% female, 44% parents of patient, mean age = 50, 85% Caucasian, 8% Hispanic, 6% Black</p>	<p>Lower caregiver SES was significantly associated with higher levels of both objective and subjective burden; Cohabitation was associated with lower levels of objective and subjective burden</p>
<p>Phelan, Bromet & Link, 1998</p> <p>U.S.</p>	<p>Examine perceptions of and reactions to stigma among parents and spouses of psychiatric patients</p>	<p>195 significant others of psychiatric patients admitted for the first time; 81% female, 48% parent living with patient, 23% parent not living with patient, 37% high school educated, median age = 49; Analysis is from 156 participants who completed entire interview</p>	<p>Predictors of high concealment of family member's illness included fewer symptoms at baseline, not living with the patient, and the patient being a female; Predictors of high perceived avoidance by others included significant other level of education, and an episode of illness in the patient during the 6 month follow-up period</p>
<p>Richardson, 2001</p> <p>U.S.</p>	<p>Examine parents' expectations about seeking and obtaining mental health care for their minor children</p>	<p>235 parents of children aged 5-19; 87% female, 58% Black, 36% White, 6% other, 58% completed high school, 51% annual income < \$20,000, mean age = 35</p>	<p>14% wondered if their child would be taken away if they sought mental health services; Black parents were twice as likely as White parents to anticipate disapproval from family members, to be embarrassed about seeking mental healthcare, to be concerned about others knowing, to lack understanding how treatment would be helpful, to lack transportation, to expect professionals to lack knowledge of treatment methods, to be untrustworthy, and to be disrespectful; Black parents were three times more likely to expect providers to provide poor care and to lack understanding of what services mental health professionals provide</p>

<p>Struening et al., 2001</p> <p>U.S.</p>	<p>Estimate caregivers' perceptions of the extent of society's devaluation of consumers of mental health services and their families</p>	<p>Group A: 180 caregivers of consumers of mental health services; 51% mothers; 50% white, 25% Hispanic, 25% African American</p> <p>Group B: 281 caregivers of consumers of mental health services; mean age = 50 years; 66% female; 85% white, 8% Hispanic, 6% African American, 1% Asian</p> <p>220 of the total caregivers lived with the consumer</p>	<p>79% of respondents from each group believed most people think a person with a mental illness is dangerous and unpredictable; 56% of respondents from Group A and 57% of respondents from Group B agreed that most people would rather not visit families that have a member who is mentally ill; 62% of respondents from Group A and 60% of respondents from Group B agreed that most people blame parents for the mental illness of their children</p>
<p>Veltman et al., 2002</p> <p>Canada</p>	<p>Gain greater knowledge of the meaning that caregivers of relatives with a mental illness derive from their situation</p>	<p>17 women, 11 mothers; age range 24-73; all acted as caregivers for more than 2 years, length of caregiving ranged from 2-38 years</p>	<p>All interviewees reported feelings of fear, concern, confusion, frustration, hope, caring, compassion, sympathy, love, sadness, grief, anger, resentment, and guilt; Themes identified in the interviews were stigma of mental illness and the caregiving role, systems issues, love and caring for the ill relative, life lessons learned</p>

studies reveal family members of mentally ill individuals as having poor resource availability. Social connection and social status appear to be particularly affected.

Relative Risk of Violence and Victimization for Family Members of Mentally Ill Individuals

Family members of mentally ill individuals are at increased risk of victimization when their relatives become violent and may, in some cases, delay seeking assistance from healthcare providers.

Risk for violent behavior. Several studies addressing the risk of violent behavior towards family members by mentally ill individuals have concentrated on at least one of three factors: demographics, clinical characteristics, or social environment. Straznickas and colleagues (1993) found that with respect to demographical characteristics, mentally ill individuals who violently attacked a parent were significantly younger than those who attacked other people. They were more likely, although not significantly, to live with their parents and not be married. Binder and McNeil (1986) found that among the 46 psychiatric patients in their sample who assaulted somebody within two weeks prior to hospitalization, patients who assaulted a family member were significantly more likely to live with their families. In contrast, Estroff and Zimmer (1994) found residence type not to be salient in predicting who would commit a violent act among those with a severe and persistent mental illness. In their study, men and women threatened family members and others in equal proportions, but when participants actually engaged in violent acts, women were more likely to direct violent acts toward family members – 75% versus 56% for men

(Estroff et al., 1994). Additionally, Estroff and Zimmer's (1994) participants who were physically or sexually abused as children were significantly less likely to engage in threatening or violent behavior than those with no history of abuse.

Alternatively, Swanson et al. (2002) found that physical abuse either before or after age 16 significantly increased the risk of violent behavior. In this large, multi-state study, violent behavior among individuals with a severe mental illness in the previous year was associated with experiencing or witnessing community violence, substance abuse, mood disorder, post-traumatic stress disorder, poor subjective mental health status, psychiatric hospital admission, and lower psychiatric symptomatology. The combination of exposure to community violence, substance abuse, and history of violent victimization substantially increased the likelihood of violent behavior beyond that of any risk factor in isolation (Swanson et al.).

In a study of clients utilizing community mental health services and their familial caregivers, characteristics significantly associated with familial violence within the previous two years were younger patient age, patient illicit drug use, and poor relationship quality between the patient and caregiver (Vaddadi, Gilleard & Fryer, 2002). Current heavy alcohol consumption and current cannabis use have also been associated significantly with higher levels of abuse towards caretakers (Vaddadi, Soosai, Gilleard & Adlard, 1997).

In an early study of assaultive behavior among psychiatric inpatients, Tardiff (1984) found no significant differences in age, gender, diagnosis, or length of stay between those who had assaulted a family member and those who assaulted any other

individual prior to hospitalization. In a later study of violent behavior among discharged psychiatric patients, Tardiff et al. (1997) found that the only significant differences between violent versus nonviolent patients were that those who were violent during the month prior to admission were nine times more likely to be violent after discharge. Further, those with borderline or antisocial personality disorders were four times more likely to be violent after discharge when compared to those without those disorders (Tardiff et al.).

With respect to clinical characteristics, Straznickas and colleagues (1993) reported that 26% of the violent attacks against parents by a mentally ill individual involved paranoid delusions. Similarly, Nestor et al. (1995) found that the delusional beliefs of severely violent forensic psychiatric patients, the majority of whom had murdered a parent, involved significantly more imposter delusions and personal targets when compared to a less violent group of patients at the same facility. In a study with family members living with individuals admitted to a psychiatric hospital, individuals diagnosed with schizophrenia, schizoaffective disorder, or bipolar disorder were more abusive towards their familial caretakers than those with other diagnoses (Vaddadi et al., 1997).

Family member risk for violent victimization. As previously mentioned, when individuals with a mental illness do become violent, family members are the most likely victims (Estroff & Zimmer, 1994; Estroff et al., 1998; Estroff et al., 1994; Steadman et al., 1998; Straznickas, McNeil & Binder, 1993; Tardiff et al., 1997). In an early study of violence perpetrated by 300 hospitalized mentally ill individuals,

Binder and McNeil (1986) found that 54% of the violent patients had assaulted a family member (34% of those assaulted were parents) and that 64% of the patients who assaulted a family member planned to return home to their family after discharge. This is particularly concerning in light of Tardiff and colleagues' (1997) findings in which 69% of patients who reported violent behavior within two weeks of hospital discharge attacked the same person before admission as after discharge, most often a family member.

Returning home after discharge may contribute to multiple hospitalizations. In a study investigating the relationship between family violence and hospital recidivism, defined as two or more hospitalizations in one year, Turkat and Buzzell (1983) found that 30% of all recidivist hospitalizations were a direct result of threats of violence against family members and 40% of all recidivists had threatened a member of their family at least once. In contrast, only 5% of the recidivist hospitalizations were a result of threats of violence to nonrelatives and 11% a result of public disturbances (Turkat & Buzzell).

Limit setting is one specific situational factor that may increase a family member's risk of violent victimization. Straznickas, McNeil and Binder (1993) found that an interaction between a caregiver and their mentally ill family member involving limit setting immediately preceded 63% of assaults against parents. These researchers speculate that individuals who assume a caretaking role, are in frequent contact with, and consequently attempt to set limits on the behaviors of their ill family members, are at risk of becoming targets of violence (Straznickas et al., 1993).

Acknowledging that violent behavior involves interaction between a perpetrator and a victim, the quality of the relationship between a mentally ill individual and the person toward whom s/he directs violent behavior has been investigated. Estroff et al. (1998) examined the relationship between mentally ill participants who were violent and the significant others who were the specific targets of that violence. Significant others who were targets perceived themselves as exceptionally more hostile towards the respondent who was mentally ill than did significant others who were not targets of violence.

Use of preventive services. Binder and McNeil (1986) classified families in which patients assaulted family members into four types. These included families with more than one individual with a severe mental illness, families with more than one violent individual, prompt help-seeking families, and delayed help-seeking families. Families with multiple mentally ill members comprised 24% of the sample and families with multiple violent individuals 16%. Prompt help-seeking was defined as seeking help for their mentally ill family member within two weeks of the onset of psychotic symptoms or after more than one episode of violent behavior. Delayed help-seeking families were those who did not seek professional help for more than two weeks after the onset of psychotic symptoms or more than two episodes of violent behavior. A large proportion of families in their study, 44%, were classified as delayed help seeking families, while only 16% promptly sought help. The delayed help-seeking families attempted to manage the patient on their own. Family loyalty

and lack of knowledge are two reasons these families provided for not seeking help more quickly (Binder & McNeil, 1986).

Utilization of outpatient mental health services may be a protective factor for families with a mentally ill individual at risk of becoming violent. In their study of the social context of violence among people with serious psychiatric disorders, Estroff and colleagues (1998) found that family members of individuals who used outpatient mental health services 51 or more times in one year were significantly less likely to be the target of violence. Similarly, baseline data from a study of the effects of involuntary outpatient commitment indicate that violent behavior in the past year was significantly higher among individuals who had low social support, were recently homeless, were substance users, had paranoid symptoms, had threat-control override symptoms, or had two or more hospitalizations within the previous year (Swanson et al., 2000). Involuntary outpatient commitment longer than 6 months resulted in significantly lower odds of violent behavior during the study year when controlling for baseline history of violence. The risk of violent behavior was three times greater among participants who misused substances and did not take prescribed medications during the follow-up period. Similarly, a combination of outpatient commitment longer than six months and three or more outpatient visits a month significantly reduced the risk of violent behavior (Swanson et al., 2000).

Family members of mentally ill individuals are at increased risk of violent victimization if their ill relative becomes violent. Table 3 includes descriptions of studies with findings related to relative risk for violent behavior and violent

Table 3. Relative Risk of Violent Behavior and Victimization for Family Members of Mentally Ill Individuals

Author/Year Location	Purpose/Aim	Sample Characteristics	Findings: Relative Risk
Bland & Orn, 1986 Canada	Examine relationship between family violence and psychiatric disorder	1200 randomly selected non-institutionalized individuals: 59% female; diagnoses included antisocial personality disorder, depression and alcohol abuse	54% of those with a lifetime diagnosis engaged in violent behavior at some point; 49% of those who were violent had a psychiatric diagnosis; Odds ratios for coexistence of a diagnosis and hitting/throwing things at partner = 4, physical abuse of children = 3.3, child neglect = 7.9
Estroff et al., 1994 U.S.	Examine the relationships between violent acts/threats by people with a serious mental illness, characteristics of their social networks, and characteristics of their social support	169 people with a serious mental illness: 70% lived with family; 80% employed; 41% white women, 30% white men, 19% African-American men, 10% African-American women; mean age = 28.6; and 59 of their most significant others	36% of respondents made threats of violence or committed a violent act during the study period – 53% of targets were family members (28% were mothers); Respondents rated the significant others who were targets of violence as more attacking than those who were not targets; Mothers of violent respondents rated themselves and their children as more hostile than mothers of nonviolent respondents
Estroff et al., 1998 U.S.	Examine which members of the social networks of people with a psychiatric disorder are likely to be targets of violence; what kinds of relationships do the targets and respondents have; among people in the social networks, what are risk factors for being a target of violence	169 people with severe psychiatric disorders who had been admitted to a psychiatric hospital; median age = 28; 53% female; 67% white, 29% African-American, 3% other ethnicities	Over 30 months, 31 respondents directed violent acts towards 51 targets, 61 respondents directed threats of violence towards 116 targets; Among the targets, 31% were immediate family members (primarily mothers) Family members living with a respondent who is financially dependent on them and is diagnosed with schizophrenia are at increased risk for violence; Respondents who were violent rated their significant others as much more hostile than respondents who were not violent
Ferriter & Huband, 2003 United Kingdom	Examine participant views on causes of schizophrenia, their emotional burden, and the helpfulness of others when seeking support	Parents of 22 patients diagnosed with schizophrenia receiving care in a secure forensic facility; all white; mean age = 60	Verbal aggression and violence were 2 of the 3 most frequently endorsed behavioral problems

<p>Straznickas, McNeil & Binder, 1993</p> <p>U.S.</p>	<p>Examine if demographic and diagnostic characteristics of violent patients vary depending on their role relationship with various familial victims; Examine what interpersonal transactions tend to precede incidents of assault on family members</p>	<p>581 patients admitted to a locked psychiatric unit</p> <p>48% female; 66% white; 59% lowest social class; mean age = 40.9 years; 19% physically attacked somebody within 2 weeks of admission</p>	<p>Of the 113 patients who attacked somebody within 2 weeks of admission, 63 attacked a family member, 27 (43%) attacked a parent; 93% of those attacking a parent lived with them; 56% of those attacking a parent were diagnosed with schizophrenia</p> <p>Concurrent substance abuse was evidenced in 15% of attacks against parents</p>
<p>Stuart & Arboleda-Florez, 2001</p> <p>Canada</p>	<p>Determine the proportion of violent, remanded crimes in the community that could be attributed to persons with a mental disorder</p>	<p>1,151 inmates at a detention facility; 91% male; mean age = 28 years; 75% Caucasian; significantly more women than men had not attended high school and significantly more women were of aboriginal origin; 61% of participants were diagnosed with Axis I or II mental disorder</p>	<p>Participants with substance abuse disorders accounted for 49% of all violent offenses and participants with a psychotic disorder accounted for less than 1%; 1 in 10 violent crimes in the sample could be attributed to people with a mental or substance abuse disorder – only 3% of these could be attributed to an offender with a non-substance abuse disorder</p>
<p>Swanson, Holzer, Ganju & Jono, 1990</p> <p>U.S.</p>	<p>Examine the relationship between violence and psychiatric disorders among adults living in the community using Epidemiologic Catchment Area data</p>	<p>10,059 household residents; 368 of whom reported violent behavior within the past year</p>	<p>56% of those reporting violent behavior met criteria for a psychiatric disorder; Rates of violence increased with number of diagnoses – 7% of those with one diagnosis vs 22% of those with three or more diagnoses were violent; Substance abuse was the most prevalent disorder among those who were violent</p>

