

Parents Caring for Adult Children With Serious Mental Illness:
A Qualitative Descriptive Study

A Dissertation Presented

by

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DEDICATION

To my mother and best friend, Jacqueline Raymond, who taught me to *never* give up.

And, to all the extraordinary people and families living with serious mental illness who trusted me with their stories of great love and bravery, I am forever grateful to you!

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ABSTRACT

PARENTS CARING FOR ADULT CHILDREN WITH SERIOUS MENTAL ILLNESS:
A QUALITATIVE DESCRIPTIVE STUDY

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The purpose of this study was to examine parents' management styles when caring for adult children with serious mental illness (SMI), as well as parents' perspectives on what type of community-based mental health interventions would support and/or enhance overall family functioning. This qualitative descriptive study was undergirded by Knafli and Deatrick's Family Management Style Framework. Thirty parents (N = 30) caring for adult children with SMI over age 18 were recruited as participants. Demographic data included age, gender, ethnicity, educational level, annual income, and National Alliance on Mental Illness membership. Parents were interviewed in their homes or other private setting. Verbal informed consent was obtained. Audio-recorded, individual, semistructured interviews were conducted until redundancy was achieved. Data were analyzed using qualitative content analysis. Four major themes emerged from the data. These themes described prolonged, difficult, and confusing phases that parents and the

family undergo in caring for an adult child with SMI. These phases have a progressive nature, moving from parents recognizing that their child has a SMI to redefining family life as a result of caring for an adult child with SMI. Successful management of these phases must include increasing access to mental health information, mental health screening, early interventions, violence prevention, and various treatment options for adult children and their families.

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CHAPTER 1
STATE OF THE SCIENCE

Introduction

Serious mental illness (SMI) significantly impacts the lives of people with the illness and their families. The most recent census in 2013 estimated 10.0 million American adults aged 18 or older have SMI (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). Deinstitutionalization and the community mental health movement of the 1960s and 1970s forced people with SMI out of psychiatric hospitals into the community (Chan, 2011). With the shortages of funding for community mental health services and residential placements, many adult children with SMI are unable to adequately care for themselves or live on their own.

Parents often become caregivers for their adult children with SMI due to the chronic and debilitating course of the illness (Chan, 2011; Ferriter & Huband, 2003; Kaufman, Scogin, MacNeil, Leeper, & Wimberly, 2010; Provencher, Perreault, St-Onge, & Rousseau, 2003; Rimmerman, Shabat, & Winstok, 2003; Stein, Aguirre, & Hunt, 2013; St-Hilaire, Hill, & Doherty, 2007). It is estimated that between one-third and two-thirds of adult children with SMI live with their families at one time after discharge from the hospital and depend on their families for assistance and continued involvement (Chan, 2011; Kaufman et al., 2010). Many adult children with SMI are living with aging parents. Statistics on the ages of parent caregivers are limited. The World Federation for Mental Health in 2007 noted that most parent caregivers are in their 50s or 60s (Kaufman et al., 2010). In a small survey conducted on subjective burden among older parents

caring for adult children with SMI, the average age of the parents (N = 69), mostly mothers, was 63.9±3.5 years (Aschbrenner, Greenberg, Allen, & Seltzer, 2010, p. 2).

Parent caregivers frequently play a vital role in the care and recovery of their adult children with SMI by providing housing, financial assistance, emotional support, case management, and advocacy (Dixon, Adams, & Lucksted, 2000; Jewell, Downing, & McFarlane, 2009; Provencher et al., 2003). Dealing with SMI is a significant health challenge that can be disruptive and burdensome to the family (Chan, 2011; Chang & Horrocks, 2006; Kaufman et al., 2010; Saunders, 2003; Stein et al., 2013). Overall family functioning is frequently affected as parents manage disabling symptoms such as hallucinations, paranoia, delusions, social withdrawal, mood swings, and lack of motivation such as apathy and isolation (Gerson & Rose, 2012). Many families are forced to deal with challenging and frightening symptoms including behavioral disturbances, destructive behaviors, self-abuse, substance abuse, and violence (Ferriter & Huband, 2003; Levine & Ligenza, 2002) as they assume this additional caregiver role.

Typically, families exhibit distinct patterns of response to the family member's illness. A family's response can be an important indicator of the loved one's outcomes (Knafl, Deatrck, & Gallo, 2008; Knafl et al., 2009; Wiegand, Deatrck, & Knafl, 2008). These patterns are identified as management styles to cope with the illness and are reflective of overall family functioning (Knafl, Breitmayer, Gallo, & Zoeller, 1996; Knafl & Gilliss, 2002).

The literature on the role of the family involvement in caring for a loved one with SMI has examined caregiver burden and stress (Aschbrenner et al., 2010; Champlin, 2009; Chan, 2011; Doornbos, 2001; Gerson & Rose, 2012; Huey Lefley, Shern, &

Wainscott, 2007; Mackay & Pakenham, 2011; Perlick, Rosenheck, Clarkin, Raue, & Sirey, 2001; Saunders, 2003; Ostacher et al., 2008), stigma (Chang & Horrocks, 2006; Henderson, Evans-Lacko, & Thornicroft, 2013; Michaels et al., 2013; Perlick et al., 2011; St-Hilaire et al., 2007; Wright, Jorm, & Mackinnon, 2011; Zauszniewski, Bekhet, & Suresky, 2009), unmet needs of the patient and family (Bogart & Solomon, 1999; Lysaker & Roe, 2012; Prince, 2005; Riebschleger et al., 2008; Shor & Birnbaum, 2012; Spaniol & Zippel, 1988), and the importance of psychoeducation (Dixon et al., 2001; Glynn, Cohen, & Niv, 2007; Jewell et al., 2009; Kreyenbuhl, Buchanan, Dickerson, & Dixon, 2010; Lehman, Steinwachs, & Co-Investigators of the PORT Project, 1998a, 1998b; Luciano et al., 2012; Sherman et al., 2009); and social support for families (Beebe, 2010; Gerson & Rose, 2012; Hendryx, Green & Perrin, 2009; Kaufman et al., 2010; Rimmerman et al., 2003). Several qualitative studies have examined the care practices of parents, coping, and stages of parental adjustment to an adult child with SMI (Chang et al., 2006; Chesla, 1991; Muhlbauer, 2002). To date, few studies have examined how parents perceive their roles as caregivers to adult children with SMI. Many qualitative and quantitative findings have identified social support as vital to parents caring for an adult child with SMI (Chen & Greenberg, 2004; Stein et al., 2013). Both qualitative and quantitative research has been conducted on the needs of families not being met by mental health professionals (Dixon et al., 1999; Dixon et al., 2001; Drapalski et al., 2008; Scharer, 2002). Yet, there is a gap in the literature on the management styles of parents caring for adult children with SMI and the influences that affect management styles.

Therefore, the purpose of this exploratory, qualitative descriptive study was to examine parents' management styles and associated management components in caring for adult children with SMI, specifically the schizophrenia-spectrum disorders (schizophrenia and schizoaffective disorder) and bipolar disorder. Understanding management styles and the associated components and contextual influences of these styles can supply useful insights to healthcare providers and guide interventions in working more effectively with families in the care of adult children with SMI (Beeber & Zimmerman, 2012; Chesla, 1991; Knafl & Deatrick, 1990; Knafl et al., 2008). The Family Management Style Framework (FMSF), a well-established framework of family responses and functioning to chronic illness in children, was used to undergird this study (Beeber & Zimmerman, 2012; Knafl & Deatrick, 1990; Knafl et al., 2008). The FMSF is in the early stages of being tested with families with adult children with chronic conditions.

The specific aims of the study were the following:

1. To describe parents' perspectives of their unique and complex roles in managing the care of their adult child with SMI.
2. To explore the parents' views on the definition of the situation, management behaviors, and perceived consequences that make up family management styles.
3. To explore parents' perspectives of what types of community-based mental health interventions (including contextual influences) would support and/or enhance overall family functioning.

SMI: Description and Treatment

Serious mental illness is defined as a mental, behavioral, or emotional disorder characterized by severe and persistent symptoms causing dysfunction in several areas of daily functioning, (i.e., work, education, interpersonal relationships, or self-care; American Psychiatric Association [APA], 2013; <http://www.nimh.nih.gov/index.shtml>; Parabiahgi, Bonetto, Ruggeri, Lasalvia, & Leese, 2006). Symptoms of SMI include delusions, hallucinations, disorganized thinking, mood disturbances, disorganized or abnormal motor behavior, and negative symptoms (diminished emotional expression and avolition; APA, 2013). Diagnoses such as schizophrenia, bipolar disorder, major depression, obsessive compulsive disorder, and posttraumatic stress disorder are included in the spectrum of serious mental illness, with the most severe and disabling illnesses being schizophrenia and bipolar disorder (<http://www.nami.org>). Organic, developmental, and substance abuse disorders are not included in the spectrum of SMI.

Approximately 10.0 million adult Americans are diagnosed with SMI (SAMHSA, 2014). The most severe of the mental disorders are schizophrenia and bipolar disorder. These are chronic brain conditions that can be treated and stabilized, not cured (<http://www.apa.org>). Symptoms of SMI such as schizophrenia and bipolar disorder usually manifest in late adolescence/early adulthood (APA, 2013; <http://www.nimh.nih.gov/index.shtml>). SMI often interrupts the developmental tasks during early adulthood (i.e., leaving home, living independently, pursuing an education and/or a career, and engaging in social relationships; Stein et al., 2013, p. 15). All of these delayed developmental tasks affect and/or impinge on family functioning.

Schizophrenia

Schizophrenia affects 2.4 million American adults over the age of 18 (<http://www.nami.org>; <http://www.nimh.nih.gov/index.shtml>). The incidence of schizophrenia is slightly higher in men than women (APA, 2013). Schizophrenia most often appears in men in their late teens or early twenties, while it appears in women in their late twenties or early thirties (<http://www.apa.org>). Symptoms are divided into categories of positive, negative, and cognitive. Women's symptoms appear more affect-laden than men's (APA, 2013, p. 103). Positive symptoms include hallucinations, delusional thoughts, and erroneous or distorted perceptions, beliefs, and behaviors (APA, 2013). Negative symptoms include a loss or reduction in the ability to adequately express oneself, and to find pleasure in activities that one previously enjoyed (APA, 2013; <http://www.apa.org>). Cognitive symptoms include poor concentration, disorganized thinking, confusion, problems with memory, impaired judgment, and decision-making (APA, 2013; <http://www.apa.org>).

Symptoms of schizophrenia can be managed by use of antipsychotic medications, rehabilitation, and psychoeducational interventions (i.e., social support, social skills training, symptom management strategies, and relapse prevention skills; <http://www.apa.org>). Some people with schizophrenia can recover and live more productive lives with effective symptom management while others have a progressive debilitating course of the illness leading to functional decline and disability (APA, 2013). Family involvement in the treatment of people with schizophrenia has been shown to reduce relapses and improve the mental health of both patient and family members (<http://www.apa.org>).

Bipolar Disorder

Bipolar disorder is a chronic brain condition with recurring episodes of mania and/or depression that can last from one day to months (<http://www.apa.org>). More than 10 million Americans have bipolar disorder, with the illness affecting men and women equally (<http://www.nami.org>). Although the illness can occur at any point in life, more than one-half of all cases begin between ages 15 and 25 (<http://www.nami.org>). This mental illness causes unusual and dramatic shifts in mood, energy, and the ability to think clearly. Cycles of high (manic) and low (depressive) moods may follow an irregular pattern that differs from the typical ups and downs experienced by most people (<http://www.nami.org>). The symptoms of bipolar disorder can have a negative impact on a person's life (i.e., damaged relationships, a decline in job or school performance; <http://www.apa.org>). People with bipolar disorder can also recover and lead productive lives depending on the severity of symptoms and efficacy of symptom management. The primary treatment to manage the symptoms of schizophrenia and bipolar disorder is medication. Antipsychotic medications are used to treat both schizophrenia and bipolar disorder. Mood-stabilizing medications are the first line of treatment for bipolar disorder (Alda, Hajek, Calkin, & O'Donovan, 2009). Other interventions for the treatment of schizophrenia and bipolar disorder include psychoeducation, symptom management, and supportive services to assist both the patient and family members dealing with the illness (Cohen et al., 2008; Dixon et al., 2011; Glynn, Cohen, Dixon, & Niv, 2006; <http://www.apa.org>; <http://www.nami.org>). Medication adherence and family involvement are important factors for positive patient outcomes (Berk et al., 2010; <http://www.nami.org>). Several studies have found a correlation between increased

caregiver and adverse clinical outcomes in patients with bipolar disorder (Goossens, van Wijnaarden, Knoppert-Van Der Klein, & Van Achterberg, 2008; Ogilvie, Morant, & Goodwin, 2005; Perlick et al., 2001; Perlick et al., 2007). Therefore, family psychoeducational interventions are important to improving patient outcomes.

In the discussion about SMI, it is important to address the relationship between violence and SMI. The number of school-related shootings caused by people with questionable psychiatric histories has flooded the media. On April 16, 2007, Seung-Hui Cho shot and killed 32 people and wounded many others on the campus of Virginia Tech in Blacksburg, Virginia, before he committed suicide. On December 14, 2012, Adam Lanza shot and killed 20 children and six adult staff at the Sandy Hook Elementary School in Newtown, Connecticut. Lanza shot and killed his mother prior to going to the elementary school, and he later committed suicide. Elliot Rodger, age 22, went on a shooting rampage on May 23, 2014 near the University of California at Santa Barbara, killing seven before killing himself. On October 1, 2015, Christopher Harper-Mercer, age 26, opened fire in a building on the Umpqua Community College campus in Roseburg, Oregon killing eight students, one teacher, and injuring nine others before shooting himself after engaging police who responded to the incident. All of these young men had histories of odd behaviors and/or psychiatric symptoms. A common misperception in the general population is that mental illness is a leading cause of violence (Elbogen & Johnson, 2009; Swanson et al., 2006). In a longitudinal study conducted on subjects (N = 34,653) by the National Institute of Alcohol Abuse and Alcoholism (Elbogen & Johnson, 2009), the results showed that incidence of violence was higher for people with SMI, but only with co-occurring substance abuse and/or dependence (Elbogen & Johnson, 2009;

Swanson et al., 2006; Volavka & Swanson, 2010). Multiple variables need to be examined when understanding the relationship between violence and SMI (i.e., substance abuse, environmental factors, and history of violence; Elbogen & Johnson, 2009; Swanson et al., 2006).

Family Caregiving for Adult Children with SMI

Parents of an adult child with SMI such as schizophrenia or bipolar disorder encounter major lifelong challenges (Aschbrenner et al., 2010; Tanriverdi & Ekin, 2012). Parents are most often the caregivers of their adult children with SMI (Chan, 2011) as symptoms of mental illness impair their social and occupational functioning and their ability to live independently (Aschbrenner et al., 2010; Awad & Voruganti, 2008; Chan 2011; Doornbos, 2002; Kaufman et al., 2010; Muhlbauer, 2002; Provencher et al., 2003). Caregivers are more likely to be women (Aschbrenner et al., 2010; Chan, 2011; Muhlbauer, 2002). Globally, approximately 80% of caregivers for people with SMI are women, including mothers, wives, or daughters (Chan, 2011, p. 343). Although fathers and siblings can be involved in the care for family members with SMI, empirical data regarding their specific roles are limited. In a community survey in the United States (U.S.) of family members (N = 697) caring for a relative with SMI, 82% were female caregivers, with 90% being mothers (Awad & Voruganti, 2008). Another finding from this study was that 70% of the caregivers were ages 60 and greater, with 33% being >70 years old (Awad & Voruganti, 2008, p. 153). As parents age, they face their own personal distress, guilt, health issues, and worry as they focus on the uncertainty about their own future and the future of their mentally ill children (i.e., Who will care for them when they are gone?; Aschbrenner et al., 2010; Kaufman et al., 2010; Stein et al., 2013).

Parents provide a variety of roles in caring for an adult child with SMI (Chesla, 1991; Gallagher & Mechanic, 1996; Kaufman et al., 2010; Mueser, Silverstein, & Farkas, 2013). Adult children with severe cognitive and functional deficits need parental assistance to meet their basic daily needs (i.e., providing living arrangements, providing reminders to shower and change their clothing, washing their clothing, assisting with household chores, preparing meals, assisting with money management, and medication administration and monitoring; Chesla, 1991; Gerson & Rose, 2012; Provencher et al., 2003). Providing social and emotional support is a critical role for parent caregivers of adult children with SMI (Gerson & Rose, 2012; Rimmerman et al., 2003; Shor & Birnbaum, 2012). SMI can affect people's ability to socialize and interact with others, often leading to social isolation and withdrawal (<http://www.nami.org>). It is vital for parents to provide and/or obtain education about illness management and social skills training to assist their adult child with SMI (Beebe, 2010; Chan, 2011; Chou et al., 2012; Muhlbauer, 2002). Providing resources, support, encouragement, and skills training can help to promote increased independence, foster recovery, and improve quality of life for adult children with SMI (Chan, 2011).

How Families Adjust and Manage SMI

A small body of literature exists that describes how families with adult children with SMI adjust and manage the condition. The seminal work conducted by Chesla (1991) focused on caring practices for their children with schizophrenia. This was a hermeneutic phenomenological study that included both mothers and fathers (N = 21). Four distinctive caring practices of family caregivers were identified reflecting how parents defined their situation: engaged care, conflicted care, managed care, and

distanced care (Chesla, 1991, p. 454). Parents described having to find new meanings and practices in their parenting role. Parents who used engaged care provided a supportive role, helping their children to ease the struggle with their illness. Parents using managed care saw themselves as managers and relied on parenting techniques and treatment based on scientific literature. Parents who engaged in conflict care were described as angry, dissatisfied, and bothered at their situation. They struggled to not allow the situation to greatly disrupt their lives (Chesla, 1991). In distanced care, a more clear division of care between parents was seen. Mothers were responsible for all the parenting tasks, and fathers worked outside the home. Fathers reported depending on the mothers to provide the direct day-to-day care of the ill child (Chesla, 1991). Specific roles and management tasks were not described. Although rich descriptions of the four caring practices were identified, further descriptions of more recent family management components and the contextual influences that support or create barriers are warranted in order to provide families with specifically tailored interventions specifically designed to meet their unique family needs.