Swanson et al., 2000 U.S.	Test whether outpatient commitment helps to reduce the incidence of violence among people with severe mental illness	262 involuntarily hospitalized patients ordered to outpatient commitment upon discharge; 114 controls released from outpatient commitment, 102 assigned outpatient commitment, 46 "seriously violent" could not be randomized and were assigned outpatient commitment; 53% male; 79% single; 66% African American, 33% non-Hispanic white, 1% other; 165 graduated high school; 137 annual income <\$6000	Controlling for baseline violence, a low degree of perceived social support was a significant risk factor for violence, a combination of extended outpatient commitment and receiving frequent services significantly reduced violence
Swanson et al., 2002 U.S.	Examine the prevalence and correlates of violent behavior by individuals with severe mental illness	802 adults with psychotic or mood disorders receiving treatment through the public mental health system; mean age = 42; 65% male, 47% white, 45% African American, 3% Hispanic, 5% other race/ethnicity; 33% less than high school education; 18% employed	The 1-year prevalence of violence was 13%; Variables significantly associated with violent behavior included homelessness, married/cohabitating, poor subjective mental health status, violence in the current environment, substance abuse, psychiatric hospital admission in last year
Tardiff, 1984 U.S.	Examine the frequency of assaultive behavior and the characteristics of assaultive patients admitted to two private psychiatric hospitals	784 patients admitted to a private psychiatric hospital accepting only voluntary admissions – 61% female; 819 patients at a different private hospital accepting voluntary or involuntary patients – 49% female	Among the assaultive patients at both hospitals, the targets were predominantly family members other than children or spouses
Tardiff, Marzuk, Leon & Portera, 1997 U.S.	Assess the frequency and types of violence by psychiatric patients two weeks after discharge and assess the characteristics of patients who were violent	430 patients admitted to a private psychiatric hospital and interviewed two weeks after discharge; 54% female; 64% white, 17% African American, 15% Latino; 4% Asian and other; 65% 18-39 years of age, 35% 40-59 years of age	16 of the patients reported one or more violent act within two weeks after discharge; Most of the attacks were directed towards family members or intimates; There were no differences between those who were and those who were not violent with respect to age, race, Axis I diagnosis, drug/alcohol use, or self reported medication compliance

Turkat & Buzzell, 1983 U.S.	Investigate the relationship between hospital recidivism and family network interactions, specifically to what extent are threats of family violence a factor in rehospitalization.	49 individuals hospitalized two or more times during one calendar year; 12 were hospitalized 4 or more times, 17 three times, and 20 twice; 52% were white males, 42% white females, 6% black males; average age = 33; average years of education = 10.3; 73% were single or divorced	83% of the individuals hospitalized 4 or more times had threatened their families with violence at least once
Vaddadi, Gilleard & Fryer, 2002 Australia	Examine the frequency with which family carers experienced verbal and physical abuse from relatives and to identify correlates and consequences of that abuse	101 patients and family member carers from a community mental health service who were either living with or had at least twice a week contact with that primary family carer; Patients – 65 men, 64 received disability, 12 employed; Carers – 44 mothers, 28 mothers and fathers, 3 fathers, average age = 57 years	40% of carers had been threatened by violence at some point in their relative's illness – 22% in the last year; 40% had been hit or struck at some point – 24% in the last year; 17% sustained a physical injury – 4% in the last year
Vaddadi, Soosai, Gilleard & Allard, 1997 Australia	Examine the prevalence of various types of abuse experienced by carers of patients admitted for acute psychiatric hospitalization and explore the correlates and consequences of that abuse	101 acutely admitted psychiatric patients and their primary carers; Patients – 60% male, age range 18-54, 43% unemployed, 47% had no schooling after age 15; Carers – age range 18->75, 54% parents (47% of total were mothers)	33% of carers were physically threatened "several/many times", 17% were hit or struck "several/many times", 20% reported some physical injury

victimization for family members of mentally ill individuals. While outpatient mental health services, including involuntary outpatient commitment, might have the potential to mediate some violent behavior, families might choose to manage the patient themselves, in their home, and delay seeking professional assistance. High risk of victimization in addition to delayed help-seeking make family members particularly vulnerable to the negative effects of violence in their homes.

Health Status of Family Members of Mentally Ill Individuals

Certain populations are exposed to greater numbers of risk factors, which are associated with increased morbidity and premature mortality (Flaskerud & Winslow). It is noteworthy that the death of a family member at the hands of a mentally ill individual is a very rare event. Table 4 includes descriptions of studies with findings related to the health status of family members of mentally ill individuals.

Unfortunately, very little available research emphasizing the health status of family members and caretakers of mentally ill individuals extends beyond burden or coping.

Some of the research on burden among family members and caregivers of mentally ill individuals has attempted to determine what behaviors contribute to perceptions of burden. Jones and colleagues (1995) found objective burden among caregivers to be much more prevalent than subjective burden. Six caregiver behaviors were perceived as objectively burdensome by 100% of the participants: grooming, housework, cooking, providing transportation, managing money, and managing time. Of the seven client behaviors, excessive demands were ranked as most objectively

burdensome by participants. Both objective and subjective burden were associated more with caregiving behaviors than client behaviors (Jones, Roth, & Jones, 1995).

Other researchers have associated perceptions of burden among caregivers with an inability to cope with troublesome behavior, feeling trapped, and lack of knowledge regarding how to respond to their child's symptoms (Ferriter & Huband, 2003). Perlick and colleagues (1999) found that 93% of caregivers, primarily parents, in their sample reported at least moderate levels of objective or subjective burden.

Moving beyond predictors of burden, researchers from London looked at the effects of burden among caregivers. In this study, both objective and subjective burden were associated with psychological distress among caregivers (Bibou-Nakou, Dikaiou & Bairactaris, 1997). Objective burden and perceived mastery were also significantly correlated. Surprisingly caregivers who reported the most burden experienced greater perceived mastery.

Few studies have investigated violent behavior and burden specifically. In an Australian study with 101 community mental health patients and their family member caregivers, the severity of the abuse experienced by caregivers was significantly associated with both emotional distress and overall burden (Vaddadi, Gilleard, & Fryer, 2002). Estroff and Zimmer (1994) found that family members of mentally ill individuals, particularly parents, described living with intimidation, threats, and fear of violence by making accommodations, placating their family member, explaining away, or denying violent behavior that occurred. Some family members described being afraid to sleep at night and taking turns sleeping so that somebody was always

awake with their ill relative. One woman minimized her husband's violence describing how he, "probably just pushed me, and I just got off balance and fell down" (Estroff & Zimmer, 1994, p. 274).

In addition to burden, family members have reported other emotional responses including "loss of what might have been," fear, grief, shock, guilt, confusion, and negative self esteem (Ferriter & Huband, 2003) and feelings of isolation and loneliness (Veltman et al., 2002). Among one sample of caregiving family members, all of whom reported threats of or actual physical harm, 79% reported significant emotional symptomology of their own (Vaddadi et al., 1997). In one qualitative study a mother of a son with schizophrenia is quoted, "I don't know what other people live like. I think of myself as a loner even though I'm a caretaker" (Veltman et al., 2002). In a Swedish study with family members of mentally ill individuals, 47% of the parents reported feeling as though their child's mental illness led to mental health problems of their own, 33% reported that the child's mental illness affected their ability to have company, and 21% endorsed that at times they believed their mentally ill child would be better off dead (Ostman & Kjellin, 2002). A smaller percentage of these parents (16%) felt that their burden was so heavy that they had suicidal thoughts; and, at times, 14% wished that the patient had never been born (Ostman & Kjellin, 2002).

Research addressing attributes with the potential to mediate some of the burden associated with providing care to mentally ill family members have also been conducted. Solomon and Draine (1995) conducted a study of adaptive coping among

225 family members, 76% of whom were parents, of mentally ill individuals. They looked at family characteristics, illness related stressors, family member response to stressors, and social support as predictors of adaptive coping. None of the illness related stressors or responses to stress were significant. Only three social support variables were significant predictors of adaptive coping. These were support group membership, larger social network, and affirming support from social network members. One of the only other significant predictors of adaptive coping was high sense of self-efficacy in responding to the relatives' illness (Solomon & Draine).

The benefits of participation in a support group for family members of mentally ill individuals were evaluated by Citron, Solomon, & Draine (1999). Among 195 family members (81% parents) who were members of a support group, greater than 50% reported benefiting a great deal from the support group. The benefits of participation came from having more knowledge about mental illness, having more information about services, feeling less alone in their concerns, feeling better able to cope emotionally, and feeling better able to cope with stigma. Length of time in the support group, information provision, and gaining support were all significant predictors of group benefit for these participants (Citron, Solomon, & Draine).

There are obvious benefits to caregivers when outpatient follow-up occurs; however, if scheduling and attendance at these appointments is their responsibility, it may also have unanticipated negative consequences for the caregiver. While Swanson et al. (1990) found that outpatient commitment and treatment decreased the risk of violent behavior, the intensity of treatment may affect caregivers in other ways

Table 4. *Health Status of Family Members of Mentally Ill Individuals*

Author/Year Location	Purpose/Aim	Sample Characteristics	Findings: Health Status
Bibou-Nakou, Dikaiou & Bairactaris, 1997 England	Examine the relationship between family burden and psychological distress among family members of psychiatric patients	"Carers" of individuals with schizophrenia included parents, siblings, spouses/partners; 73% women; 52% parents; 40% over age 55	Significant positive associations between "carer" mental health and subjective burden; Perceived mastery and psychological distress significantly positively associated
Citron, Solomono & Draine, 1999 U.S.	Examine perceived helpfulness of self-help groups for families of people with a mental illness	202 members of Alliance for the Mentally Ill in Pennsylvania – 81% parents, 9% siblings, 5% spouses, 3% adult children; Mean age = 60; "predominantly white middle-class mothers"	Reported support resources outside of group: 24% other family members, 22% professionals, 17% friends; 19% felt more overwhelmed by their relative after group involvement
Ferriter & Huband, 2003 United Kingdom	Examine participant views on causes of schizophrenia, their emotional burden, and the helpfulness of others when seeking support	Parents of 22 patients diagnosed with schizophrenia receiving care in a secure forensic facility; all white; mean age = 60	Despite clear signs of danger, some parents remained protective of their child; Evidence of desensitization to violence and associated fear, and failing to appreciate the level of danger
Groff et al., 2004 U.S.	Examine factors contributing to subjective strain experienced by caregivers of people with severe mental illness	Involuntarily hospitalized patients awaiting period of court-ordered outpatient commitment and their caregivers – 270 patients and caregivers at baseline, 177 patients and caregivers at 12 month follow-up; Caregivers were 59% female, 43% parents, 63% had a high school education, mean age = 52 years, 63% black	At baseline, caregiver subjective strain significantly positively associated with patient age, psychotic diagnosis, problem behaviors, problems with daily living, caregiver education and age, cohabitation; At 12 month follow-up, caregiver subjective strain significantly positively associated with baseline strain, and high service intensity (>3 visits/month), and significantly negatively associated with number of days patient assigned outpatient commitment, and treatment adherence

<p>Jones, Roth & Jones, 1995 U.S.</p>	<p>Predict objective and subjective burden among caregivers of chronically mentally ill individuals</p>	<p>189 caregiver-client dyads; Caregivers: mean age = 52, 78% female, 78% white; Clients: mean age = 43, 60% female, 76% white, 36% lived with caregiver</p>	<p>When client lived with caregiver, significant predictors of objective burden were grooming, housework, cooking, and being kept up at night; Significant predictors of subjective burden were grooming, medication, housework, shopping, cooking, and managing money</p>
<p>Perlick et al., 1999 U.S.</p>	<p>Assess impact of problem behaviors, role dysfunction, and adverse effects on burden among family caregivers of individuals with bipolar disorder</p>	<p>266 in or outpatients diagnosed with Bipolar I, II, or schizoaffective disorder manic type and their primary family caregivers Patients: 58% female, mean age = 39; 54% lived with caregiver Caregivers: 66% female, 44% parents of patient, mean age = 50, 85% Caucasian, 8% Hispanic, 6% Black</p>	<p>54% reported severe burden; A belief that the patient can control his/her symptoms was positively associated with both objective and subjective burden; Caregiver unawareness of the illness, and believing that the caregiver can control the patient's behavior were inversely associated with both objective and subjective burden</p>
<p>Solomon & Draine, 1995 U.S.</p>	<p>Describe factors associated with adaptive coping among family members of people with serious mental illnesses</p>	<p>225 family members (parent, child, spouse or other) with major responsibility of relative with schizophrenia or a major affective disorder; 76% parents, 88% female, 84% white, mean age = 55 years, 54% some college education, mean annual income = \$36,600</p>	<p>Adaptive coping was significantly associated with: being female, being white, having a large social network, affirming support from social network, membership in support group for families, and a sense of self-efficacy in responding to relative's mental illness; Social support was the strongest factor in explaining adaptive coping</p>
<p>Vaddadi, Soosai, Gilleard & Allard, 1997 Australia</p>	<p>Examine the prevalence of various types of abuse experienced by carers of patients admitted for acute psychiatric hospitalization and to explore the correlates and consequences of that abuse</p>	<p>101 acutely admitted psychiatric patients and their primary carers; Patients – 60% male, age range 18-54, 43% unemployed, 47% had no schooling after age 15; Carers – age range 18->75, 54% parents (47% of total were mothers)</p>	<p>15% of carers (all of whom experienced threats of or actual harm) reported "living in fear of their relative"; Amount of abuse experienced was significantly positively associated with GHQ score; Total burden score was significantly positively associated with amount of abuse experienced; Significant tendency for carer relationship ratings to become more negative with increasing duration of their relative's illness and the length of time the carer had to look after the patient</p>

Veltman et al., 2002 Canada	Gain greater knowledge of the meaning that caregivers of relatives with a mental illness derive from their situation	17 women, 11 mothers; age range 24-73; all acted as caregivers for more than 2 years, length of caregiving ranged from 2-38 years	8 of the caregivers had been diagnosed and treated for depression at some point after the onset of their relative's mental illness
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as well. Groff and colleagues (2004) assessed the impact of outpatient commitment on caregivers of mentally ill individuals. These researchers found that baseline caregiver strain and high service intensity defined as more than three visits per month were significant predictors of caregiver strain after one-year. However, reductions in caregiver strain were significantly associated with increased number of days on outpatient commitment and treatment adherence (Groff et al.).

Conclusion

Use of the Vulnerable Populations Conceptual Model provided an organizing framework for the review of literature that clearly identifies family caregivers of individuals with a mental illness as a vulnerable population. Family members are at increased risk of being victims if their mentally ill relative becomes violent. A great deal of research has been conducted emphasizing risk factors for violent behavior and violent victimization among mentally ill individuals and their families. Specific diagnoses and symptomology have been associated with increased risk of violent behavior as have younger age, cohabitation, substance abuse, and exposure to community violence. Additionally, family members who have a poor relationship with or set limits on their mentally ill relative's behavior may be at increased risk of becoming victims of violence. Increased risk of victimization in combination with a lack of social connection and available resources increases the family's vulnerability to further violence and its negative consequences.

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Chapter Two

Getting to “The Point:” The Experience of Mothers Getting Assistance for Their Violent Mentally Ill Adult Children

Although no more prone to violence than the general population, research has shown that when individuals who are mentally ill become violent, family members are most often the victims of these violent acts (Arboleda-Florez, 1998; Binder & McNeil, 1986; Steadman et al., 1998; Tardiff, 1984). Parents are the most common family member victim (Binder & McNeil, 1986; Straznickas, McNeil & Binder, 1993), specifically mothers (Estroff, Zimmer, Lachicotte & Benoit, 1994; Estroff, Swanson, Lachicotte, Swartz & Bolduc 1998; Estroff & Zimmer, 1994). However, little is known about the experiences these family members have attempting to get help for their violent, mentally ill children. The purpose of this research was to describe the experiences of mothers who have been victims of violence perpetrated by their mentally ill, adult children, including their understanding of their children’s illness and behavior, as well as the process they go through to get assistance. The results of this study address the gap that exists in the literature with respect to mothers’ perceptions of access to mental health treatment, in the form of hospitalization, and interactions with police and mobile psychiatric evaluation (PET) teams when their mentally ill children become violent towards them.

Background Literature

Family members play a very important role in accessing mental health treatment for their relatives. In this role, they often assume a great deal of responsibility for getting their mentally ill relatives to the hospital. Additionally, family members are as good as, if not better, than mobile crisis teams and/or police in determining whether or not their relatives need hospitalization. In one study of 311 psychiatric emergency room referrals, 43% of patients evaluated were brought in by relatives while 36% came in with police (Dhossche & Ghani, 1998). In terms of hospital admissions, Strauss and colleagues (2005) found that individuals brought to the hospital on mental inquest warrants initiated by family members were significantly more likely to be hospitalized than individuals brought to the emergency room under the direction of a mobile crisis team. However, mobile crisis teams and police officers remain gatekeepers to mental health treatment for many individuals and the determination to hospitalize a person is often at their discretion, regardless of the family's sense of what is best for the person (Lamb, Weinberger & DeCuir, 2002; Teplin, 2000).

As gatekeepers to mental health treatment, the police often prefer to handle situations with individuals who are mentally ill informally rather than arrest or involuntarily hospitalize them (Lamb, Weinberger & DeCuir, 2002; Teplin, 2000). This could be, in part, due to a lack of cooperation between mental health systems and police. In a study of police perspectives on responding to mentally ill individuals in crisis in four U.S. cities, less than half of the officers reported that their mental health

systems or emergency rooms were moderately or very helpful (Borum, Deane, Steadman & Morrissey, 1998). The lack of cooperation from emergency room staff may be a result of unavailability of resources to manage psychiatric patients. In a survey of 223 California emergency departments, 50% reported that no mental health professional was available for evaluation of suicidal patients (Baraff, Janowicz & Asarnow, 2006).

The mental health system is not only perceived as unhelpful by police officers. Family members report dissatisfaction with their inability to access mental health treatment during periods of their relatives' decompensation (Winefield & Harvey, 1994). Most civil commitment laws only allow involuntary hospitalization when a person is imminently dangerous or gravely disabled. Some states, however, permit involuntary hospitalization if an individual with a mental illness may deteriorate to the point where they become dangerous or gravely disabled (Petrilla & Levin, 2004). Therefore, in situations where laws prohibit commitment until an individual is actually dangerous or gravely disabled, family members must attempt to manage their relatives' behavior while also watching their mental health deteriorate.

Family members are often experts in the practical aspects of their mentally ill relatives' illnesses. This study contributes to the understanding of how involuntary commitment laws directly affect family members of individuals who are mentally ill, and how the police and psychiatric evaluation teams (PET) are perceived by mothers who rely on their assistance as gatekeepers in order to get their children mental health treatment.

Methods

Design

Grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1998) was used to guide this study, leading to the development of a theoretical map of the process mothers use to get immediate assistance when their mentally ill adult children become violent. Tenets of the sociological theory of symbolic interactionism provided a foundation for this research. Symbolic interactionists believe that people act in a manner consistent with the meaning of objects in their world. Meaning is derived through social interaction and through the person's interpretation of those interactions (Blumer, 1969). Consistent with the tenets of symbolic interactionism, in this study it was assumed that mothers interpret their children's mental illness and the violent behavior they exhibit in a way that makes sense to them in the context of their daily lives. The meaning of both, as understood by the mothers, affects their decisions and actions in response to the violence they experience.

After obtaining institutional review board approval, the purpose of the study was explained to social workers and charge nurses at two adult locked inpatient psychiatric units. These staff members were trained and then assumed responsibility for study recruitment. One unit was at a free standing, large, for profit psychiatric hospital; the other was a small unit at a not for profit, large medical center. Both units are situated in a large urban area. At both units, trained staff identified patients with a known history of violence directed towards their mothers. These mothers were then contacted by recruitment staff who explained the study to them, invited them to

participate and provided them with the primary investigator's contact information. Participants were also recruited through a local NAMI chapter at which the primary investigator made an announcement, explaining the study and inviting participants, at a single meeting. Interested women were then responsible for contacting the primary investigator who screened potential participants and arranged meeting times and places with those who met eligibility requirements. Eligibility requirements included: having a child (biological, step or adopted) with a DSM – IV Axis I psychotic, mood or anxiety disorder in the absence of a co-occurring substance abuse or personality disorder, this child being age 17 or older, this child exhibiting violent behavior towards the mother, and the mother being under age 65. Violence was defined as the use of physical force, in the absence of self-defense, including explicit threats of physical harm. The primary investigator conducted all interviews and is a monolingual English speaker and could therefore not accommodate women wishing to be interviewed in another language.

Data were collected via open-ended interviews. An interview guide was developed to elicit the mother's experience of getting immediate assistance for themselves and/or their children when their children became violent. Special probes were used to explore the mothers' (a) understanding of their children's mental illness, (b) experiences of violence perpetrated by their mentally ill adult children, and (c) decision-making process used to seek immediate assistance when their children became violent.

Sample

Fourteen women interested in participating in the study contacted the primary investigator; however, six women were not eligible. One woman's son was currently using drugs, two women wished to conduct the interview in a language other than English, and three women were over 65 years of age (two were in their eighties). Therefore, the sample consisted of eight women. All were interviewed one or two times in their homes or in another safe and private location of their choice such as a park or place of worship.

Of the eight participants, two identified themselves as white, two as African American, one as African, and three as Latina or Hispanic. Five of the women were married, one was single, one was divorced and one was widowed. All children of the participants were single, and three of the children were residing with their mothers. The mothers reported that all of the mentally ill children were diagnosed with a psychotic disorder (4 schizophrenia, 3 schizoaffective, 1 bipolar/schizophrenia, and 1 psychotic disorder not otherwise specified/attention deficit hyperactivity disorder). All of the mentally ill children were biological sons or daughters except one who was an adopted nephew. Five women were mothers of sons who were mentally ill, two women had daughters with a mental illness, and one woman had both a son and daughter who were mentally ill. Only half of the women felt that their household income was adequate to meet their needs. The ages, education attained, and work and insurance status of the mothers and their children are presented in Table 5.

Table 5. *Sociodemographic Characteristics of Sample*

	Mothers (n = 8)	Children (n = 9)
Age Range	42 - 60	20 - 38
Education		
Less than HS	2	3
Graduated HS	3	5
Some College	3	1
Employed		
Part Time	2	0
Full Time	3	0
Reported Monthly Income	1 - Unreported	
Under \$1000	2	
\$1100 - \$2000	1	
\$2100 - \$3000	0	
\$3100 - \$4000	1	
\$4100 - \$5000	3	
Number of People Supported by Monthly Income		
1	3	
2	1	
3	3	
4	1	
Uninsured	4	2

Data Collection

Written informed consent was obtained from participants before proceeding with the interviews. Interviews were audio-taped and lasted 1.5 - 2 hours. The women received \$20 for their participation. Sociodemographic data were collected using a researcher generated form which was either completed in written form by the participant alone or by verbal report and recorded by the researcher. Written observational, theoretical, and methodological field notes, as described by Schatzman & Strauss (1973), were written immediately after each interview. These notes included events seen or heard during the interview, interpretations of the interview,

early hunches, self reflection, and self critique of behavior and tactics of the researcher throughout the interview (Schatzman & Strauss, 1973).

Data Analysis and Interpretation

All interviews were transcribed verbatim by the primary researcher and checked against the audiotapes to verify accuracy. Recruitment and screening of participants, data collection, and data analysis occurred simultaneously consistent with grounded theory techniques (Polit & Hungler, 1999). First, the transcripts were coded line-by-line. Then open coding was used to break each sentence into small pieces and as many codes as possible (Hutchinson & Wilson, 2001). These codes were words and phrases describing what the mothers were talking about in each sentence. Data analysis then moved to a higher level of abstraction as open codes of shared meanings were grouped together as categories and their relationship with each other were surmised. This led to a process of identifying the various properties and dimensions of each category, which were subsequently linked by relational statements (Strauss & Corbin, 1998). This process allowed the variability within each identified category to be made more explicit and thus more readily explored and analyzed. Similar categories identified in each interview were compared to each other in order to clearly differentiate the categories from one another and to explore the depth and range of each category. This led to the process of recognizing the potential relationships between the categories. These hypothesized relationships were then confirmed or refuted through an ongoing process of further data collection and more analysis of new data as it was collected.

By taking notes and writing memos throughout data collection and analysis, an audit trail was generated (Stauss & Corbin, 1998). This audit trail was useful in outlining how the interviews were interpreted, the logic of those interpretations, and how decisions were made regarding ongoing data collection and both the use of and the development of new interview prompts. While the primary investigator conducted the interviews, each interview was discussed with the co-investigator. Both investigators analyzed each interview individually and then analyzed them collaboratively using the process described to ensure rigor.

Results

Understanding of Mental Illness

The themes identified with respect to the mothers' understanding of their children's mental illness, included the origin of their child's mental illness, symptoms of their child's mental illness, and their prognosis.

Origin of the Mental Illness

The women attributed the origin of their children's mental illness to a variety of biological, relational, historical, and personal factors. Most mothers seemed to feel that biology, including heredity, is involved, but were not willing to accept that as a singular explanation. Rather, they believed that their children's illness was due to a combination of heredity or a chemical imbalance coupled with a trigger of some sort (drug use, trauma). For example, a mother acknowledged a chemical imbalance in the brain as the root of her son's illness, but went on to describe his illness as manifesting

itself as a result of the way he was raised. Another mother understood the mental illness to be the product of a weak mind and lack of will, acting in combination with faulty brain chemistry or heredity. Every potential explanation was scrutinized and no participant accepted just one causative factor. Mothers also agreed more with certain explanations in particular circumstances such as specific symptoms. For example, auditory hallucinations were more likely to be attributed to brain chemistry, while an inability to follow directions or cope with stress was attributed to parenting style or lack of structure in the home.

Some women revealed intermittent confusion in their understandings of the origin of their children's illness. For example, one woman specifically mentioned that she had been told schizophrenia is hereditary. She later stated, "I don't know how this schizophrenia even came about with her" because nobody in her family had a history of schizophrenia. However, she failed to take into account the father's family history.

Symptoms and Characteristics of the Mental Illness

Women described early symptoms of their children's illness as rebellion, disobedience, and "acting out." Later these symptoms expanded to include talking to themselves, paranoia, suicidal talk and/or gestures, mood swings, poor hygiene, isolation, and auditory hallucinations. Behaviors such as not following directions, and being intrusive or unpredictable were also part of the symptom clusters.

The women perceived lack of motivation and lack of insight as personality traits or characteristics of the children rather than as symptoms. For example, several women described their child's lack of motivation to leave the house, to socialize, to

work, to go to school, and to spend time with the family. However, lack of insight on the part of their children was one of the most distressing symptoms for these mothers, particularly because it hindered their children's ability to get treatment. One woman felt strongly that what her daughter needed most was to be educated regarding her illness. Her daughter had been ill for more than fifteen years, but she felt that her daughter simply did not understand her illness. She believed that if her daughter was educated and learned about her illness that she would then seek treatment.

The mothers were confused by the transient nature of some symptoms exhibited by their children. The mothers felt the ability to display or hide their symptoms was volitional on their children's part. Children were regarded as manipulating healthcare providers, police, or psychiatric evaluation team (PET) members because they were able to control their symptoms in the presence of these individuals. For this reason, children were sometimes perceived as manipulative or "playing a game" because they could hide their symptoms when contacted by these professionals.

Prognosis

Mothers spoke of their children's progressive and unanticipated decline in functioning. At the time of diagnosis mothers knew their children had a chronic mental disorder; they did not however, expect their children to become increasingly impaired as they got older. They believed that the illness would never go away, but if their children took medication for the rest of their lives, they could function normally. All of the mothers believed their children needed medication in order to function

optimally. Most women felt that if their children did not receive treatment, specifically medication, they would end up institutionalized long-term or homeless.

Mothers described their children as unexpectedly “getting worse over time,” and themselves as having increased difficulty “dealing with” their children as they aged. Their children’s decline in functioning was described in multiple ways. Women felt that their children were being hospitalized more frequently over time. The children’s progressive decline was also manifested by what they perceived to be longer and longer lengths of time needed to restabilize between episodes of decompensation. Some of the women described their children as never returning to the level of functioning they experienced prior to each episode of decompensation.

Understanding of Violence

Mothers described the origin and onset of their children’s violent behavior, and how they perceived this to be a key to mental health treatment.

Origin of Violent Behavior

Most of the women described the origin of their children’s violent behavior as their mental illness. Thus, the violence occurred as a result of the symptoms their children were experiencing and was not intentional or goal directed. As said by one mother regarding her daughter’s violent behavior, “I think it’s delusions because I can’t imagine it being on purpose.” Only one woman differentiated the origin of her son’s violent behavior as intentional at times and a product of his illness at other times. She reported that her son, “can’t process things so he gets angry,” but during a

separate episode of violence she said her son, “was angry because he wanted his money and he figured he could bully mother into giving it to him.” Regardless of how she interpreted the origin of her son’s violent behavior, her reaction was the same; she called the police for assistance.

Onset of Violent Behavior

Although the onset of their children’s violence was sometimes described as sudden and unexpected, it was more often described as the climax of a period of escalating, acting-out behavior. First there would be verbal altercations and/or property damage. Then the women described themselves as confronting their children for not following house rules (i.e. smoking, bringing strangers to the house, flooding the bathtub), and for being disrespectful or “misbehaving” in the home (slamming doors, breaking household items, locking other family members out of the house, keeping other family members awake at night, throwing valuable items in the trash). One woman said of setting limits on her son’s behavior,

He totally takes things and turns it around, but at the same time I can’t stop saying what I’m saying because if I do then things would be totally out of control. So I had to keep things in control regardless of how he thought, but at the same time it was just building up like I’m against him.

Eventually the cycle of acting-out behavior and confrontation or limit setting culminated in the children’s violence.