Another qualitative descriptive study (N = 26: 15 mothers, 6 fathers; 2 women and 2 male spouses or significant others; one female sibling) was conducted by Muhlbauer (2002) to examine how family caregivers adjust to their ill family member's diagnosis. The findings revealed that the participants went through a progression of six phases of adaptation described as "navigating the storm." These phases included the following: "Development of awareness: Storm warnings; Crisis: Confronting the storm; Cycle of instability and recurrent crises: Adrift on perilous seas; Movement toward stability: Realigning the Internal Compass; Continuum of stability: Mastering

Navigational Skills; and Growth and Advocacy: Sailing Existential Seas” (Muhlbauer, 2002, p. 1082). Specific topics were identified by family members across all phases affecting their caregiving ability: the need for communication with mental health providers; limited resources (financial and social); the need for access to information to assist the family member; and knowledge regarding symptom management care patterns (Muhlbauer, 2002, p. 1091). A qualitative descriptive study was conducted as part of a larger quantitative study on family health in caregiving families (Doornbos, 2001). The purpose of the study was to obtain rich descriptions of the family caregiving process and family health in families caring for a young adult with SMI. A packet with four open-ended questions was sent to family caregivers of young adults with SMI asking about their caregiving experiences. The questions included the following: What was involved in caring for your relative with SMI? What type of information did you need in caring for your relative? How do you know when you are doing a good job? And what do you want mental health professionals to know about your experience caring for your relative? (Doornbos, 2001, p. 333). These family caregivers (N = 76) were recruited from National Alliance on Mental Illness (NAMI) chapters throughout the U.S. Five major caregiving processes were identified: “monitoring, managing the illness, maintaining the home, supporting/encouraging and socializing” (Doornbos, 2001, p. 335). Caregiving families identified the need for extensive information to prepare for the caregiving role, specifically information on the illness, interventions for dealing with symptoms, and available resources (Doornbos, 2001, p. 340). In the descriptive empirical literature, parent caregivers identified major problem areas in caring for and managing their adult children with SMI, such as coping with their child’s problematic behaviors, social role

performance, and inability to carry out activities of daily living; dealing with isolation; disruptions in household routines and family life; meeting the personal needs of other family members; dealing with treatment nonadherence of the adult child; receiving no respite from caregiving responsibilities; and receiving inadequate help from mental health professionals (Chan, 2011; Kaufman et al., 2010; Levine & Ligenza, 2002; Lucksted, Stewart, & Forbes, 2008; Stein et al., 2013). In a systematic review of the literature on families living with SMI, Saunders (2003) examined the following variables: coping, psychological distress/caregiver burden, caregiver resiliency, caregiver depression, social support, and behavioral problems, and family functioning. Families were noted to have different ways of coping. Families who used problem-solving strategies to adjust to their child's mental illness functioned more effectively (Saunders, 2003). Coping strategies frequently used by families were seeking social supports, seeking spiritual support, avoidance, mobilizing resources, and reframing the situation (Saunders, 2003). Caregiver burden and psychological distress were lessened with social support and when both parents shared in the caregiving of the adult child (Saunders, 2003). Caregiver resiliency was identified as an importance factor in family coping. Research findings summarized that families who could use their strengths to overcome fears and attitudes, maintain supportive relationships, and maintain family stability experienced less psychological distress and caregiver burden and dealt more effectively with the behavioral problems of the ill child (Saunders, 2003). Family functioning was noted to be significantly affected by family psychological stress and behavioral problems exhibited by the ill family member. Family functioning needs to adjust and adapt over time. Family coping to

chronic mental illness may result in a positive family experience that can promote growth, strength, cohesion, and stability (Saunders, 2003).

Research on the emotional climate of families dealing with chronic mental illness has been examined as affecting the course of the person's illness and patient outcomes (Hooley & Campbell, 2002; Hooley & Parker, 2006; Rose et al, 2002). Expressed emotion has been used as a measurement of the family environment influencing family management styles (Knafl et al., 1996; Knafl & Deatrck, 2003; Walton-Moss, Gerson, & Rose, 2005). As an adult child should be moving toward greater independence, many parents caring for an adult child with SMI see themselves as taking on more control and responsibility for helping and protecting the child (Milliken & Northcott, 2003; Rose, Mallinson, & Gerson, 2006; Walton-Moss et al., 2005). The grounded theory study by Rose, Mallinson, & Walton-Moss (2002) was conducted to describe families' responses to the severe mental illness of a relative over time. Families (N = 17) were interviewed three times over a 2-year period. The central concept emerging as families strived to manage the illness was normalcy (Rose et al., 2002). Families engaged in an ongoing process to accept the mental illness and to manage it in their day-to-day functioning. Striving for normalcy within the family has been investigated in parents caring for a chronically ill child (Deatrck, Knafl, & Murphy-Moore, 1999; Knalf & Deatrck, 1990; Rose et al., 2002). In the process of normalization, families were found to be confronting the uncertainty of the illness by keeping watch, being consumed by the illness, seeking control over the illness, and moving from fear, sadness and grief to possibilities, hope, and recovery (Rose et al., 2002). In 2005, Walton-Moss, Gerson, and Rose did a secondary analysis of the result from the grounded theory study of 2002. They identified

family functioning in three management groups: families that are *hanging on*, those that are *stable*, and those that are *doing well* (Walton-Moss et al., 2005). Families that are hanging on were overwhelmed as they attempted to cope with extreme grief over the loss of functioning and goals for the ill family member (Walton-Moss et al., 2005). These families focused on crisis management and ways to fix the illness. Stable families acknowledged the changes the family went through due to the illness by coming through difficult times. The goals of the family were trying to prevent their relative from relapsing and minimizing the impact of the illness by developing daily routines (Walton-Moss et al., 2005). Families who saw themselves as doing well were able to view their relative's mental illness as being in the background rather than the foreground (Walton-Moss et al., 2005). These families had more supports and resources and saw their situation as having more opportunity for growth (Walton-Moss et al., 2005).

The Emotional Toll on Family Functioning

Caring for adult children with SMI can have significant consequences on family functioning because of the chronic and persistent nature of the illness. Mental health research in the mid-1960s started to examine the “costs” associated with caring for a family member with SMI on the caregivers (Cook, Lefley, Pickett, & Cohler, 1994; Gallagher & Mechanic, 1996; Kreisman & Joy, 1974). Some of these costs incurred by families are the loss of the adult child's previous level of functioning (Mohr & Regan-Kubinski, 2001), increased family conflict, the stigma attached to mental illness, disruptions at work, financial problems, and negative effects on psychological and physical health of caregivers (Chen & Greenberg, 2004; Karnieli-Miller et al., 2013; Perlick et al., 2007; Rose et al., 2006).

Later studies identified the concept of “family or caregiver burden,” meaning the negative consequences on families related to their caregiving roles (Rose et al., 2002; Walton-Moss et al., 2005). Burden includes the subjective and objective effects of living with and caring for a person who is acutely or chronically mentally or physically ill (Gallagher et al., 1996; Perlick et al., 2001; Saunders, 2003; St-Hilaire et al., 2007). Subjective burden refers to the caregiver’s perception of the caregiver role and the factors affecting that role, whereas objective burden refers to the effects of the illness and the family response to the illness on the household (Awad & Voruganti, 2008, p. 150; Rose et al., 2006). Families’ responses to the burden of adjusting to a family member with SMI influence family management styles (Doornbos, 2002; Knafl et al., 1996; Knafl et al., 2003; Walton-Moss et al., 2005).

Dealing with the severity of symptoms of SMI has been identified as having the most impact on family members caring for adult children with SMI (Kaufman et al., 2010; Milliken & Northcott, 2003; Rose et al., 2002; Rose et al., 2006). Family functioning is affected when attempting to manage severe symptoms (i.e., hallucinations, paranoia and problematic behaviors [i.e., disruptive, bizarre, or violent behaviors]; Awad et al., 2008; Kaufman et al., 2010; Rose et al., 2002). A pilot study was conducted by Gerson and Rose (2012) to explore contextual factors influencing patient adjustment to the community (i.e., symptom severity and functional status, coping, satisfaction with care, and social support among persons with SMI and their families following an inpatient psychiatric admission). Exploratory interviews with family members (N = 10) related the impact of the illness on the family were conducted. All 10 family members reported distress related to the ill-family member exhibiting ongoing symptoms and

expressed feeling at a loss as to how to deal with the symptoms despite recent hospitalization (Gerson & Rose, 2012, p. 268). Family caregivers have expressed frustration with not having adequate information about the adult child's mental illness, problem-solving skills for managing the illness, medication management and adherence, and crisis management to reduce relapse and rehospitalization (Cohen, Glynn, & Niv, 2007; Drapalski et al., 2008; Gerson & Rose, 2012; Kaufman et al., 2010).