Violent Behavior as a Key to Mental Health Treatment

In addition to describing the origin and onset of their children’s violent behavior, the mothers understood the violence as crucial for getting their children

mental health treatment. The women all had extensive experience attempting to get their children mental health care. They understood that their children are adults, and therefore they cannot be hospitalized involuntarily unless they meet certain criteria for involuntary hospitalization, one of which is being a danger to others. While their children were decompensating, experiencing worsening symptoms, and exhibiting disruptive behaviors, the mothers knew that hospitalization would not occur unless their children's behavior escalated to the point of being dangerous towards themselves or somebody else, perhaps them. Once their children became violent, they knew that they could get their children into the hospital so they would call either the police or the PET team for assistance with involuntary hospitalization.

Getting Immediate Assistance

Getting immediate assistance when their children became violent often resulted in involuntary hospitalization. For the mothers, the process of getting immediate assistance involved a period of living on high alert and a period of frustration while having to wait, which culminated in fear or uncertainty outweighing their ability to manage their children's behavior. This was the point at which point they called the police or PET team evaluators for assistance. This process is illustrated in Figure 2.

Living on High Alert

Mothers felt as if they were on "high alert all the time." Their living environments were filled with stress, tension and chaos. Mothers characterized their children as going into "spirals" and getting "out of whack and out of control." One

mother described the difficulty she and her family had living with her mentally ill daughter in the following way,

They do a lot of things that are very overbearing, bizarre, crazy you know. Your life is crazy, ups and downs. Your life is intense. You walk around on egg shells. You know your life is not happy, especially when they get really, really ill, you know because they have their swings and sometimes my life gets, my whole family has this intensity of drama and anxiety in the family.... There was a time where she was just constantly bathing every 5 minutes, every 5 minutes, every 5 minutes. She would overflow my house and water would go through the living room, through the kitchen and stuff like that. Pots were being burned, um the carpet almost catching on fire. I mean it's bizarre you know.... And then when she wakes people up at night cussing and yelling and screaming and you're like trying to go to bed cause you need to go to work and she leaves nobody going to sleep. And then everybody wakes up for days and days you're going to work tired, exhausted because you haven't gone to sleep, you know so it's not easy living with her.

During this period mothers balanced their ability to manage their children's behavior with their own fear and uncertainty, while they remained aware and alert amidst the building stress and pressure.

Frustrated Waiting

While their children decompensated right before their eyes, mothers waited, in frustration, for the inevitable point at which their children met criteria to be held involuntarily. This was a period of tension building and uncertainty. Mothers knew that their children needed help and would benefit by hospitalization at this point, but they were forced to wait until something dangerous happened before any help could be sought. As one woman said of this period,

So what do I have to do? Wait and wait and wait and wait and wait and wait until until it's um the PET team um um what do you call those criterias. Do I have to sit here and wait until that explosion happens?

Another woman who tried to get help as her daughter began decompensating, before her behavior escalated to violence, was told, “well she’s not sleeping [at night], ok as long as she’s not threatening you right now.’ But I have to wait, and wait, and wait, and wait. Why do I have to wait so long? Why do I have to wait so long?”

While the mothers waited for their children to become overtly dangerous, they were exposed to and were forced to manage a barrage of troublesome behaviors from their children. One mother said of these other behaviors,

Most of the time it was screaming and throwing things and kicking the walls and breaking the doors and slamming the doors and throwing anything that’s on the shelf off the shelves. Then it got to the point where it was starting to get physical. I mean I guess you could deal with the other stuff.

The mothers were very experienced at attempting to seek help, and as one woman said, “being that I’ve called more than once or twice, I know the system.” Because the children were unwilling to be hospitalized voluntarily, mothers needed to wait until their children became overtly dangerous before attempting to hospitalize them against their will. While waiting to get help for her son who would not accept voluntary hospitalization, one woman said of her experiences

It’s like you wait till something horrible happens before something can be done and that’s one of my frustrations about, there’s a lot of mental illness out on the street and the longer it goes unchecked, the worse the state becomes for that particular person.... I don’t know what he’ll do. And I don’t want the button pushed to that point because I’m not, I don’t want him to hurt me.

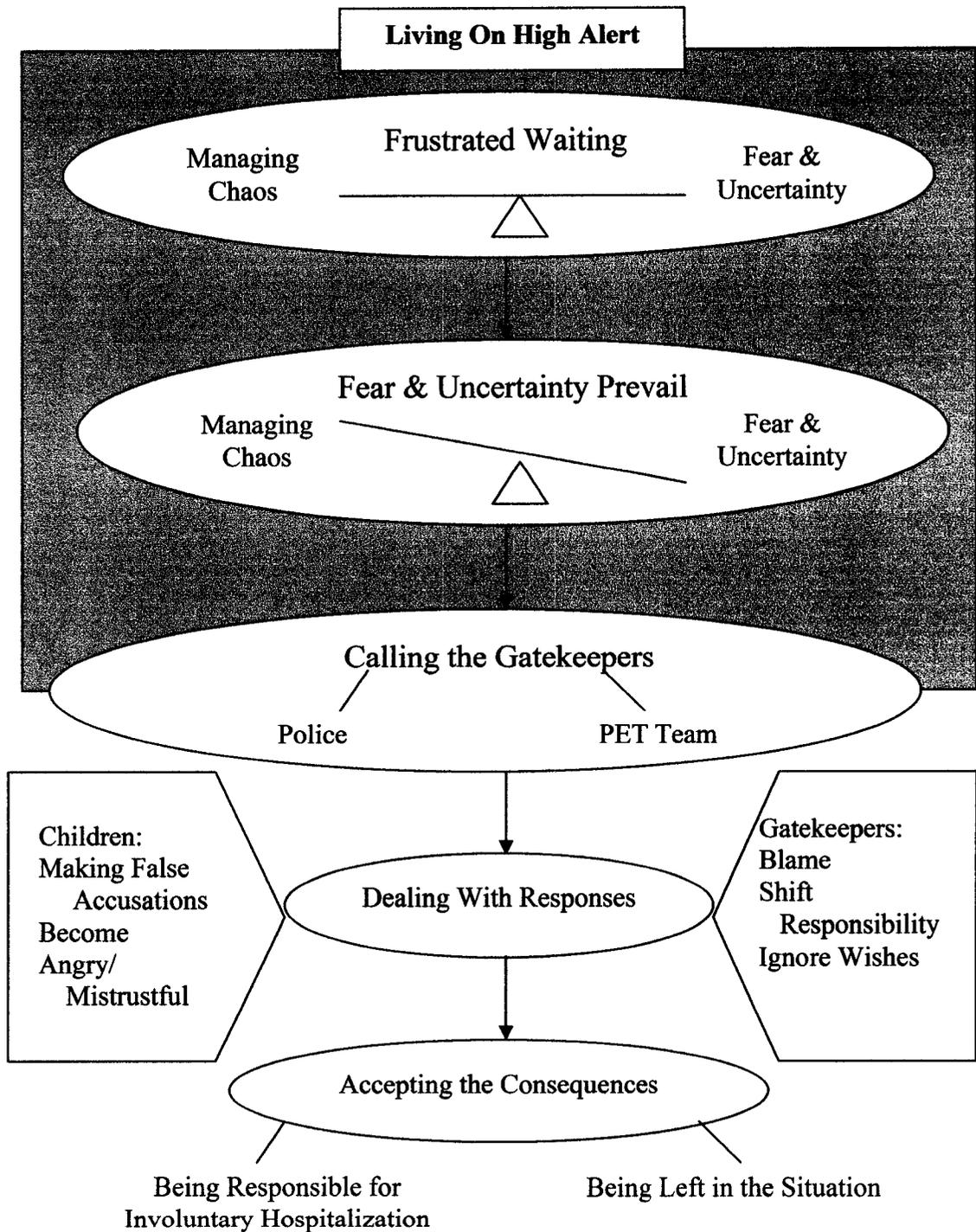


Figure 2. Mothers' process of getting immediate assistance when mentally ill, adult children become violent.

During this period of decompensation and waiting, most of the children were not taking any medication. The longer they went without medication and/or other treatment, the more unpredictable their behavior became. Because their children were not receiving professional treatment during this period, the women understood that their children might behave in certain ways, but not be cognizant of what they were doing or why they were doing it. One woman said of her son,

In my spirit I felt like, geez this boy may pull a knife or something and he'll do something and really he won't have that intention of doing, doing it.... I'm just not sure what he will do and if it keeps escalating and his anxiety level goes up, cause one time we were in the living room and he came and I could see his fists and I said, 'what are you gonna do?' He said, 'uh sometimes I just want to kill you.'...I don't know when that's a breaking point you know.... I know it keeps escalating if he doesn't get help or medication... but as time goes on and he doesn't sleep it escalates. And that's my point, I don't know how far it will escalate... but there are times when I know that it's an unsafe time for him and for me or anybody that is around.

The women didn't know what their children might do. They did not want their children to hurt them, but danger was inevitable. While mothers knew that a violent outburst was looming, they did not know how, when or under what circumstances it would manifest.

Managing the Chaos

While they awaited their children's violent outburst, mothers used a variety of techniques as a means of "dealing with," "struggling with," and "handling" the unpredictability characteristic of the chaotic environment in which they were living. One mother coped by finding "things to occupy his time...to find something to keep

him busy.” Other women attempted to distract their children with music and activities. One woman described how she and her husband were

constantly, trying to tell her, ‘come on, stop it, stop it.’ You know she’s like, ‘ok’ and then all of a sudden back into the thing again. And that’s why I said, ‘come on let’s put some music, let’s come on you know...come on let me try to comb your hair.’

Some mothers did not attempt to distract their children, but avoided them by isolating themselves. One mother described herself as “a prisoner up in my room, watching tv.” Mothers also reoriented their children to the present and set limits on their children’s behavior by telling them not to engage in certain behaviors. One mother told her son “you need to stop and think, that’s not real, stop it” or “you need to back up...you need to go and sit down and just be still” when he would make delusional comments or “get in [her] face.”

For many mothers, this was a period of 24 hour, vigilant caregiving amid the chaos. One mother discussed her situation as always checking and watching,

She’s just done a lot of things you know just yelling and screaming in the middle of the nighttime, it’s like loud shouting and screaming... You’re just like ‘X, stop it, it’s too much, it’s way too much.... You know it’s, it’s looking to see...you have to walk into her room to see that she’s not catching the house on fire you know in the middle of the night and you have to wake up constantly like you know to see ok is she awake, asleep or not.

The mothers continued to set limits for their children to manage their bizarre behavior, not knowing if it would trigger violence. Sometimes their limit setting was misinterpreted. When one woman told her son to behave a certain way,

He felt like I was tormenting him. He didn’t see it as you know I’m trying to ask you not to do something that you shouldn’t do. He felt like it was a

torment. So he'd get upset and say that I was messing with him, or irritating him, or picking on him.

Other family members (husbands and sons) were sometimes involved in attempts to manage and control the environment in order to maintain everybody's safety. One woman told her husband that her son "almost punched me. And he said 'well do we need to call the police?' I said 'no, he didn't punch me, he just almost punched me.' And so he said 'ok' and then he talked to [her son] about it and you know lectured him, we both did and said 'you can't act like that.'" Another woman described her husband as "the person who comes down and stops everything and even then he can't really control her anymore like he used to." For several families, in order to "control" their children, it was necessary to physically restrain them in order to prevent them from "really hurting themselves or someone else."

Tipping the Balance: Fear and Uncertainty Prevail

The period of frustrated waiting came to an end when the mothers no longer knew what to do to control their children's behavior. Some women became increasingly scared for their own safety because their children's condition continued to worsen without treatment.

One woman noted she would wait until her child "actually hit" her, or until she sensed it was leading to violence. As another mother said, "it got to the point where it was starting to get physical. I mean I guess you could deal with the other stuff." This woman said she "didn't call the police in the beginning because we were able to settle her down, but then the attacks got more violent." Other women reported feeling too

threatened and overwhelmed to manage their children prior to that point. Despite variable tolerance levels for threats to their safety, each woman finally came a point when she didn't "know what to do" and felt that she could no longer help her child. The techniques the women used to manage their children (distraction, reorientation, isolation) became ineffective or too tiresome to continue.

The family's response was an additional important indicator of the level of danger. One woman noted that the situation "gets too hard, too much to handle...when finally the family gets worried and too tired." This helped the women know their efforts were no longer effective in "settling down" their children or that they themselves could no longer "just deal with it." It was at this point that they called for assistance.

The "point" at which the PET team was called was described by all mothers as when the women "didn't know what to do." They reported, "I'm the mom, I'm not the doctor, but I just knew something was terribly wrong. And I knew why, but I didn't know what to do about it. So I did my best and like I said, at one time I had to call the PET team because I was actually scared of him." Another woman commented, "I only put her [in the hospital] when I feel that it's, it's that point. That thing where you know, I can't help her." Another said of her son,

He was just so unmanageable and boisterous.... You know he would throw objects at me and. So it got , at one point, I had to put him, I had to call the PET team and they came and got him because I just, I didn't know what to do with him. He was just, he was hurting me by, you know. He would shove me against the wall.

Therefore, once the mothers experienced a heightened fear of harm and were uncertain about what more they could do to manage their children's behavior, they called for outside assistance from either the police or a psychiatric evaluation (PET) team.

Calling the Gatekeepers

For mothers who were unable to get their children into the hospital up to this point, the police and PET teams were the first set of gatekeepers to mental health treatment. Once their children actually became violent, mothers knew their children could enter the mental health system and be treated involuntarily. When the police or PET team evaluators came, they not only decided whether or not to remove the children from the home, but they also had the responsibility to decide if they should be taken to a hospital or to jail. For some women calling these gatekeepers was as easy as asking them "to take (their children) away." Others described the police as "not a help at all." It wasn't perceived as helpful when the police tried to give mothers advice to get restraining orders against their children, because most mothers did not want to do this. Also, mothers indicated that they felt the police had behaved unprofessionally. One mother explained that the conversation became heated when the police arrived. She stated that the

police is (sic) not a very helpful thing either. They're not, I didn't like their attitude this time when they came. The guy tried to be really funny like said 'well who am I gonna pick up? Who's the one who am I taking to jail?' And I even turned around and told him 'look this is a mental patient. She's my daughter and is very ill.' But the sarcasm that they walked into the house with I didn't particularly care for.

In most instances it was clear to the police that the child was mentally ill.

During some altercations, however, another woman's daughter would call the police before her mother was able to. She described situations in which her husband was nearly arrested.

It got to the point where she would kick, sock, you know, dig her nails into me, pinch, but really hard like so you have to defend yourself so I always thought you know I'm gonna sock her really hard you know and get her off of me, and I did that a couple times and she called the police on me. And the police come and then you have to explain what's going on and my husband will come down and my husband has like an aura about him that the police don't like I think because they're always like telling him 'you go over there and you sit down and you shut up.' And he goes 'hey wait a minute this is what', 'no you just be quiet we know what's happening here.' And I would tell them 'you guys are wrong, you guys are wrong.' I don't know how many times they almost arrested my husband because of them, 'You just sit there and don't say a word and don't even get up and approach my partner.' And he would just, you could see him fuming because he's like mad because he's desperate. Desperate for the situation and desperate because nobody's listening. She would use that. She would call the police and say 'they're hitting me' or 'my father is dragging me across the floor', and in order to defend ourselves sometimes we, things did happen.

For all of the women, calling the police or PET team was not an immediate reaction to the first signs of their children's decompensation. In many instances, such as the one described, the situation had escalated to the point where the mothers needed to defend themselves from their children.

Dealing With Responses From Both Sides

In addition to feeling "desperate" because they felt as if the police were not listening to them, when mothers called the police or PET teams they had to deal with responses, primarily negative, from the gatekeepers themselves, as well as responses from their children.

Responses From the Gatekeepers

Blame. The women cited blame as a common reaction of the police when they arrived at their house. The police primarily blamed mothers for allowing their children to be in the home. Women sometimes felt as though the police were interrogating them. One mother said,

It got to the point where the police were down here three or four times a week. And I think they were getting a little mad, and they would ask, 'why do you let her come back?' 'She's my daughter. She's sick. She has nowhere to go, what do you think?' 'Well you need to, you need to evict her, you need to do this you need to do that.' I go 'well you need to take her to jail.' 'Oh no ma'am we're not taking her to jail.' I go 'why not? She needs to go in front of a judge to show that something is wrong, that she needs some long term care.'

Often, the police insinuated that if the women did not allow their children in their homes, the children would not be violent and the mothers would not need to call the police for assistance. They inferred that the mothers were responsible for their own victimization and resulting need for assistance.

Ignore Wishes of the Family. Mothers sometimes felt as though they needed to talk the police into taking their children to a hospital. The police "just try to settle it down and then they would leave" despite the mothers' requests to have their children taken to a hospital. Even when mothers were assaulted and requested to press charges, the police were hesitant to take the children to jail. One woman described her experience trying to press charges against her daughter in the following way,

So it has escalated to you know violence, to the point where I say, 'yeah go ahead and charge her with assault.' It's really hard to talk the police into that. So finally they did take a report because she came running up to me with a knife outside and she, she stabbed my tires and I took off and I called the police. She punctured my tire. She, I got a flat tire because of her. And that's

when I did the report and that's the only report out of the maybe 25 times that's the only time they took a report. Because I insisted. They would say 'ok tell me exactly what happened' and I'd tell them and they would go, 'but you're not answering correctly.' You know cause I'm not really saying the right, I guess the right word, like yeah she attacked me with a knife, she was gonna kill me. You know it's like you have to spell it out to them before they take the actual report.

The women frequently felt as though the police simply did not want to help them. The police officers' unwillingness to help was perceived as a result of their children's mental illness. When the police would not assist them, mothers wishing to have their children hospitalized felt it was because they did not wish to take the time or energy. When the police refused to press charges, mothers thought it was because the police would rather only take their children to the hospital and let the situation be handled via the mental health system, rather than bother with formal legal charges. Either way, the women often described having to "beg" the police to either hospitalize their children or press charges.

Shift Responsibility. In addition to blaming the mothers for allowing their children to be at home in the first place, the police also attempted to shift responsibility for the violence back onto the mothers. Sometimes the mothers were told that the PET evaluators were out on other calls and therefore the mothers themselves needed to get their children to a hospital on their own. When the police did come to one woman's home she felt the police

didn't want to take the time to take her [to the hospital] for me and I kept on saying 'you know, she's giving me a hard time.' And they said 'well you take her to the hospital.' I understand they could if they want to, you know, to take her. They were not doing anything um at that time and they said 'oh no,

no...well we'll get her in your car for you, you know' and I said 'but she'll just jump out.' They said, 'we don't want to take her, you take her.'

This woman did attempt to take her daughter to the hospital and as she predicted, her daughter jumped out of the car on the way. A Sheriff's Department officer later found the daughter and took her to the hospital. Several women said the police told them it was "difficult" to take their children either to the hospital or to jail. One mother reported that the police "would tell me, 'well it's really hard because [we] take her down to, to the hospitals and the nurses, all they do is yell at [us] because they don't want, they don't want to take them [patients]'. So I go 'well, I don't know what to tell you.' " It seemed that the police were using the responses of the emergency room nurses as an excuse not to take the child to the hospital. They were not telling the mothers that they could not do anything for legal reasons, but from the mothers' perspectives, it was simply because they wanted the mothers to take care of the situation themselves.

Responses From the Children

Make False Accusations. Mothers called the police or PET team in what they thought was their children's best interests, but their children frequently reacted by making false accusations about their mothers. They accused their mothers of stealing their money, using drugs, molesting, and beating them. One woman said,

the police will come in here and she'll tell the police when they're taking her, 'my mother's a drug addict, she's a drug addict, she's using my money, she's robbing my money and she's buying drugs with it'.... And the police would come and they would look at me like that. They give me a look like almost, 'hmmm I wonder about that lady.' And I felt very uncomfortable even though they say well don't worry she's delirious, but to me, I don't like that.

When trying to get her daughter mental health treatment, this woman was faced with these accusations, and wondered to herself if the police would believe her daughter. Another woman whose daughter also made false accusations had similar fears saying, “I know she did it because she’s angry and mad you know, but somebody might believe her.”

Become Angry. As illustrated above, the false accusations made against the mothers are often a result of their children’s anger. One woman said of her daughter’s hospitalization, “she only came back out more defiant with me, not understanding. Mad at me because you know ‘you put me into the hospital’ like she never forgave me for that. Well she still doesn’t.”

Mothers Accept the Consequences

Being Responsible for Involuntary Hospitalization

Calling the police or PET team to hospitalize their children conjured up mixed emotions. At times the mothers felt sorry that they were responsible for hospitalizing their children against their will despite the children’s violent behavior. One woman said of the situation, “I don’t want to see the police to take (sic) my son out of the house. I feel terrible you know.” On the other hand, another woman said of her son’s hospitalization, “Naturally I didn’t want him in the hospital if he could live here, but actually when he was in the hospital was the only time I could breathe. That I felt like he was safe cause he was locked up.” The mothers felt both sad and relieved for being responsible for having their children hospitalized involuntarily.

Being Left in the Situation

Sometimes the police or PET team evaluators chose not to involuntarily hospitalize the children. On one occasion a woman said she called “the Sheriff’s department and asked them to take him [her son] away and so they took him around the corner and let him out.” Another woman said the police “come and talk to him, and they leave.” In these cases the police simply tried to handle the situation themselves. Despite one mother’s wishes to hospitalize her daughter, the police “would always just try to settle it down and then they would leave, and then I would tell them, ‘you know she needs, she needs to be taken,’ and they wouldn’t take her.”

In situations such as these, the women were left in the same situation they were in prior to calling for assistance. Once the police were gone, mothers were required to once again attempt to manage their children’s behavior on their own. Without intervention in the form of involuntary hospitalization, the children began to create chaos in their homes again. All of the mothers whose children were left in the home eventually needed to call for assistance once again after the mothers attempted to manage their children’s behavior on their own and became overwhelmed or afraid.

Discussion

The mothers in this sample had a great deal of experience dealing with the behavior of their mentally ill children. They had an understanding of the origin, symptoms, and prognosis of their children’s mental illness that made sense to them overall even if some mystery shrouded the details of “why”. They understood the

violence their children exhibited as a manifestation of their deteriorating mental health. The mothers could, with what seemed to be 100% accuracy, predict episodes of violent behavior which occurred in the context of their children's decompensation. Despite knowing that they could ultimately be the victims of their children's violent behavior in the absence of mental health treatment, they had no choice but to watch helplessly as their children's mental health deteriorated and await their own impending violent victimization. They could not force their children into treatment against their will; the children were adults and did not meet criteria for involuntarily hospitalization until they were actually violent. Had these mothers been able to obtain involuntary treatment for their children earlier, it is possible that they would not have been victims of violence and their children would not have experienced as dramatic a decompensation.

Longer periods of untreated psychotic episodes have been associated with poor treatment outcomes (McGlashan, 1999; Keshavan et al., 2003). Mothers in this sample wanted their children to have access to mental health treatment earlier. Without conservatorship of their children, however, they could not initiate involuntary treatment. The primary goal of involuntary hospitalization laws is to ensure that no individual is committed without evidence that s/he suffers from a mental illness and consequently is dangerous or gravely disabled (McCullough & Reinert, 2002). The reverse, although, is equally important – ensuring that individuals suffering from a mental illness who are dangerous or gravely disabled are hospitalized and treated - seems to have no support. The mothers felt that their desire for involuntary mental

health treatment for their children was in their children's best interests. They wanted early intervention for their children. Also, they did not want to be violently victimized. During this study, these mothers repeatedly voiced their frustration at having to wait until violence actually occurred before being able to access mental health treatment for their children. This situation resulted in worse outcomes for both mothers and their children. At the time of this study, it seems that mothers and their children were all in a worse position for having to wait than they would have been had treatment been available earlier.

In 1982, the American Psychiatric Association approved a Model State Law on Civil Commitment of Mentally Ill Individuals. Within this model, an individual's potential dangerousness is balanced with treatment needs. Commitment under this Model Law requires that an individual "suffers from a severe mental disorder, lacks capacity to make a reasoned decision concerning treatment, is treatable, and is likely to harm himself or others" (Stromberg & Stone, 1984, p.64). Harm in this context includes the likelihood of substantial mental or physical deterioration or the inability to care for one's needs (Stromberg & Stone, 1984). In the present case, the implementation of this Model Law would have increased the likelihood that the children suffering from mental health deterioration would receive the treatment they needed before any violence occurred.

Another strategy that may have been helpful for the mothers in getting their children involuntary treatment and avoiding violent victimization is outpatient civil commitment. Under the auspices of outpatient civil commitment, individuals who are

living in the community can be involuntarily hospitalized when they become treatment noncompliant or begin to experience an escalation in their symptomatic behavior prior to actually becoming violent (Hyde, 1997). Several of the mothers had tried to become their children's conservator, but could not do so because their children's doctors did not believe they needed it. It is possible that these same doctors would not see the need to initiate outpatient civil commitment proceedings either. Given the degree of decompensation the mothers described and the violence they experienced, however, it again seems likely that both the children and the mothers would have benefited from outpatient civil commitment earlier rather than later or not at all.

Due to the lack of early intervention, some of the mothers wanted to press charges against their children, but the police refused. Mothers perceived pressing charges as one avenue to get their children mental health treatment for two reasons. First, they believed that if their children were jailed for assault, the jail term would be longer than if they were involuntarily hospitalized, and their children would receive mental health services while incarcerated. Second, they believed that if their children faced a judge, the judge would see that involuntary long-term care was indicated. In order to arrange involuntary treatment for their children it somehow needed to be court ordered. A record of violent behavior was desired by the mothers seeking conservatorship of their children. They felt that evidence of legal involvement would be valuable in proving that their children needed long-term care.

Given their inability to access treatment for their children, at a minimum mothers need supportive services for themselves to help manage their children and to

prevent their own violent victimization. Family psychoeducation, which is delivered by professionals within the mental health system, has been shown to reduce relapse and the need for hospitalization in addition to improving the well-being of family members who participated (Dixon, et al., 2001). The Schizophrenia Patient Outcomes Research Team (PORT) recommends that family members who have contact with a relative who is mentally ill be offered family psychosocial intervention lasting a minimum of nine months and includes illness education, family support, crisis intervention, and skills training (Dixon, Goldman & Hiras, 1999). Despite its proven benefit for patients and their families, family psychoeducation is rarely offered (Dixon et al., 2001). This could be a reflection of the lack of state policies for funding such family oriented services. Only three states fund family psychoeducation programs such as those recommended by PORT (Dixon, Goldman & Hiras, 1999). In 1998, the amount of state funding devoted to mental health family programs ranged from \$11,500 - \$150,000 (Dixon, Goldman & Hiras, 1999). Since the era of deinstitutionalization family members have been forced to assume care of their mentally ill relatives, but funding to support their efforts is extremely limited.

Because there is no system wide emphasis on family oriented mental health services, mothers continue to attempt to manage their children who are mentally ill on their own. Because there is no system wide emphasis on prevention of decompensation until something dangerous occurs, violent behavior is a key to mental health treatment and mothers know this. Caretaking mothers have been thrust into a position where they are expected to provide care to their children, without support and

at times under the threat of impending physical harm. Without changes in the provision of services for mentally ill individuals and their family members it is possible that caretaking mothers will decide that they can no longer care for their children, resulting in more mentally ill individuals being homeless and further taxing an already overburdened, underfunded community mental health system. As a society we respect and value individual autonomy and the right to freedom. However, Wasow, a social worker and parent of a son with schizophrenia, suggested that family members “pay a heavy price for the freedom of their ill relatives” (1993, p. 208). If freedom from involuntary hospitalization is the ethical ideal our society is going to maintain, what about an ethical obligation to protect and support those family members held responsible for providing care to mentally ill individuals in lieu of hospitalization? Utilitarian ideals drive the public health system, but not the mental health system. It seems that in order to protect both mentally ill individuals and their family members, such as those in this study, either hospitalization at the first sign of illness related decompensation or intensive supportive assistance for families is necessary.

Implications for Practice, Research, and Policy

Most mental health professionals take for granted the support caretaking mothers provide to their mentally ill, adult children. Additionally, the support these mothers provide is sometimes at the expense of their own personal safety. Their own needs, as they affect their ongoing abilities to provide care for their children, are not

routinely assessed by mental health professionals. Education regarding diagnosis and/or medications and side effects is likely the most common service provided to family members by mental health professionals. The women in this sample did not express a need for further education regarding their children's illnesses or medications. Rather, the mothers expressed a need for supportive services to help manage their children at home, particularly during periods of decompensation. They were interested in respite from their caretaking responsibilities so they would have an opportunity to focus attention on their own needs.

Intervention, in the form of in-home respite care provided by experienced mental health nurses or social workers during periods of the children's decompensation may decrease the level of decompensation the children experience, prevent mothers' violent victimization, and improve caretaking mothers' quality of life and ability to continue to provide care to their mentally ill, adult children. Research is needed to identify what in-home respite for mothers such as those in this sample would consist of, and at what frequency and over what duration it would need to be provided in order to be effective.

Despite knowing that they would ultimately be victims of violence in the absence of their children's mental health treatment, because their children were adults, the mothers could not force their children into treatment against their will. Mothers were forced to watch helplessly as their children's mental conditions worsened because their children did not meet criteria for involuntary hospitalization. Had they been able to acquire mental health treatment earlier, it is possible that the children

would not have experienced as dramatic a decompensation and that the mothers would not have been victims of violence. Several of the mothers wanted to be their children's conservator which would give them the legal ability to hospitalize their children early in their decompensation, rather than waiting for their children to become violent towards them. Perhaps clinicians need to more carefully consider familial caretakers' rationale and desire for conservatorship and more readily file such petitions on behalf of caretaking family members. In this way, some petitions may be granted and others dismissed, but a court would ultimately be responsible for deciding if conservatorship is necessary. In the absence of conservatorship, involuntary hold criteria, such as that proposed by the APA permitting hospitalization for individuals who are "likely to harm themselves or others," would provide some mentally ill individuals with access to mental health treatment more quickly. It would also prevent at least some episodes of violent behavior perpetrated by mentally ill individuals in the context of their deteriorating mental condition. Professional organizations committed to mental health issues and familial support groups can promote legislation to make such changes to involuntary commitment laws in order to improve access to care for those who need it, before tragic acts of violence occur.