The stigma of mental illness has an adverse impact not only on persons with mental illness but also on families. Stigma is defined as the negative stereotyping, rejection, and discrimination of people with mental illness (Karnieli-Miller et al., 2013). Family members have described feelings of embarrassment, shame, blame, loneliness, isolation, and guilt as a result of the stigma of mental illness (Chan, 2011; Ferriter & Huband, 2003; Karnieli-Miller et al., 2013; Larson & Corrigan, 2008; Rose et al., 2006). Some families internalize the public stigma of mental illness, referred to as "self-stigma," which can affect perceptions of how people view themselves and their situation (Corrigan & Wassel, 2008). Family members' goals and expectations can be affected by the stigma attached to mental illness (Corrigan & Wassel, 2008). Stigma has resulted in negative consequences on families affecting availability of employment, obtaining insurance, and seeking higher education (Huey et al., 2007). Families need education and support in order to challenge this stigma and to focus on recovery.

Chronic disruptions to family life and the household routine is associated with poor physical and mental health of family caregivers (Chan, 2011; Mohr & Regan-Kubinski, 2001; Perlick et al., 2007; Rose et al., 2002; Rose et al., 2004; Walton-Moss et al., 2005; Wrosch, Amir, & Miller, 2011). The lifelong responsibility of the caregiving

role and lack of respite can lead to increased anxiety, depression, insomnia, and physical illness (Awad & Voruganti, 2008; Doornbos, 2001; Kaufman et al., 2010; Rose et al., 2002; Rose et al., 2006; St-Hilaire et al., 2007; Stein et al., 2013). A study by Perlick et al. (2007) examined the caregiver burden in caring for a family member with bipolar disorder. Family caregivers (89.1% of N = 465) reported moderate-to-severe burden. Those caregivers who identified high burden (n = 155) reported “scores of 16 or higher on the Center for Epidemiologic Studies Depression Scale (CES-D) for depression ($x^2 = 37.44$, $df = 2$, $p < 0.001$), poorer general health ($F = 3.79$, $df = 2, 459$, $p < 0.001$), and a higher number of chronic medical conditions ($F = 6.21$, $df = 2, 461$, $p = 0.014$) than caregivers with lower levels of burden” (Perlick et al., 2007, pp. 268–269). These results were comparable to results from previous studies on burden in the care of relatives with schizophrenia and dementia (Perlick et al., 2007).

Song, Mailick, and Greenberg (2014) conducted a study examining the effects of work schedule flexibility and work stress spillover on the health of parents of an adult child with SMI. Parents of an adult child with SMI (N = 100, n = 67 mothers, n = 33 fathers) were compared with parents without a child with disability (N = 500, n = 335 mother, n = 165 fathers) using data from the Wisconsin Longitudinal Study. When comparing the two groups of mothers for socioeconomic status, work schedule flexibility, and the negative impact of work-to-family spillover, the mothers of adult children with SMI reported more physical illnesses than the mothers of adult children without disability ($p < .05$; Song et al., 2014). From the demographic data, the mothers of adult children with SMI were more likely to have more children, be unmarried, and be living with the adult children than the comparison group of mothers. The physical health of fathers with

adult children with SMI did not differ from the comparison group of fathers except for reports of musculoskeletal problems ($p < .01$; Song et al., 2014). No demographic differences were noted from both groups of fathers (Song et al., 2014).

Community-Based Supports for Families Caring for Adult Children With SMI

The importance of family involvement in the caring of people with SMI has been discussed in the research as far back as the 1950s. Research has identified that families need support and resources in the management of caring for their family member with SMI (Zipple & Spaniol, 1987). In 1992, the National Institute of Mental Health and the Agency for Health Care Policy and Research funded the Schizophrenia Patient Outcomes Research Team (PORT) with the goal of developing evidence-based treatment recommendations for improving the quality and cost effectiveness of care for people with schizophrenia (Lehman et al., 1998a, 1998b). The PORT recommendations included the use of anti-psychotic medications, family intervention, vocational rehabilitation, assertive community treatment, and intensive case management (Lehman et al., 1998a, 1998b). Family intervention was described as offering families at least nine months of family psychoeducation including information about the illness, family support, crisis intervention, and problem-solving skills training (Lehman et al., 1998a, 1998b). Family psychoeducation programs have been identified as an evidence-based practice in the treatment of SMI that has been shown to reduce relapse and rehospitalization rates and promote recovery and well-being in persons with SMI and reduce family stress and burden and improve family relationships (Cohen et al., 2007; Dixon et al., 2000; Dixon et al., 2011; Kreyenbuhl et al., 2010; Lehman et al., 1998a, 1998b; Lukens & McFarlane, 2004). Family psychoeducation provides information on mental illness and illness

management, social support, skill development for problem-solving, stress management, crisis management, and network-building (Cohen et al, 2007; Dixon et al., 2000; Dixon et al., 2001; Jewell et al., 2009; Lukens & McFarlane, 2004; Murray-Swank & Dixon, 2004). Family psychoeducation should be provided by trained mental health clinicians who promote partnerships and collaborative decision-making among the patient, family, and clinician (Kreyenbuhl et al., 2010). The dissemination of family psychoeducation has been limited and inconsistent by mental health providers (Cohen et al., 2008; Dixon et al., 2004; Kreyenbuhl et al., 2010).

The role of mental health professionals working with parents of adult children with SMI is an important contextual influence affecting family management. Both professional and family care is necessary in the management of SMI. Families can benefit from the knowledge and skills of mental health professionals, and mental health professionals can benefit from the knowledge and involvement of parents caring for their children in the community (Nicholls & Pernice, 2009; Prince 2005). Despite the PORT recommendations and evidence of the benefits of family psychoeducation on health outcomes, families reported decreased rates of mental health provider contact and dissatisfaction with the mental health system (Dixon et al., 2011; Doornbos, 2002; Murray-Swank & Dixon, 2004; Prince, 2005; Rose et al., 2004). In a descriptive, retrospective survey study conducted by Kaas, Lee, and Peitzman (2003) on barriers to collaboration between mental health professionals and families of persons with SMI, mental health professionals (N = 31) identified not having time for family involvement, feeling conflicted about treatment of the patient versus the family, and believing family involvement was many times harmful to the patient (Kaas et al., 2003). A Canadian study

by Perreault, Rousseau, Provencher, Roberts, and Milton (2012) was conducted on caregiver satisfaction (N = 154) with outpatient mental health services. The researchers found that greater perceived collaboration between caregivers and professionals resulted in greater satisfaction with mental health services ($r = .55$, $df = 152$, $p < .001$) as well as significant correlation between caregiver satisfaction and the ratio of met needs ($r = .33$, $df = 152$, $p < .001$; Perreault et al., 2012, p. 235).

Parents caring for adult children with SMI have identified social support/social networks as being important contextual influence on family management. Social support/social networks have been found to have positive effects on health outcomes of the ill child and the family and on family resilience (Cohen et al., 2008; Corrigan & Phelan, 2004; Stein et al., 2013; Zauszniewski et al., 2010). Family support programs such as the NAMI in the U.S. and Rethink in the United Kingdom have been crucial to assisting consumers and their families to manage SMI (Dixon et al., 1999; Glynn et al., 2007; Murray-Swank et al., 2007; Perlick et al., 2011; Riebschleger et al., 2008; Solomon, 2000). The NAMI has developed programs run by family members and consumers affected by SMI such as “Family to Family,” “NAMI Support Group,” and “In Our Own Voice—Family Companion” to support and educate families about their relatives’ mental illness, problem-solving and management strategies, advocacy, and available resources in the community (Dixon et al., 2011; Lucksted et al., 2008; Perlick et al., 2011; <http://www.nami.org>).

Another important contextual influence affecting family management is resources. Families need resources to assist them in the daily operation of caring for the adult child with SMI (i.e., financial resources, public assistance, employment

opportunities, housing, transportation, access to mental and physical health services, respite services, day treatment programs, and legal advocacy; Compton et al., 2011; Hendryx et al., 2009; Jewell et al., 2009). Access to resources can be limited due to systems-level issues such as lack of administrative support for programs and public funding constraints as well as families' lack of information about available resources (Compton et al., 2011; Green et al., 2013; Murray-Swank & Dixon, 2004; Pickett-Schenk, 2003).

The President's New Freedom Commission on Mental Health of 2003

(<http://w.w.w.govinfo.library.unt.edu/mentalhealthcommission/reports/reports.htm>)

emphasizes the shift from a healthcare system that promotes symptom management to a more integrated healthcare system focusing on recovery-oriented services (Green et al., 2013; Huey et al., 2007). Recovery-oriented services promote patient autonomy living in the community and support for both loved ones with SMI and their families (Compton et al., 2011; Huey et al., 2007; Lyman et al., 2014; Stein et al., 2013). Therefore, it is vital to address the gaps in the literature regarding parents' perspectives of their roles in managing the care of their adult child with SMI, the components of family management styles in dealing with an adult child with SMI, and parents' perspectives on what type of community-based mental health services will support and enhance overall family functioning. Understanding how parents manage the day-to-day demands of caring for an adult child with SMI can offer useful insights to mental health professionals in providing more effective and accessible interventions.

CHAPTER 2

THEORETICAL FRAMEWORK

Introduction

The Family Management Style Framework (FMSF; Knafl & Deatrick, 1990, 2003) was used to undergird this research study. A theoretical framework is central to qualitative research. The FMSF is a well-established conceptual representation examining patterns of family response and typologies of family functioning to a child's chronic illness (Beeber & Zimmerman, 2012; Knafl & Deatrick 2003; Knafl et al., 2008). The framework has been adapted in recent studies for families managing other serious and chronic health conditions (Beeber & Zimmerman, 2012; Wiegand et al., 2008). This study used the FMSF to examine parents' roles and management behaviors in caring for adult children with SMI. The FMSF was used to guide the initial interview questions and to analyze and interpret the findings (Sandelowski, 1993, 2004).

FMSF Description and Development

The FMSF was developed over a 20-year span to understand how families respond to a child's chronic illness (Knafl & Deatrick, 1990; Knafl et al., 2003). Earlier research examined the conceptualization of family response to a child's chronic illness focusing primarily on the management style of normalization (Knafl & Deatrick, 1990). A qualitative study in 1996 on family response (N = 63 families) to a child with chronic illness was able to delineate five family management styles (Knafl et al., 1996). The management styles are as follows: Thriving, Accommodating, Enduring, Struggling, and Floundering (Knafl et al., 1996). Each style was found to have distinctive characteristics (Knafl et al., 1996). These findings led to subsequent research and the review of 46

studies on family response to childhood chronic condition. This culminated in the development of the original FMSF for examining how families and their individual members respond to a child's chronic illness (Knafl et al., 2003).

Components.

The major components of the FMSF were identified as the definition of the situation, management behaviors, and perceived consequences (Knafl & Deatrick, 1990). Each component is in an interactive relationship with each other. The definition of the situation is the subjective meaning that family members give to the situation of dealing with a chronic illness and is critical to how they will manage the situation (Knafl & Deatrick, 1990). This first component has several dimensions that contribute to the overall definition: “(a) child identity or the parental views of the child and extent to which those views focus on illness or normalcy and capabilities or vulnerabilities, (b) illness view or the parent's beliefs about the cause, seriousness, predictability, and course of the illness (c) management mindset or the parents' view of the ease or complexity of carrying out the treatment regimen and their ability to carry out treatment effectively, and (d) parent mutuality or caregiver's beliefs about the extent to which they have shared or discrepant views of the child, illness, their parenting philosophy, and their approach to illness management” (Knafl et al., 2003, pp. 243–244).

The second component of FMSF is management behaviors. These are defined as the specific behavioral adjustments that family members make to manage the illness on a day-to-day basis, reflecting changes in roles, norms, and family interactions (Knafl & Deatrick, 1990). Management behaviors are directly influenced by the family's definition of the situation. The dimensions of management behaviors are (a) parenting philosophy,

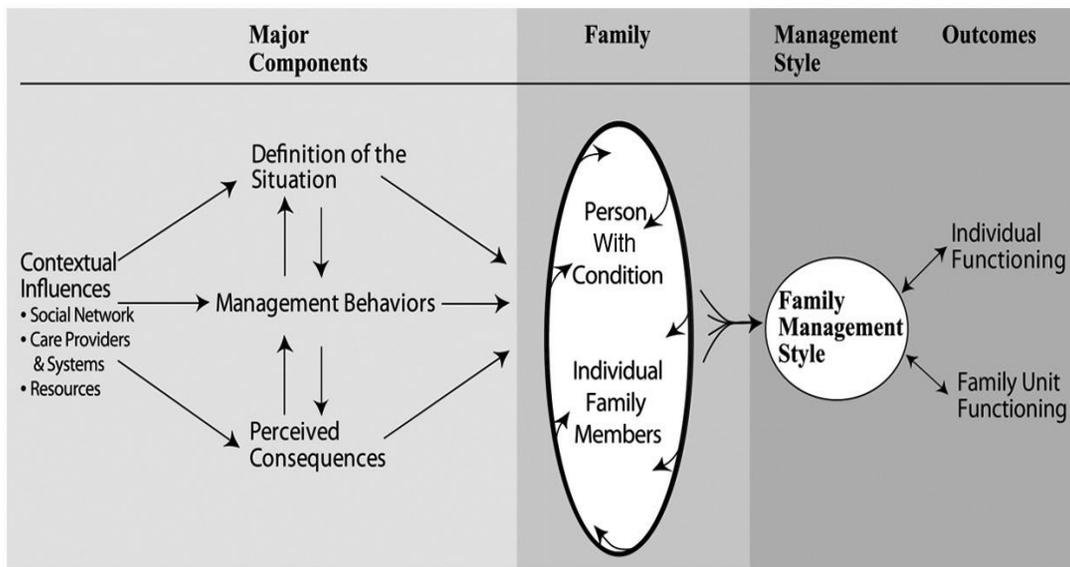
meaning the parents' goals and principles that direct the behaviors, and (b) management approach or the parents' ability to develop a routine for illness management.

The last component is perceived consequences. This component refers to the perceived or actual outcomes as a result of the interaction between management behaviors and the definition of the situation (Knafl et al., 2003; Wiegand et al., 2008). The dimensions included in perceived consequences are (a) "family focus or parents' assessment of the balance between managing the illness and other aspects of family life, and (b) future expectations or the parents' assessment of the implications of the illness for their child's and family future" (Knafl et al., 2003, p. 245).

Refinement and revision.

The FMSF has undergone conceptual refinement since its development. The original framework identified a sociocultural context of family management. Sociocultural context was seen as perceived influences on family management (i.e., cultural, ethnic, social, religious, economic, and political; Knafl & Deatrick, 1990; Knafl, Deatrick, & Havill, 2012). Further analysis of the sociocultural context revealed three other influences contributing to family management, including "the family's social network, healthcare and education professionals, system, and resources" (Knafl et al., 2012, pp. 17–18). The word "perceived" gave the impression that these influences were not real. Therefore, the label was changed to "contextual influences," giving the framework a broader applicability (Knafl et al., 2012, p. 24). The revised FMSF was expanded by changing the terms from child, mother, father, and sibling to person with the condition and individual family members (Knafl et al., 2012). The revised FMSF (Figure 1) has provided greater elaboration of the dimensions that shape family life and ways

families integrate the healthcare demands and challenges into everyday family life (Knafl et al., 2012). The revisions have allowed a broader use of the framework to examine families managing more than childhood chronic illness (i.e., spiritual influence on family management in Parkinson’s disease; Bingham & Haberman, 2006); withdrawal of life-sustaining therapy from adults with acute illness or injury (Wiegand et al., 2008); and caring for older adults with dementia (Beeber & Zimmerman, 2012).



*Figure 1. Model of Revised Family Management Style Framework. From “Continued Development of the Family Management Style Framework,” by K. A. Knafl, J. A. Deatrck, and N. L Havill, 2012, *Journal of Family Nursing*, 18, page 25. Copyright (2012) by the Author(s). Reprinted with permission.*

A qualitative descriptive study conducted by Bingham and Haberman (2006) used the FMSF as the theoretical framework to examine the influence of spirituality on the family management of a loved one with Parkinson’s disease (PD). From the analysis of the data (N = 56), five specific categories emerged: (a) depending on belief and faith to manage the situation, (b) providing purpose and meaning in living with PD, (c)

establishing a connection with God by praying, (d) establishing a connection with other individuals, and (e) feeling a sense of gratitude and hope (Bingham & Haberman, 2006, pp. 425–426). The FMSF proved useful in this study as the role of spirituality influenced the definition of the situation and affected management behaviors and perceived consequences in managing PD.

Wiegand et al. (2008) examined the data from an earlier hermeneutic phenomenological study conducted by Wiegand (2003) on the lived experience of families (N = 56) participating in the process of withdrawing life-sustaining therapy from a family member with an unexpected life-threatening illness or injury. From the analysis of these data, a typology of five management styles emerged that included progressing, accommodating, maintaining, struggling, and floundering (Wiegand et al., 2008). Major dimensions similar to the FMSF were revealed. These dimensions were definition of the situation, management behaviors, and consequences. The FMSF was useful in illustrating family processes and incorporating the family management styles for dealing with life-threatening illness or injury.

A secondary analysis of qualitative interview data from two previous studies conducted in 2005 and 2006 adapted the FMSF to families caring for older adults with dementia (Beeber, 2008; Beeber & Zimmerman, 2012). The dimensions within the major components of the FMSF were adapted for caring for an older adult with dementia. See Table 1 for comparison of the revised FMSF (Knafl et al., 2003) and Beeber and Zimmerman's adaption of the FMSF (Beeber & Zimmerman, 2012).