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Chapter Three

Choosing “The Best of the Hells:” Limited Housing Options for Mothers of Violent Mentally Ill Adults

When individuals who are mentally ill become violent they are typically hospitalized. Psychiatric hospitalization, initiated for any reason, is generally for a short period of time and most patients are discharged home to family (Goldman, 1982; Hatfield & Lefley, 1987). However, if an individual who is mentally ill becomes violent, family members are most often the victims (Estroff & Zimmer, 1994; Steadman et al., 1998; Straznickas, McNeil & Binder, 1993). Even psychiatric inpatients who have been violent towards their family members return home in most cases (Binder & McNeil, 1986). Their family members may be at particularly high risk for revictimization in light of evidence that the majority of psychiatric patients who were violent both before and after hospital discharge attacked the same person each time, typically a family member (Tardiff, et al., 1997).

Since the deinstitutionalization of state psychiatric hospitals, family members have, whether by choice or out of necessity, assumed greater caretaking roles of their mentally ill relatives. They have done so with little support from the mental health system (Biegel, Milligan, Putnam & Song, 1994; Saunders, 2003), despite evidence based treatment recommendations to involve family members in psychosocial education (Dixon, 1999). Unfortunately, increased caregiving responsibilities have been associated with increased psychological distress among familial caregivers

(Saunders, 2003). Families who are attempting to provide in-home care for their mentally ill relative who has a history of violence may need more, or different, support than families whose relative does not have a history of violence. The results presented in this paper describe how mothers who have been victims of violence perpetrated by their mentally ill adult children decide whether or not to allow their children to live in their homes.

Background Literature

Burden among caretakers of individuals who are mentally ill has been the focus of much research (Bibou-Nakou, Dikaiou & Bairactaris, 1997; Horwitz & Reinhard, 1995; Jungbauer, et al., 2003; Stueve, Vine & Struening, 1997; Winefield & Harvey, 1994). Caregiver burden has been linked to behavior problems of individuals who are mentally ill (Biegel, Milligan, Putnam & Song, 1994; Jungbauer, Wittmund, Dietrich & Angermeyer, 2003), and is especially high among parents living with children who have schizophrenia (Pruchno & Patrick, 1999). Distress associated with caregiving responsibilities and experiences of burden associated with disruptive behavior, in combination with a lack of support from the mental health system combine to create a very difficult situation for family members attempting to care for their mentally ill relatives in the home. If families are unable to continue caring for their relatives, homelessness may result. It is estimated that nearly two million adults in the United States are homeless (National Coalition for the Homeless, 2006a) and that 22% of homeless individuals are mentally ill (National Coalition for the Homeless, 2006b). Therefore, recommendations for evidence-based-care for homeless

individuals with a mental illness involve mental health treatment combined with housing support (Young & Magnabosco, 2004). Housing has also been shown to be a critical element in reducing psychiatric hospitalization rates (Rosenfield, 1990). In fact, there is evidence that in the absence of quality housing, mental health treatment and rehabilitation is jeopardized (Stroul, 1989; Moxam & Pegg, 2000). Indeed, Baker and Douglas (1990) reported a causal relationship between appropriate housing and quality of life and global functioning among consumers of mental health services.

If not homeless or living with their family, individuals who are mentally ill may live independently or in structured living facilities. Living independently is typically more desirable than structured living among individuals who are mentally ill (Fischer, Shumway & Owen, 2002; Goldfinger, et al., 1999; Tanzman, 1993).

However, family members and mental health professionals are more likely to believe that structured living arrangements are more appropriate than independent living (Rogers, et al., 1994; Wasow, 1993). Placement in structured living facilities may help prevent homelessness among individuals who are mentally ill. A study of group home versus independent living among mentally ill individuals found that people assigned to group homes experienced more days homeless than did those assigned to independent living during the study period (Goldfinger, et al., 1999).

Family members are often primary caretakers for relatives with a mental illness. Despite this, studies of family housing preferences for their ill relative have not included the family's home as an option. For example, one of the few studies examining family and client residential preferences and perspectives included

independent living, supported housing with on-site staff visits, and 24 hour on-site support as options (Friedrich, et al., 1999). The family's home was not investigated as a potentially preferred housing option for the clients or their family members. Other studies of the effect of housing arrangements on homelessness (Goldfinger, et al., 1999) and functioning (Browne & Courtney, 2004) also only included comparisons of individuals living independently and those living in staffed group or boarding homes. Since many individuals who are mentally ill receive care from and reside with family, studies addressing housing preferences and the effects of various housing scenarios on clinical outcomes could be improved by the inclusion of living with family.

The purpose of this analysis was to explore mothers' perspectives on the housing options available to their mentally ill, adult children who were violent and the effect those options had on them as mothers. The results of this study illuminate the factors that mothers of violent, mentally ill adult children consider when deciding whether or not their children can live with them.

Methods

Design

Grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1998) was used to guide data collection, analysis, and the subsequent development of a theoretical framework of the decision-making process mothers of violent, mentally ill adults use when deciding whether or not to allow their children to live with them. Grounded Theory methodology is useful in understanding social processes and in

learning the ways in which individuals understand and manage their lives in ever-changing environments (Streubert Speziale & Rinaldi Carpenter, 2003). It recognizes the multidimensionality of human existence and our ability to make sense of our lives and world (Charmaz, 2003). The concepts of active participation in the world, meaning derived from such action, and truth as contextual are critical in the conduct of research employing Grounded Theory as a methodology (Clarke, 2005).

After approval was obtained from the human subjects review boards at two institutions with locked, adult inpatient psychiatric units, the purpose of the study was explained to charge nurses and social workers on these units. After being trained, these staff members served as recruitment staff for the study. One unit was a small unit at a large, not-for-profit medical center; the other was a large unit at a free-standing, for profit psychiatric hospital. Recruitment staff was responsible for identifying patients with a known history of violence towards their mothers. The mothers of these patients were contacted by recruitment staff. The purpose of the study was explained to the mothers and they were invited to participate. The mothers were provided with the primary researcher's contact information. The primary researcher also recruited participants at a single meeting of the local NAMI chapter. As interested mothers contacted the primary researcher they were screened for eligibility. Eligible mothers were those who had a biological, adopted, or step child, over age 17, who had been violent towards them and who had a DSM –IV Axis I psychotic, mood, or anxiety disorder without a comorbid personality or substance abuse disorder. Violence was defined as the use of physical force, other than self-

defense, and included explicit threats of physical harm. Mothers who were under age 65 were included in the study. The primary researcher is a mono-lingual English speaker and conducted all interviews. Therefore, participation was limited to mothers able to conduct the interviews in English.

The open-ended interviews were conducted using a researcher generated guide developed to elicit the mother's experiences of getting help when they were victims of violence perpetrated by their mentally ill adult children and results were reported elsewhere (in process). However, each mother brought up the subject of housing options when interviewed. Because the issue of housing was identified as important by participants, the topic was explored further as data collection and analysis occurred, consistent with grounded theory research methods. Special probes were used to explore the mothers' (a) perception of treatment needed by their children, including placement/housing (b) experiences with different housing options, and (c) decision-making process with respect to choosing housing options for their children.

Sample

One or two interviews were conducted with eight mothers who met eligibility requirements. Interviews were done in a safe and private location chosen by the women. Six women who contacted the primary researcher with interest were excluded: one due to her son's current drug use, two who wished to conduct the interview in a language other than English, and three who were over age 65. Two of these women were in their eighties.

This sample of eight women had a total of nine mentally ill children, all of whom had a reported diagnosed psychotic disorder (4 schizophrenia, 3 schizoaffective, 1 bipolar/schizophrenia, and 1 psychotic disorder not otherwise specified/attention deficit hyperactivity disorder). With the exception of an adopted nephew, all of the children were biological children of the mothers interviewed. Six of the children were males, three were females. Three women reported that their children were living with them at the time of the interview. The children ranged in age from 20-38. The mothers' ages ranged from 42-60. Half of the women were uninsured, two of the children were uninsured. Three of the children had not graduated from high school, five had graduated from high school, one had some college education. Two of the mothers had not graduated from high school, three had completed high school, and three others had some college education. Half of the women reported that their monthly income was not adequate to meet their needs.

Data Collection

Written informed consent was obtained from the mothers prior to the interviews. A researcher generated sociodemographic questionnaire was completed prior to each interview either by the participant, or if the woman preferred, it was read to them and their verbal responses written on the form by the primary researcher. Each interview lasted 1 ½ - 2 hours and was audio-tape recorded. Participants received \$20 at the end of each interview. Observational, theoretical, and methodological field notes were written following each interview. These notes included topics covered in the interview, questions generated by the interview,

comments on the behavior of the participant, comments regarding interaction with the woman, and general reactions to the interview (Levy & Hollan, 1998).

Data Analysis and Interpretation

Interviews were transcribed verbatim by the primary researcher and verified against the audiotapes for accuracy. In Grounded Theory research, participant recruitment, data collection, and data analysis occur concurrently (Strauss & Corbin, 1998). First, transcripts were coded line-by-line using techniques articulated by Strauss and Corbin (1998). During this process of open coding, each line was analyzed for its primary topic or theme, and given a conceptual label. These concepts were compared within and between each interview to identify similarities and differences. Related concepts were then grouped together as categories. Deeper analysis was then done with axial coding to identify properties and dimensions of the categories (Strauss & Corbin, 1998). During this stage of analysis, categories were compared to one another in order to determine their range of variability, and to ensure that they were mutually exclusive of one another. If not, categories were combined and refined. Relationships between the categories were then articulated. The process was ongoing and simultaneous. That is, data collection with additional participants and analysis of newly collected data continued while analysis of already collected data continued. This allowed for additional scrutiny of and further refinement of the proposed relationships between the categories across interviews.

An audit trail was made using notes and memos throughout data collection and analysis. These notes and memos enhanced credibility by allowing self reflection

related to assumptions about the phenomenon, detailed descriptions of the interviews, reactions to the interviews and a critique of the research process (Strauss & Corbin, 1998). The first author conducted all interviews; however each individual interview was discussed by both authors together as a preliminary step, with a focus on the overall experience. Then, each interview was analyzed as described separately by each author and then each interview was analyzed by the authors together. This collaboration allowed both researchers to describe and compare their interpretations of the data and therefore aided in ensuring rigor.

Results

How mothers understood their children's housing options was a product of their day-to-day experiences. Allowing their children to live with them might have been an option one day, however if the next day the children became violent, the situation needed to change because the meaning of having the children at home changed. As described, the mothers knew of only three housing options for their children, none of which were appealing to them: homelessness, their home, or temporary board and care placement. Board and care facilities typically provide shared rooms, prepared meals, and staff to distribute medications to residents. They vary in the amount of structured activities provided and physician visits to the facility. All of the women in this sample reported that they could afford board and care placement for their children, or that their children received enough Social Security Income to afford board and care placement on their own. Mothers of mentally ill,

adult children with a history of violence often were faced with deciding whether or not to allow their children to live with them during a period of their children's homelessness or hospitalization. The housing options for the children were limited. All of the mothers wanted stable, long-term placement for their children. Many wanted their children hospitalized long-term in order to optimally stabilize their mental disorder. In order to have their children hospitalized against their will, a court order was needed or the mothers needed conservatorship of their children. Several of the women wanted to be their child's conservator, but despite their efforts, none were able to accomplish this. In order for a person to be conserved, a petition must be filed with the court, typically by a psychiatrist. None of the doctors to whom the women requested filing the petition would do so. The only explanation the women provided was that hospital staff told them that their children did not need it.

Knowing that long-term hospitalization was not available in the absence of conservatorship or a court order, the mothers at least wanted their children in stable, long-term placement. For the mothers, long-term placement would provide the opportunity for both them and their children "to all have lives," as phrased by one woman. Only one woman's son was in stable board and care placement at the time of the interview. For the rest of the women, however, stable, long-term placement remained out of reach. Their children either walked away from or refused long-term placement, or the care provided at the placement facilities where the children were willing to stay was perceived as inadequate by the mothers. Therefore, the decision made regarding their children's housing was not the decision the mothers really

wanted to make. Rather, they were forced to choose among the limited options available to them: homelessness, living with the mothers, or temporary board and care placement.

The women wavered in their decisions between these three available housing options, each with their own unappealing qualities. For the mothers, it was a matter of choosing between what one woman termed, “the best of the hells.” For most, their decisions were temporary, dependent on certain contingencies, and involved a dynamic blend of the three “hells.” For example, children might have been allowed to stay at home only if they were compliant with treatment/medications and their behavior was not overly bothersome. Some of the children were homeless after leaving board and care placement, at which point the mothers allowed the children to stay in their home rather than remain homeless until other arrangements could be made. One son was not allowed to stay in his mother’s home, but she helped pay for an apartment or stayed in a car with him when she could no longer pay for the apartment. Some children also agreed to temporary board and care placement with the understanding that they could return home after a certain period of time or after they were stabilized on their medication.

With the exception of the one mother whose son was already in a board and care placement she described as safe and stable, board and care placement was described as temporary by all of the other mothers. The temporary nature of the board and care placements described by the other women was due to what they perceived as

inadequate staffing and/or poor conditions with respect to behaviors exhibited by staff or other residents.

The women perceived mental health treatment and housing as critically intertwined. In the mothers' minds, if their children received the mental health treatment they needed, their behavior would be under control, they would not be violent, and would therefore be allowed to stay at home. Additionally, if their children received proper treatment they could live on their own because they could "function more, and learn how to... maintain and care for [themselves] to be independent." For some mothers, having a stable and safe roof over their children's head was a form of treatment in and of itself. One woman said that her son "would be alright if he could be secure and have a place to live." She felt that having a place to stay would provide the stability to allow her child to consistently participate in treatment, a place to keep medication, and ultimately enable them to work and continue living independently because their illness and behavior would be stable.

Greater independence for their children was a goal for every one of the mothers. In each case, however, total independence was not a possibility. Most of the children had tried to live independently. All of those who tried, failed in their attempts at independent living, and ended up either hospitalized or homeless. The children were too impaired to be able to be independent. Even the mother of the only child who was stable in board and care placement said, "He'll say, 'I'm so independent I'm ready to move on.' And in his mind that's what he thinks. But he's nowhere near it." The women wanted their children to be more independent because they thought it

would be best for their children, but they also wanted their children to be more independent for their own sake. At this stage in their lives the mothers anticipated their retirement when they would visit with their grandchildren and relax with their spouses at home. They expected their children to be living lives of their own, independent of them. Instead, they were still engaged in active parenting. When their children were at home the women were unable to focus attention on their own needs. They mourned the loss of the life they envisioned for their children, but also felt cheated out of the life they wanted and expected for themselves.