Table 1

Adaptation of the Major Components of the Revised FMSF for Adults With Dementia

Revised FMSF Components	Revised FMSF Dimensions	Adapted FMSF Components	Adapted FMSF Dimensions
<p>Definition of the situation: Subjective meaning family members attribute to important elements of their situation related to the child's illness.</p>	<p>Child Identity: Parents' views of the child and the extent to which these views focus on illness, normalcy, and capabilities or vulnerabilities.</p> <p>Illness View: Parents' beliefs about causes, seriousness, predictability, and course of the illness.</p> <p>Management Mindset: Parents' views on the ease or difficulty in carrying out treatment regimens and ability to manage effectively.</p> <p>Parent Mutuality: Parents' beliefs regarding the extent that they have similar or differing views of the child, illness, parenting philosophy, and approach to illness management.</p>	<p>Definition of the situation: Subjective meaning family members attribute to the important elements of their situation related to dementia care.</p>	<p>Older Adult's Identity: Caregivers view of the older adult with dementia with normalcy versus dementia related deficits based on comparison with past personality, function, activities, and interests.</p> <p>Illness View: Caregivers' beliefs about the seriousness and disruptiveness of dementia. Dementia is viewed as a long, steady decline leading to death.</p> <p>Management Mindset: Caregivers' views of the level of difficulty carrying out daily care, their ability to manage effectively, and to maintain a balance between independence and safety.</p> <p>Family Mutuality: Caregivers' beliefs whether they have shared or opposing views with family members and health care providers related the older adult, dementia, and approaches to care.</p>

<p>Management Behaviors: The principles guiding parents' management behaviors and abilities.</p>	<p>Parenting Philosophy: Parent's goals, priorities, values guiding overall approaches and specific strategies for illness management,</p> <p>Management Approach: Parents' assessment and strategies for managing the illness and incorporating it into family life.</p>	<p>Management Behaviors: Discrete behavioral adjustments family members use to manage dementia on a daily basis.</p>	<p>Caregiving Philosophy: Caregivers' goals, priorities, values guiding overall approach to caregiving in the context of dementia care. Philosophy frames by beliefs (i.e., desire for independence, dislike for nursing homes).</p> <p>Management Approach: Caregivers' assessment of the extent to which they developed a routine for dementia care on a daily basis and for avoiding illness related problems.</p>
<p>Perceived Consequences: The extent to which parents view the child's illness as the foreground or background of family life.</p>	<p>Family Focus: Parents' assessment of balance between illness management and other aspects of family life.</p> <p>Future Expectations: Parents' assessment of the implications of illness for the child's and family's future.</p>	<p>Perceived Consequences: The expected family, older adult, and dementia care outcomes that shape management behaviors and effect subsequent definitions of the situation.</p>	<p>Family Focus: Caregivers' assessment of the balance between dementia management and other aspects of family life.</p> <p>Future Expectations: Caregivers' assessment of the implications of dementia including effects of slow decline associated with the disease on the older adult and the family.</p>

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The findings of this study revealed some differences between the use of the FMSF to guide the research and clinical care for families caring for a child with chronic illness and families caring for older adults with dementia. The illness view for the chronically ill

child usually involves some expectation that the child will maintain some function, obtain an increased level of independence, and compensate for the illness (Beeber & Zimmerman, 2012). Whereas for the adult with dementia, the expectation is that the older adult will become more symptomatic, less independent, and more reliant on family caregivers (Beeber & Zimmerman, 2012). Another difference between the use of the FMSF for adults with dementia has to do with the management approach, which may be more complex than the management approach with ill children due to the caregiver needs being more diffuse (Beeber & Zimmerman, 2012). The perceived consequences can also be different for adults with dementia regarding residential options. It is usual that parents will be caring for the ill child in the home. For the adult with dementia, there may be various living situations (i.e., family bringing the adult to live with them, family moving into the home of the adult, or moving the adult into assisted living or a nursing home; Beeber & Zimmerman, 2012). This study showed that the FMSF can be used to identify characteristics of caregivers' efforts to manage dementia care in daily life and to identify strengths and challenges within families in order to develop interventions and improve patient outcomes (Beeber & Zimmerman, 2012).

The FMSF has been used successfully to guide qualitative and quantitative studies, as well as for integrative reviews. Knafl et al. (2012) conducted a systematic review of 64 studies using the FMSF. The findings support further use by other researchers and development of the model by applying it to diverse situations and families and identifying a wider array of family management style themes and patterns (Knafl et al., 2012, p. 26). The researchers acknowledged the scope of the FMSF is amenable to use in research with other conditions and family contexts such as

breastfeeding in premature infants, adolescents and young adults with brain tumors, and decisions regarding end-of-life care in an adult family member (Knafl et al., 2012).

Therefore, the FMSF was used to examine the internal and external influences affecting parents' management of their adult child's SMI into everyday life.

Summary

Parents of adult children with SMI are a vulnerable population facing unique healthcare challenges (White, McGrew, & Salyers, 2013). Parent caregivers do not manage the physical symptoms of illness but manage various personal, interpersonal, and systemic problems (i.e., coping with the ill child's odd behaviors, dealing with the stigma of mental illness, and maneuvering through complex and cumbersome systems such as mental health, legal, and social welfare; Ward-Griffin, Schofield, Vos, & Coatsworth-Puspoky, 2005). The FMSF was used by this researcher to explore parent perspectives on their roles, definition of the situation, management approaches, and contextual influences they perceive as helpful for overall family functioning. This information was used to improve the assessment of family management styles, identify potential family needs related to the management styles, and develop more effective supportive and education interventions for families caring for an adult child with SMI.

CHAPTER 3

METHODS

Introduction

A qualitative descriptive design was used to examine the roles of parents caring for their adult children with SMI, parents' views on the contextual influences on family management, family management style and its components, and parents' perspectives on community-based mental health interventions that support the management needs of families caring for adult children with SMI. The FMSF (Knafl & Deatrck, 1990, 2003) guided the study. The FMSF was applied to parents caring for adult children with SMI.

The purpose of this chapter is to describe the research methods used in the study. The setting, sample selection, procedures for data collection, data management, and qualitative content analysis are discussed. Procedures to assure trustworthiness, reflexivity, and human subject considerations are also discussed.

Qualitative Descriptive Design

An exploratory, qualitative descriptive design was used in this study. Qualitative description is a naturalistic paradigm of inquiry (Sandelowski, 2000, 2010). The qualitative descriptive approach provides a comprehensive summary of a phenomenon through rich description of the event, with its goal being descriptive and interpretive validity (Sullivan-Bolyai, Bova, & Harper, 2005). Qualitative description stays close to the data and the surface of the event, using low inference interpretative deduction (Sandelowski, 2000; Sullivan-Bolyai et al., 2005). The naturalistic paradigm is based on holistic philosophy where the researcher has prolonged contact with participants in a naturalistic setting to capture participants' perceptions of a specific phenomenon. This

process requires deep attentiveness, empathetic understanding, and suspension of preconceptions about the topic under study (Miles, Huberman, & Saldana, 2014, p. 9).

Setting

The study interviews took place in the homes of parent participants and/or private settings agreed upon by the parent and researcher in the Central Massachusetts and Boston areas.

Sample

Qualitative description utilizes purposeful sampling (Sandelowski, 2000). The objective of purposive sampling is to focus on the event or experience of interest (Sandelowski, 1995) and to create a frame that will assist the researcher to “uncover, confirm, or qualify the basic processes or constructs that undergird the study” (Miles & Huberman, 1994, p. 27). Sample size is determined by achieving maximum variation and informational redundancy of the data collected (Sandelowski, 1995).

A purposive sample of parents in the caregiver role for their adult children with SMI was recruited. A snowball sampling technique (Polit & Beck, 2008) was also used. The snowball sampling method was conducted by asking previously recruited parents to recommend participation in the study to other parent caregivers who may be interested. The participants then informed potential parents giving them the investigator’s contact information. Sampling continued until common themes and informational redundancy were reached. A sample size of 25–30 parent participants was anticipated to provide for maximum variation (i.e., age, gender, educational level, socioeconomic status, psychiatric diagnosis of the adult child, age of the adult child with SMI, and number of years of caregiving). Thirty parent caregivers were recruited for the study.

Inclusion Criteria.

The sample included the following:

- A mother, a father, or a mother-father dyad (who were interviewed separately) in the caregiver role for an adult child with SMI, specifically schizophrenia, schizoaffective disorder, and bipolar disorder
- Parents who were biological or adoptive
- Participants who were able to give informed consent
- Participants who were able to understand, read, and write English

Exclusion Criteria.

- Non-English-speaking parents

Recruitment Procedure

The researcher met with agency administrators and mental health clinicians in Worcester, MA of two inpatient psychiatric units, 8 East at UMassMemorial Medical Center and the Psychiatric Treatment & Recovery Center at UMassMemorial and with the outpatient community mental health clinic, Community HealthLink, to discuss the research study and to ask permission to use their agencies for recruitment. Once permission was obtained, mental health clinicians recruited potential parent participants by providing information about the study along with the researcher's contact information. Potential participants contacted the researcher by phone or e-mail or requested that the researcher contact them via phone or e-mail. Potential participants were also recruited from monthly chapter meetings of the NAMI in Central Massachusetts and the Boston area by inviting parents to participate in this research opportunity. Study fliers were posted at Community HealthLink and at NAMI chapter meetings with the researcher's

contact information. Information about the study and the researcher's contact information were also included in several online NAMI newsletters.

Data Collection

Institutional Review Board (IRB) approval was obtained through the University of Massachusetts Worcester Medical Center prior to the initiation of data collection. Initial IRB approval recommended a written informed-consent agreement be signed by each subject prior to participating in the study. Signed written informed-consent agreements were obtained by the first 11 parent participants. A Waiver of Documentation of Consent was submitted to the IRB by the researcher after the initial IRB approval. After review, the IRB granted approval to waive signed written informed consent, citing this study as a minimal risk to participants (see Appendix A for these three documents). Subsequently, the investigator provided and explained the written informed-consent statement, and verbal informed consent for participation was obtained from the remaining 19 participants at the start of each interview. A demographic data sheet (See Appendix B) was completed by each participant.

Individual, private, semistructured interviews were conducted with 30 parent caregivers at times and locations agreed upon by the participants and researcher. All the interviews were done face-to-face. Each interview was audio-recorded using a backup recorder in the event of recorder failure. Interviews ranged in length from 34 to 90 minutes with a mean of 65 minutes. The investigator used open-ended questions with interview guides (see Appendix C). The interview questions were derived from the specific aims of the study based on the conceptual framework, the FMSF (Knafl & Deatrick, 1990, 2003; Knafl et al., 2012). Probes were used as a means to stimulate

discussion, gain further understanding, and clarify areas of uncertainty. Interview questions and probes were added and revised throughout this iterative and reflexive process. The transcribed interviews produced 1,016 double-spaced pages of data. Interviews were conducted until informational redundancy was achieved.

An audit trail was conducted using various techniques for establishing confirmability (Lincoln & Guba, 1985). To help capture as much data as possible about the experience, field notes were taken immediately after each interview on the researcher's observations and the participants' responses (Sandelowski, 2000). Process notes were taken while listening to interviews, noting what and how information was stated. Reflexive journaling was done to increase the researcher's self-awareness and identify influences that could affect data collection or analysis (Clancy, 2013). Member checks were conducted when the researcher needed clarification of data. Member checks are an important technique for establishing credibility (Lincoln & Guba, 1985) and ensuring interpretative validity (Bradbury-Jones, Irvine, & Sambrook, 2010; Sandelowski, 1998).

Data Management

Audio-recorded interviews were listened to in their entirety following each interview. Process notes were taken to supplement the field notes taken after the original interviews, noting methodological concerns (i.e., ensuring questions were asked to evoke rich descriptions, dealing adequately with emotional content of participants). Data were de-identified by assigning a subject number to each participant. The link between the identity of the participants and assigned subject numbers was known only to the researcher and was stored in a Subject Contact Log filed within a UMass encrypted R

Drive installed on the researcher's laptop computer for security purposes. The 11 signed written informed consent agreements were stored in a secure, locked cabinet in the Graduate School of Nursing at the UMass Worcester Campus. Interview audio-recordings were downloaded into the encrypted R Drive on the investigator's laptop computer and were then downloaded into a password-protected database provided by the transcription agency. The completed transcripts were stored on the investigator's encrypted R Drive. The audio-recorded interviews were transcribed verbatim by professional transcriptionists who were required to sign a confidentiality statement to protect the privacy of subjects. The transcriptionists were instructed by the researcher to eliminate names of any adult children or other persons mentioned during the interview process by adding the participant subject number followed by an asterisk *. IBM SPSS 22.0 was used for examining the demographic data.

Data Security

Audio-recordings, field notes, process notes, and data materials were stored on the encrypted R Drive on the investigator's laptop computer. The audio-recordings were destroyed after transcription was completed and confirmed. The transcription agency deleted the transcripts and audio-files 60 days after completion. Other data sources (i.e., demographic data and signed informed consent agreements) will be kept for 5 years, then destroyed.

Data Analysis

Qualitative descriptive data analysis uses the inductive process to seek understanding of complex experiences, events, or processes inherent in human nature (Sandelowski, 1995, 2000; Sullivan-Bolyai et al., 2005). Qualitative descriptive data

analysis is a method of knowledge development achieved by staying close to the data, separating elements of data, and looking for patterns and themes (Creswell, 2007; Sandelowski, 1995; 2000). The goal of qualitative description is descriptive and interpretive validity (Sandelowski, 2000; Sullivan-Bolyai et al., 2005). Descriptive validity is achieved through rich descriptions of an experience or event from participants in their own words that most people observing the event would agree on its accuracy (Sandelowski, 2000; Sullivan-Bolyai et al., 2005). Interpretive validity is achieved through insuring accuracy of the meanings participants give to an experience or event that these participants would agree is accurate (Maxwell, 1992; Sandelowski, 2000).

Conventional content analysis is a qualitative research technique used when the aim of a study is used to describe a phenomenon (Hsieh & Shannon, 2005, p. 1279). Conventional content analysis is used to uncover embedded information and make it explicit by coding the data (Lincoln & Guba, 1985). The conventional content analysis approach was chosen for this descriptive study due to limited research on this specific phenomenon. Constant comparison of the data was done until informational redundancy and saturation were achieved and the emergent themes were apparent (Lincoln & Guba, 1985).

Six analytic strategies described by Miles and Huberman (1994) and Miles et al., (2014) are used in qualitative content analysis. These strategies are the following: (a) coding of data from field notes, observations, or interviews; (b) recording insights and reflections on the data; (c) identifying similar phrases, patterns, themes, sequences, and important features; (d) looking for commonalities and differences among the data and extracting them for further consideration and analysis; (e) deciding on generalizations;

and (f) examining these generalizations in relation to current knowledge about the phenomenon (Miles & Huberman, 1994; Sullivan-Bolyai et al., 2005, p. 128). Memos were taken of the researcher's reflections on the conceptual meaning of data. Descriptive statistics were used to summarize and further clarify the phenomenon of interest (Sullivan-Bolyai et al., 2005). The process of coding and analysis is an iterative process that helps to refine and improve the interview process; to identify similar phrases, relationships between variables, patterns, themes, categories, and differences between subgroups, and to promote accuracy, clarity, and validity of the data (Miles et al., 2014).

Trustworthiness

Establishing trustworthiness in qualitative research is the hallmark of evaluating the research findings. In the naturalistic paradigm, the researcher wants to demonstrate "truth value," meaning that the inquiry is credible to the multiple realities of the participants and the event under investigation (Lincoln & Guba, 1985). Five criteria are used when examining trustworthiness: "credibility, dependability, confirmability, and transferability" (Lincoln & Guba, 1985, p. 328); and "authenticity" (Beck, 2009, p. 544). The researcher utilized various techniques to maintain trustworthiness during this study.

Credibility refers to the data being believable and the researcher's confidence that the findings are truthful (Beck, 2009; Lincoln & Guba, 1985). Credibility was established through prolonged engagement and persistent observation allowing the researcher sufficient time to be oriented to the experience (Lincoln & Guba, 1985, p. 303) of parents caring for their adult children with SMI. Credibility was established using member checks, meaning the researcher contacted participants (n = 4) by phone and e-mail after the interviews to verify the accuracy of the information (Lincoln & Guba, 1985, p. 314).

Peer debriefing was an important part of establishing credibility in this study. Peer debriefing is a process that parallels an analytic session where the researcher shares experiences that occur during the interview process with a knowledgeable peer. The researcher did peer debriefing with an experienced advanced practice psychiatric nurse to explore meanings of a participant's experience, to evaluate the data for agreement on findings, to probe for researcher biases, to keep the researcher honest, and to provide catharsis for the researcher due to uncomfortable emotions evoked by participant experiences during an interview process (Lincoln & Guba, 1985, p. 308).

Dependability refers to the stability of data over time within varying contexts and conditions (Beck, 2009). Demonstrating credibility is noted to be sufficient for establishing dependability (Lincoln & Guba, 1985). Dependability was established through the researcher's use of the audit trail by multiple methods (i.e., field notes, member checks, process notes, and dependability audits; Lincoln & Guba, 1985, pp. 317–318). Dependability audits are conducted with a content expert in the subject matter who can critically evaluate the study's methods, data, and findings believability (Lincoln & Guba, 1985). The researcher conferred with the members of the dissertation committee who were experts in qualitative research, in working with families, and in psychiatric nursing. Confirmability reflects objectivity, which is seen as agreement between two or more people reviewing the data for accuracy (Beck, 2009, p. 544). The researcher conducted member checks with participants for accuracy of information and consulted with content experts who were members of the dissertation committee to maintain objectivity. The researcher has experience of more than 30 years as a psychiatric nurse

working with adults with SMI and their families, which lent to the credibility of the study.

Transferability shows the ability of the findings to be transferred to other contexts (Beck, 2009, p. 544) and is established through thick descriptions to provide the widest range of information (Lincoln & Guba, 1985, p. 316). The goal of qualitative descriptive research is to obtain rich descriptions of an experience rather than thick descriptions. Therefore, this research study's findings may not be transferrable to other situations.

Authenticity is also important in qualitative research. The researcher must describe the participants' experiences faithfully, fairly, and accurately (Beck, 2009, p. 544). The use of the audit trail through member checks, field notes, and process notes allowed the researcher to truthfully and accurately report parent participants' experiences. Authenticity is also reflected through the use of rich in vivo quotes directly from the participants to capture salient aspects of their experiences.