Mental health professionals assumed that the mothers were willing and able to care for their mentally ill children, which included the provision of housing. Not only did the women make personal sacrifices to provide a safe place for their children, they did so with no perceived appreciation from their children and no reciprocation from the mental health system. Their children were unaware and/or ungrateful for the care their mothers provided for them and the mental health system provided no compensation. As one woman shared,

I don't even think my daughter even thinks about it, that we've tolerated her and have put up with her for many years and I don't even think she's, I think she's very clueless about that. You know, that it doesn't even dawn on her to even think about that part. You know, we've given her shelter, a home.

Choosing the Best of the Hells

With long-term placement and independence both inaccessible, the mothers were forced to choose between the only housing options available for their children: homelessness, temporary board and care placement, and their own homes. No

singular reason was credited with being the ultimate deciding factor. The following seven categories were identified as being critical in how the mothers decided which arrangement was most suitable for them and their children: concern for safety, the children's refusing or leaving placement, advice from others, maternal obligation, imposing consequences, quality of available placement, and the mother's inability to provide care. Each of these played a role in the mothers' decisions, but were conceptualized and prioritized differently by different women. Figure 3 illustrates how these seven categories are related to one another and form a web, around which a decision regarding housing is made.

Concern for Safety

Safety was among the top priorities of the women in deciding how to make a decision regarding their children's housing. The mothers were often in a position where the decision was to either protect themselves or their children.

For some mothers, their children's safety superseded their own safety. As one mother said, "I wasn't even thinking about my interests, I was thinking about his." Placing their children's safety above their own was the most obvious choice for mothers who chose to allow their children to stay in the home, despite the child's history of violent behavior directed at them. When the children refused to accept or subsequently left board and care placements, the mothers' decision to keep them at home was made in order to prevent them from potential victimization on the streets. One mother said, "I don't think he can survive on the street.... We [her family] have just been afraid that somebody's gonna kill him or hurt him and he's out there at all

times of night...and if he stays out on the street somebody's gonna kill him or he's gonna do something.”

The women tolerated a great deal of disruptive behavior from their children. In their experience, the escalation of this disruptive behavior culminated in their children becoming violent. Some mothers had decided that in order to maintain their own safety, their children could not return home, even if that meant the children would be homeless and vulnerable to victimization themselves. One mother said of her daughter being released from the hospital,

The social workers would tell me, ‘we try to place her but she doesn’t want to be placed. We’re just going to let her out.’ I go ‘don’t let her out in the streets. She doesn’t know how to take care of herself.’ ‘Oh well, it’s our obligation to.’ ‘Fine, ok then fine, tell her we’re not gonna take her back.’ We got to the point where we took her back many, many times and she would attack me.

Another woman recognizing that it was unsafe for both herself and her son said, “I know he cannot live in here with me because he’ll either end up being so angry that he’ll hit me and hurt me, and if I see him try to hurt me before I may just do something which is not, it’s not a good thing.”

Children Refusing or Leaving Placement

Most of the children either refused board and care placement or were placed in one, but left shortly after arriving. When either happened, the only other options were to return home or live on the streets. One mother was unable to work because she stayed home to care for her son. When he was placed in a board and care he left it. She said,

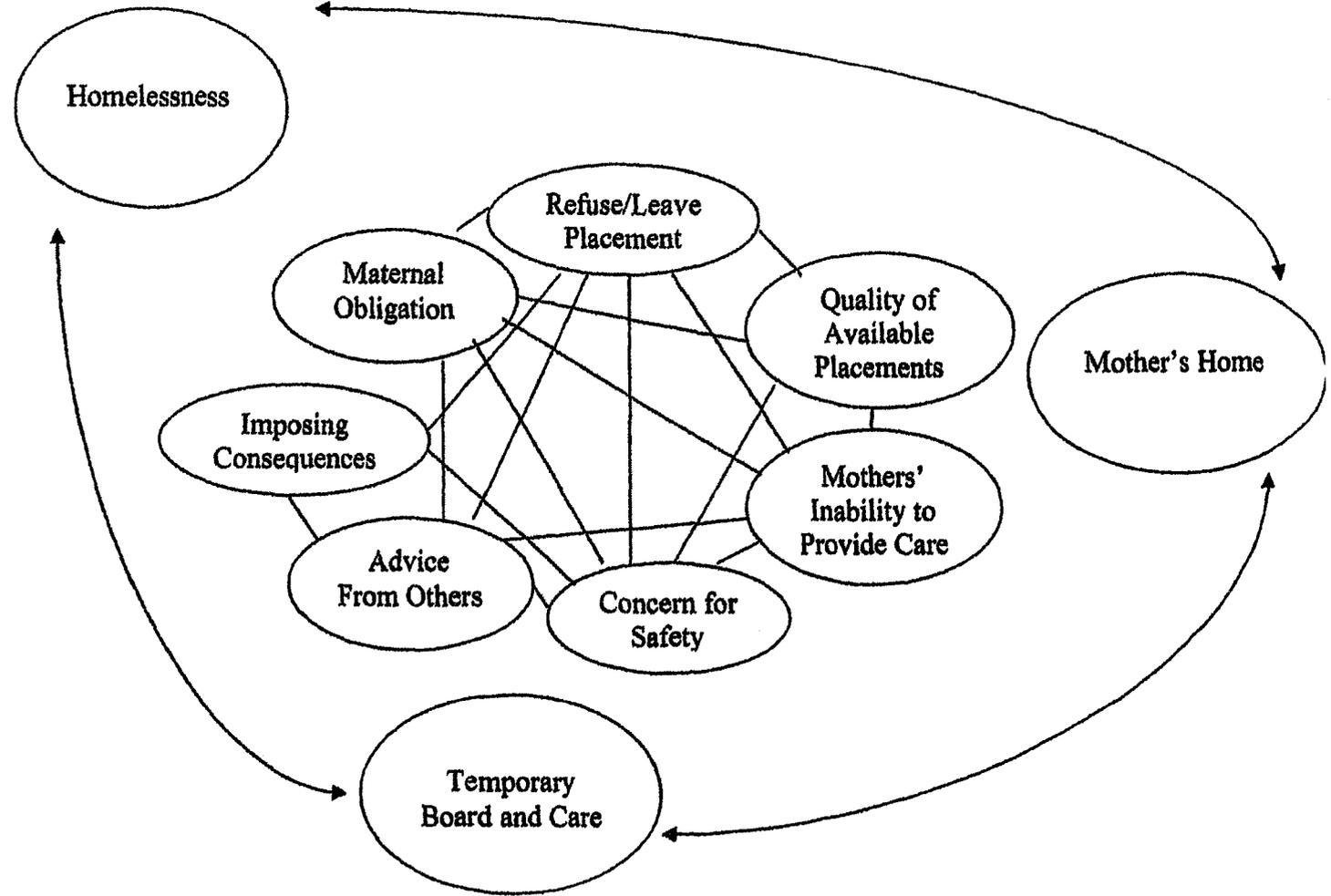


Figure 3. Factors affecting the housing preferences for mothers of mentally ill, adult children who have been violent.

He left there so he was on the street and I really was worried to death. I really was worried about that, but he said he wanted to come home, but I knew it wasn't the best thing so I went and talked to him and you know I didn't know what to expect when I saw him out there living on the street for 2 or 3 days.... He didn't want to go back there and I just kind of talked to him and I explained to him...that even if you came back, if you came with me, I, it doesn't make sense if, if I can't pay the rent then we'll both be on the street. Why don't you just stay there and you just, can try to maintain and hold on there until I get myself together, until I get some quarters and then we'll talk and when you get well we'll talk.

Some of the children told social workers at the hospital that they were willing to accept placement, but after placement they left and attempted to return home. The mothers recognized this pattern with their children. One woman whose daughter accepted board and care placement in front of a social worker while in the hospital said,

And then I happened to look at my daughter and I said, 'when you say that you are going to a board and care are you sure or are you just telling them that and then you're just going to come home?' Because that's what she's done in the past. She got mad and she says, 'you know what I don't want to be in here, I don't want to be in this meeting any longer,' and she took off.

The mothers wanted their children to want placement. All of the women felt that having their children in stable placement was the best scenario for both their children and themselves. One mother shared,

It'd be nice for her to be in a home, a nice home, make her friends if she can. She's capable of doing that. Have her own life, come and visit us. It would be like ideal, but she just won't do it so she's becoming like a thorn in our side because we just don't want her around.... Maybe he [her husband] could pay attention to himself and I could pay attention more to myself, if we could just get her settled somewhere then we could all have lives, but she's just adamant, 'I'm not, I'm not going to a board and care.'

Advice From Others

The mothers were given advice from mental health professionals, police, and family members. Most of the advice they received was perceived as unhelpful because it contradicted what they felt was their obligation as a mother. Nobody advised the women to allow their children to remain in the home with them.

Family members, fearing for the mothers' safety, begged the women not to allow their children to return home. One mother said,

So everybody all my family is saying, 'you can't let her come home, you can't let her, she can't be home with you alone, you can't....' When I would be here alone [my sister] would come and stay with me cause she, she would say 'I'm so afraid to leave you, I'm afraid what, what's gonna happen. Please don't let her come home.' Everybody that I talk to doesn't want her to come home. And I said, 'well you know she's my daughter, I love her.'

The police, and occasionally mental health professionals, advised the women to throw their children out on the streets. For the mothers, this was not useful advice.

As one mother shared,

I don't like it when they tell 'me throw her out, let her in the street.' I mean I'm talking about the workers, people from the hospital say 'throw her out, let her in the street, let her find out.' Well I say, 'well she can land on skid row' so, 'well that's ok somebody will pick her up, that's alright.' And I'm not comfortable with that.... They say 'throw her in the street,' I mean this is what the county says, 'she's an adult, throw her in the street.' I can't.... I don't want her to be homeless. I want her to have a place, a safe place. I can't do that. I just can't throw her out knowing that she's just walking around all day or something like that I just can't, I just can't. So maybe I am having a hard time, but that's not the answer that I want... I want her a safe place (sic) and I want her to get the treatment that she needs.

Social workers and doctors sometimes told the mothers that there was nothing more they could do for their children at home and advised board and care placement.

This advice was only helpful for those mothers with children who would accept board

and care placements. One woman whose son ended up walking away from his placement said,

It came up when he was in the hospital. I really wasn't gonna do it at all, but one of the workers at one of the programs he was going to she said, 'you know what, you need to put him in a board and care because you're, you know there's no more you can do, you've done all you can do, you've done all you can do, you need to put him in board and care.'

Maternal Obligation

The women knew that no one who advised them not to allow their children to return home was connected to the children like they were as mothers. The rationale "I'm the mother" was theirs alone; nobody else could make that claim. For most of the mothers, motherhood did not end when their children turned 18. No matter the children's ages, the mothers were still ultimately responsible for their safety. No doctor, social worker, police officer, or sibling had that same responsibility.

Some of the spouses shared this sense of responsibility, but not all of them. One woman was told by her friends, "just remember you (sic) a mother first and wife later." Her husband threatened to get a restraining order against her son if he came to their house. This woman had a great deal of resentment towards him for putting her in a position to make a choice between him and her son. She felt that her husband did not understand the predicament she was in and described his threat to disconnect her from her son as "slamming my face, putting a knife in my heart."

The women recognized that they had very limited options and whichever housing decision they made was a difficult one. One woman said of her daughter, "She's calling me from the bus station, so what am I supposed to do? What do you

do? My husband and I go, ‘what do we do?’ Alright, we went to go get her and brought her back.” Days later this woman’s daughter assaulted her once more. Another woman described the difficult position she was in by saying, “Because you can’t sleep in a comfortable bed in a warm house, your son (sic) is sleeping in the street. Who will be happy that way? It’s not easy, it’s not even easy. But it’s a very miserable life that way.... If he don’t have a place to go where, what do I have to do? Leave him outside in the cold?”

Several women did not work because their children needed constant monitoring and they chose to stay home in order to care for them. For some, however, as money ran out this option became less feasible. One woman left her own home and other family members when she found out that her daughter was homeless and temporarily stayed in a motel with her daughter. She was not willing to allow her daughter back into her house, but was not willing to have her out on the streets either.

Imposing Consequences

For some mothers, their children’s homelessness was understood as a consequence of their children not accepting available placement and/or an inability to follow rules in their own home. The act of not allowing their children to return home was often a consequence for the disruptive or violent behavior the children exhibited. Most of the women were willing to allow their children to live with them when they were “not sick” i.e. when they were compliant with their medications/treatment, were willing and able to comply with house rules, and were not violent. Several women cited their child’s inability or unwillingness to do what she and her partner told them

to do as a reason they could not allow their children to stay in their homes. One mother said of her son,

I thought maybe he could stay here and we'd work things out, but [my son] had developed habits. He, he's not compliant, he's intrusive.... I realized that we have different ideas of living.... I had told him the rules and regulations of the household. If you're gonna stay here you have to abide by the rules and one of the rules was that you don't bring people up in the room.... I didn't feel safe in a sense.

Typically it took years of disruptive and dangerous behavior, sometimes involving total strangers in their home, before imposing this consequence. When another woman's daughter wanted to return home from the hospital she told her,

'You got yourself in this predicament you just stay there.' You can't have a person around here living with you like that. Where can a person live like that? She has to have the consequences I'm sorry and her consequence is that she can't live here. And we're sticking to it. It's taken all this time for us to finally say no to her.

Quality of Available Placement Facilities

The mothers complained about the conditions of board and care facilities and group homes in which their children had been placed. The women described board and care facilities as "atrocious" and "extremely horrible." One woman shared, "They didn't treat him right there and they stole his meds, the people there who were staff, they stole his meds to get high. I couldn't believe it. And they would steal his mail."

Another woman said,

I had to pull her out of there because one of the people that works there was threatening to kill her, and I know it's true because I talked to another staff member who actually heard him say it so I had to pull her out.... I just can't put her in jeopardy like that. I don't want them in a place where they're not being taken well care of and where people are mean, even the staff. It's just, I just can't handle it. I get too upset.

Drug use at board and care facilities was also problematic in these mother's experiences. One woman stated that her daughter who walked away from her board and care told her,

'Mom, they have drugs over there.' I'm like she's lying to me, that's not true. I called the place up and I said, 'my daughter is supposed to be there, there was an arrangement for her to show up over there, but she's saying that there's drugs.' And the lady said 'yeah.' I said what? What kind of place is that? I said I don't understand they're sending her to a place with drugs, so I kept her. That's it, I don't want her to go to something like that, nor do I want her to go to skid row.

For some mothers, the level of care provided by board and care facilities was considered inadequate, particularly in light of the 24 hour care they were providing at home. Most of the women wanted intensive long-term placement or hospitalization for their children, at least temporarily until their children could be stabilized and functioning at their optimal level. Some mothers believed they could provide better care for their children than would be available at the placements they had been offered. They kept their children at home with them because long-term hospitalization was not available and "there aren't any other options right now." Another woman said, "I think it's a bad environment. I think it's a bad environment. I don't know these board and cares and these aftercare programs, really I don't get them. They're not doing anything. What are they, they're not doing anything for people. I see them, they act worse." The level of care the children required, however, often exceeded what the mothers were able to provide.

Mothers' Inability to Provide Care

There was a point at which some mothers felt that they could not provide the level of supervision that their children needed. They recognized that they were not professionals and knew their limitations in their abilities to provide care for their children. One mother said,

He would call, and call, and call and I knew that he was in a condition where he couldn't stay at home because he needed supervision as far as those meds and stuff and he needed a doctor constantly looking after him and he needed someone to you know to constantly give them to him.

Most of the women whose children were at home provided around-the-clock care. One woman shared, "Everyone said, his doctors said you need respite, you really do. And, but nobody wanted to help me." The mothers wanted respite from their caretaking responsibilities, but respite care did not exist. Most mothers eventually reached a point where their caretaking was "too much" and they decided that they "need a break."

The only opportunity for them to experience such a break from their caregiving responsibilities was to not have their children living with them. As one mother said, "Too much is too much and we should just break away. So that's what we're planning on, breaking away." It was not merely routine caretaking that caused mothers to desire respite. During periods of decompensation the children had a history of violent behavior directed towards their mothers. They attempted to continue to provide care, but as one mother said of her violent daughter, "So finally, finally after all of these other incidents, I'm trying to, I'm almost, I'm like to the point where, you don't want to take it anymore so that's, that's the point my husband and I are."

When their children were out of the house the mothers realized how tired they actually were and how much they needed rest. One mother, whose son had recently been placed in his first board and care, said about life without him in her home, “I’m less stressful. Yeah, I’m less stressful. I’m kind of tired. I think I was just numb then. I’m tired, I’m kind of trying to rest cause I think I was just numb when I was taking care of him in that situation.” Another woman told me that when her daughter was in the hospital “It’s so peaceful and nice and quiet. It’s kind of nice. It kind of makes me feel guilty, but it’s nice.” She said she and her husband enjoy “the peace and quiet, serenity that we have. We both feel guilty about it. We wish we could help her, but we can’t.” The only mother whose son was accepting of and stable in board and care placement reinforced this sentiment by saying, “it feels real good to feel that there’s some quiet now and peace.” She was no longer experiencing the stress and chaos that the other mothers were feeling because she knew that her son was safe and she no longer had to provide around-the-clock care.

Another woman, on the other hand, felt that she was the only person capable of providing the level of supervision her children needed, specifically because long-term placement was not an option and previous board and care placements provided an inadequate level of care. She said, “I’m hoping that sometime in the future they can live somewhere where they’re well taken care of without me being the only caregiver 100% of the time, but I don’t know if that’ll happen or not. I would hope it would, but I kind of doubt it.”

Another mother who thought that she had done everything she could do for her daughter, but still felt unsatisfied with the lack of help she had received, decided to throw her daughter out of the house as a last resort. She said she “thought about it and thought about it and I said to myself, ‘well if this is what it takes hopefully nothing bad happens to her.’ But yes I’m willing, I’m willing to let her go because you know it was tough for me but I want to do the right thing for her. If this is what it takes to get help finally.” This mother felt that she had exhausted all available services that she was aware of and still did not have enough support to care for her daughter at home. She hoped that by allowing her daughter to be homeless she would come in contact with or become eligible for services not otherwise available.

Discussion

The women in this sample of mothers of mentally ill, violent, adult children faced frustrating dilemmas no matter which of the three available housing options they chose for their children. Their quality of life was affected whether their children lived with them or not. They could not rest knowing that their children were not safe. Because some of the mothers became unable to allow their children to live with them, they felt like they were not fulfilling their role as a parent. For them, denying their children a place to stay was perceived as a denial of love. They felt they had abandoned their children, even if they were still involved in other ways. The mothers felt that deciding whether or not to allow their children to live with them was a decision either to be happy with their own living environment but feel guilty, or to be

free of guilt but unhappy in their home, and in many cases unsafe if their children lived with them. Living a peaceful life without their children meant living with a guilty conscience.

Other research has found that providing care to children who are mentally ill can provide parents with a sense of satisfaction and purpose (Schwartz & Gidron, 2002; Winefield & Harvey, 1994). The mothers in this study, however, did not describe their experiences living with and providing care to their children as rewarding. They felt an obligation to protect and care for their children, but that obligation was at odds with their desire to attain some of the other goals they had for themselves. The care they were providing consumed their time and energy and resulted in their own victimization when their children became violent. The discrepancy in these findings may be related to the fact that all but one of the women in our study were recruited from inpatient psychiatric units, whereas Schwartz & Gidron (2002) recruited participants from support groups. Perhaps the sense of purpose described by the parents in that study was an artifact of their participation in such groups. Involvement in self-help groups has been described as more helpful by families than interaction with mental health professionals (Ferriter & Huband, 2003). Also, while some caregivers in Winefield and Harvey's (1994) sample described benefits of caretaking, 96% reported that, when ill, their relatives did nothing for them, only 22% wanted their relatives to live with them, and among those who lived with their relatives, 46% preferred the arrangement in order to avoid worse outcomes, such as medication noncompliance and their relatives' unhappiness in other living

arrangements, not because of its intrinsic enjoyment. Additional explanations for the divergent findings might be that the children in the current study required more intensive supervision at home. Furthermore, the adult children of mothers in this sample were violent towards their mothers which may have negated some of the satisfaction the women might otherwise have experienced.

The mothers knew that violence was inevitable if their children remained at home. At the same time, they were fearful of what might happen to their children if they were forced to live on the streets. If that occurred the children were likely to be victimized in some way. Either way, the adult child or their mother was destined to be a victim. Most often the women, at least temporarily, jeopardized their own safety by allowing their children to stay with them, rather than allowing their children to remain homeless and vulnerable themselves. A study in Canada of familial caregivers of individuals who were mentally ill found that caregivers wanted safe and affordable housing that met the needs of their mentally ill relative (Ward-Griffin, Schofield, Vos & Coatsworth-Puspoky, 2005). Family members in that study also described placements of poor quality, attempting to prevent their relatives' homelessness, and a need for respite and more support for themselves.

Respite care for family members of individuals who are mentally ill is rare, with the exception of caregivers of people with dementia/Alzheimer's disease. Consequently, there is little available research regarding the utility of respite for familial caretakers of mentally ill individuals (Jeon, Brodaty, & Chestersn, 2005). In a literature review of respite care, Jeon and colleagues (2005) found that less than 3% of

the articles published during a 35 year period from 1967 to 2002 addressed respite and mental illnesses excluding dementia. In their review, respite care was identified as a critical area of support that familial caregivers both desired and required. Respite care decreased caretakers' perceived burden and allowed the families an opportunity to pursue other activities (Jeon, Brodaty & Chesterson). In addition to wanting to pursue their own activities, women in the current study also desired respite to recharge themselves in order to maintain their strength, ability, and desire to continue providing care to their children. This is consistent with other research in which familial caretakers expressed their need for supportive services of their own, such as respite, in order for them to maintain their role as primary caretaker (Ward-Griffin, Schofield, Vos & Coatsworth-Puspoky, 2005; Veltman, Cameron & Stewart, 2002).

Dixon (1999) suggests that a better understanding is needed about the services family members of mentally ill individuals are receiving and from whom. Women in the current study were not receiving any supportive services. The lack of supportive services and their inability to care for their children in combination with their children's violent behavior resulted in some of the children being homeless. The mothers viewed mental health treatment and housing as a single, complex issue, not two distinct problems for which their children needed assistance. The provision of mental health services, however, does not often incorporate housing as a treatment related need (Newman, 2001).

There is evidence that familial caretakers of individuals who are mentally ill desire and need services, including respite, in order to maintain their own quality of

life and to continue providing care to their relative. Poor living conditions for mentally ill individuals living independently and inadequate placements in structured environments have also been described by their family members (Ward-Griffin, Schofield, Vos & Coatsworth-Puspoky, 2005). Given these factors, it is possible that the simplest intervention to incorporate into the treatment of mentally ill individuals to prevent their homelessness and maintain their care outside of structured placement facilities is to provide respite services to familial caretakers.

Another intervention that could have positively impacted the women and their children is conservatorship. Conservatorship of mentally ill individuals has been shown to decrease rates of hospitalization, violence, arrest, and homelessness (Lamb & Weinberger, 1992). Conservatorship can also reduce stress in families affected by mental illness because it results in stabilization and a reduction in chaos in the home (Lamb & Weinberger, 1993). Despite experiencing burden or distress, and being violently victimized, the women of this sample were willing to continue taking care of their mentally ill children. However, they wanted their children to receive appropriate mental health services; services that would have been more easily available had their children been conserved.

The women in this study were concerned enough for their children's safety that they were, at times, willing to sacrifice their own safety by allowing their children to live with them at times despite the impending threat of violence. They felt that the options of either board and care or homelessness were unacceptable and that independent living was not an option for any of their children. Most of the mothers

were willing to allow their children to live with them if their symptoms were under control, hoping that violent behavior would be less likely to occur. While not directly examined in this study, it is likely that many of the women's children preferred living at home because they refused or walked away from placements. Nonetheless, families in which the children preferred living at home and mothers were willing to allow it are in need of two crucial services in order to survive: assurance that the children are receiving adequate mental health treatment and supportive services for the mothers so that they may continue to care for their children and prevent their homelessness. Without these basic services, mothers continue to face the choice of "the best of hells" and children remain vulnerable and dangerous to self and those who love them.

Implications for Practice, Research, and Policy

The mothers' quality of life was impacted regardless of where their children lived. Their obligation to help their children was often at odds with their desire to pursue activities of their choosing. Caretaking mothers, such as some of those from this sample, may reach a point where they decide to pursue their own desires in lieu of continuing to provide care to their mentally ill, adult children. The absence of this familial care is likely to result in increased burden on other systems of care such as homeless shelters, community mental health centers, or hospitals. Supporting caretaking family members in their efforts to provide care to their mentally ill, adult children in their homes may improve their willingness and ability to continue to provide that care. Mental health professionals do not routinely assess the needs or

desires of caretaking family members. Focusing clinical attention on some of their needs and desires may positively impact familial caretakers, which may ultimately positively impact the identified mentally ill individual. Assessment protocols should be amended to include familial caretakers who live with their mentally ill relatives and what supportive services they need in order to continue to provide those relatives with stable housing.

The mothers in this sample described a need for respite care in order to recharge themselves to enable them to continue caring for their children. The development of respite care as an intervention desired by the women is reported elsewhere (see Copeland and Heilemann, in review). Research is needed to determine how such an intervention could be optimally delivered.

The mothers repeatedly described their children's need for mental health treatment as intertwined with their need for stable housing. Their safety was jeopardized if their children remained in their homes, consequently some mothers did not want their children in their homes any longer. If caretaking mothers such as these are unable to continue to provide care, in the form of stable housing, more mentally ill adults may become homeless. The expansion of mental health service provision to incorporate the housing needs of mentally ill individuals is necessary. Whether services are offered to support familial caretakers such as the women in this study, or greater attention is placed on the quality and care provided by board and care type facilities, the end result is likely to be a reduction in the number of homeless, mentally ill adults. Funding agencies responsible for reimbursing mental health service

providers and placement facilities need to expand their services to include reimbursed support for familial caretakers and greater oversight of the placement facilities they help to financially support. Money spent on services for familial caretakers to enable them to continue to provide care and on creating placement facilities people wish to reside in would likely be saved by reductions in other mental health costs such as emergency room visits and psychiatric hospitalizations.

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Conclusion to Dissertation Overall

The literature review and research presented indicates that family members, particularly mothers, experience a great deal of burden and deterioration of their quality of life when taking care of their mentally ill adult children who have been violent. While mothers such as these assume a huge responsibility in their caretaking efforts, they receive inadequate support from the mental health system. This lack of support increases their vulnerability to violent victimization. Family members cannot hospitalize their mentally ill relatives at the first signs of decompensation. Instead, they must wait until their relative's condition deteriorates to the point where dangerous behavior is imminent. In situations where there is a history of violence directed towards familial caregivers, such as those described in this research, the failure of the mental health system negatively affects the entire family. The individuals who are mentally ill do not receive timely intervention and are allowed to experience deterioration in their mental health to the point where they become dangerous. Familial caregivers watch helplessly, unable to access treatment for their relatives, vigilant in their efforts to protect themselves and their ill relatives, unable to experience any respite from their caretaking, and fearful of their own violent victimization.

Additionally, these periods of decompensated mental health, inability to access treatment, vigilant caretaking, and violence are typically cyclical, not isolated incidents. The repetition of this inescapable pattern leaves familial

caretakers questioning their abilities and desires to continue providing care. The women in this sample struggled in their decision to allow their mentally ill, adult children to live with them. Not only did they wonder if they were capable of continuing to provide care to their children, some were uncertain if they even wanted to continue to try. Because their children were adults, most of these mothers saw their efforts to access mental health treatment and housing for their children as futile. The mothers were trapped in a double bind; in order to receive services such as mental health treatment and housing, the children needed to initiate the process. From the caretaking mothers' perspectives, however, their children were too ill or had too little insight to be capable of seeking these services on their own.

The experiences of the women in this sample illustrate the need for professional intervention at multiple points. Despite the fact that the mothers who participated in this study came from diverse cultural, educational, and socioeconomic backgrounds, and had varied mastery of the English language, all reported very similar experiences. That is, all of the women had similar experiences facing barriers to getting immediate assistance when their children became violent, they all expressed a desire for stable, long-term housing for their children, and they all described a need for more assistance from the mental health community. The women expressed a need for respite during periods of their children's decompensation, during the period of time while they waited for their children to meet criteria for involuntary hospitalization.

Perhaps home visits from experienced mental health nurses would alleviate some of the stress and burden familial caretakers experience when providing 24 hour care to their mentally ill relatives during periods of decompensation. A pilot program could be developed by mental health nurses with experience in crisis intervention and treatment of acutely, mentally ill individuals. Such a home health program might be able to provide any services the mentally ill individual is willing to accept, but it would also provide a period of respite to the familial caretakers. Experienced mental health nurses could provide the level of monitoring the ill relative required, affording the caretakers an opportunity to attend to some of their own needs. While the mothers in this sample expressed a need for such respite, further research is needed to investigate what type of assistance would be most helpful to them during their relatives' periodic deterioration in mental health.

It is particularly important for mental health professionals to determine what services, offered over what duration and at what intensity, are necessary for familial caretakers to continue in their roles as primary caretakers for their mentally ill relatives. If the mental health community continues to expect family members to provide the bulk of care to their mentally ill relatives, it has an ethical obligation so support them in their endeavors. Mental health professionals have a particular ethical responsibility to protect caretakers from harm. Family members are not mental health professionals, yet there is an expectation from mental health providers that they provide high levels of care

with inadequate support. Without a change in mental health policy and service provision, the mental health community risks the loss of the tremendous resources familial caretakers provide. Services provided to familial caretakers, particularly during periods of their relatives' acute decompensation, have the potential to ensure ongoing participation in the treatment of their mentally ill relative. Further research is needed to test the effectiveness of professional intervention offered to familial caretakers during these periods.