Protection of Human Subjects

Protection of human subjects was achieved by requesting approval of this study through the IRB at UMassMemorial Medical Center. Initial IRB approval recommended that a written informed-consent agreement be signed by each subject prior to participating in the study. The researcher submitted a Waiver of Documentation of Consent to the IRB after 11 interviews were completed. After modification of the researcher's Independent Study Plan, approval was obtained to waive the signed written informed consent and to allow that verbal informed consent be obtained for participation in the study, citing that this study was of minimal risk to participants. The investigator provided and explained

the written informed-consent statement and verbal informed consent for participation was obtained from the remaining 19 participants at the start of each interview.

This study was considered to be of minimal risk to participants. Participants were assured that all information including their identities and their families' identities would be kept confidential. The only risk associated with this study was a breach of confidentiality. In order to minimize the breach, all data from the participants were de-identified by assigning a subject number. The subject number served as the only link between the participants and their identifiable information. These data were kept on the researcher's encrypted R Drive installed on her laptop computer. The researcher explained to all subjects that participation in the study was voluntary and stressed that they could withdraw at any time without repercussions.

The researcher acknowledged that the interview process may evoke uncomfortable feelings due to the sensitivity of the topic of caregiving for an adult child with SMI. The researcher explained that she is a psychiatric nurse with 34 years of clinical experience working with people with SMI, their families, and acute trauma. In the event that parent participants became upset during the interview process, the researcher offered to provide therapeutic interventions (i.e., support, education, and validation) until the interview could continue. Other options were offered to participants: to stop the interview and reschedule it for another time or to cancel the interview completely. In the event that parents needed continued supportive intervention that could not be provided within the interview, the researcher offered to refer them for two 50-minute sessions with an experienced psychiatric social worker at no cost to them.

No parent participant asked to stop the interview process or requested the additional sessions after the interviews. The researcher made phone contact with three participants on the day after their interviews to check in as the interviews had been extremely emotional for them. All three parents stated they were doing fine and appreciated the follow-up call. All parent participants were given a \$20 gift card in appreciation for their participation in the study.

Reflexivity

The concept of reflexivity refers to the researcher's conscious disclosure of biases, values, and experiences that can influence the research findings (Creswell, 2007). The researcher had experience of more than 30 years as a psychiatric nurse working with adults with SMI and their families. As a psychiatric nurse, it can be difficult to balance differing needs and expectations of patients and their families. The goals of the researcher in this study were to be transparent and aware of potential biases that could arise during the interviews and data analysis. Maintaining objectivity during the interviews was vital in order to gather the richness of experiences of the parent participants. Taking field notes immediately after each interview helped the researcher to flag thoughts and emotions evoked during the interview process. These notes were then explored in more detail while playing back the audio-recordings and taking the process notes. Reflexive journaling was an important part of the audit trail to document personal thoughts, areas of concern, and methodological issues. The researcher reviewed the reflexive journal routinely with a colleague who acted as peer debriefer and with members of the researcher's dissertation committee.

Summary

A qualitative descriptive design was used to examine parents' management styles and associated management components in caring for adult children with SMI. The sample of parent participants was recruited through several mental health agencies and the NAMI as well as through a snowball technique. Individual face-to-face interviews were conducted as the method of data collection. Qualitative content analysis was an iterative process occurring throughout data collection utilizing the criteria outlined by Miles and Huberman (1994) and updated by Miles et al. (2014). In this naturalistic inquiry, techniques were utilized to establish trustworthiness. The researcher followed the protocols for insuring protection of human subjects.

CHAPTER 4

RESULTS

Introduction

A qualitative descriptive study design was utilized to examine parents' management styles and associated management components in caring for adult children with SMI, specifically schizophrenia, schizoaffective disorder, and bipolar disorder. This exploration was used to provide recommendations from parents regarding community-based mental health interventions that could enhance overall family functioning in the care of adult children with SMI. The purpose of this chapter is to report the study findings.

Four main themes emerged from the data: Theme 1. "When it hits your family": *Recognition of a Problem*; Theme 2. "Here I am a new parent (to mental illness) with no idea what to do": *Scrambling for a Diagnosis*; Theme 3. "It's very clear what we need to do, but not clear how to get there": *Learning to Maneuver Family Life and the Mental Health System*; and Theme 4. "It's not a sprint...It's Heartbreak Hill": *Enduring the Illness*.

Briefly, Theme 1, "When it hits your family": *Recognition of a Problem*, describes the experience when parents notice behavioral changes in their adult children and when mental illness initially emerges in the family. This theme is comprised of three subthemes: *Child's behavioral changes*, *It's a serious problem*, and the *Decision to act*.

The second main theme, "So, here I am a new parent (to mental illness) with no idea what to do": *Scrambling for a Diagnosis*, refers to parents' situations of being new to dealing with mental illness and searching for help to diagnose and treat their adult

children. This theme included one subtheme: *My child has what? (shock and disbelief that the child has a mental illness)*.

The third theme, “It’s very clear what we need to do, but not clear how to get there”: *Learning to Maneuver Family Life and the Mental Health System*, describes the upheaval created in the family as a result of SMI, parents’ efforts to regain stability in the family, and the difficulty in obtaining appropriate mental health services for their adult children. This theme is comprised of two subthemes: *Family in turmoil* and *Access to appropriate mental health services*.

The fourth theme, “It’s not a sprint...It’s Heartbreak Hill”: *Enduring the Illness*, describes the burden as well as triumphs that mental illness can have on the family, including the ongoing day-to-day management of the illness, and the effects of the illness on parental goals and expectations for their adult children with SMI and the family as a whole. Three subthemes were identified: *Family life redefined*, *Expectations and goals redefined*, and *Fears for the future*. Themes and subthemes are depicted in Figure 2.

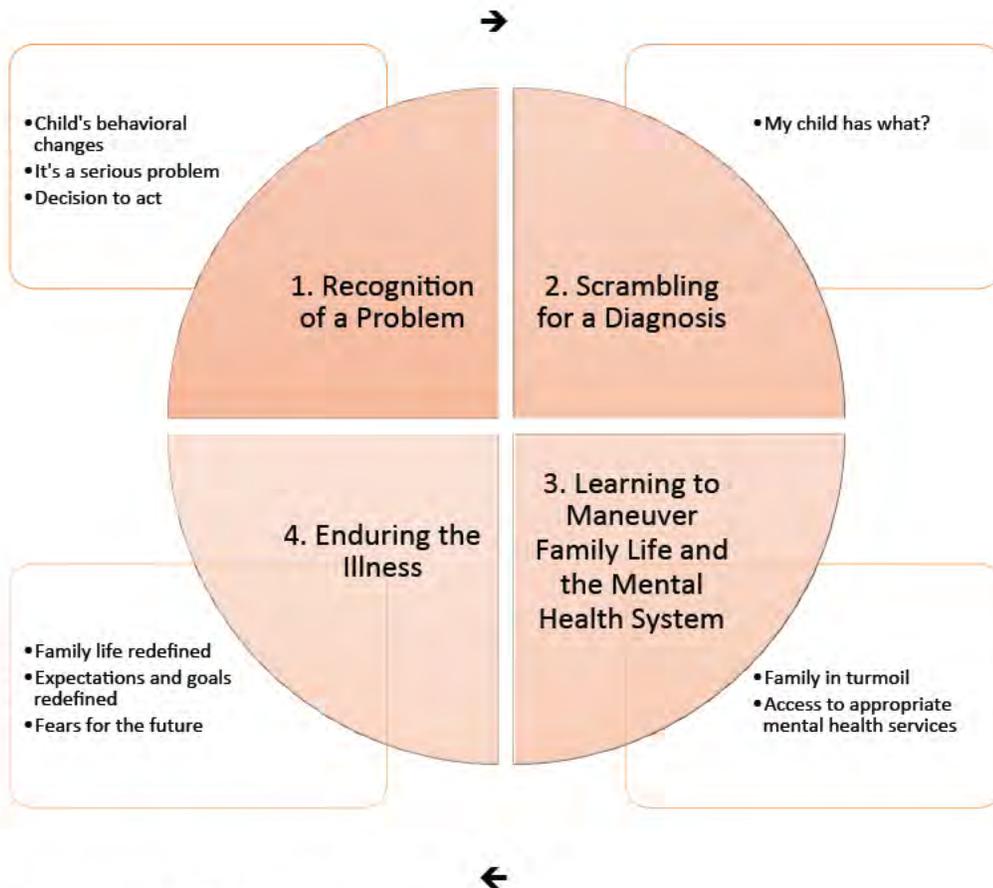


Figure 2. Themes and Subthemes.

Sample

A total of 52 parents contacted the researcher for participation in the study. Due to the sample size limitation (N = 30) in the researcher's Investigator Study Plan, 30 parent participants were selected on a first-contact basis. The researcher developed a waiting list of parents with their permission in the event of interview cancellations. Data collection occurred between March and June 2015.

Demographic data including age, gender, ethnicity, marital status, employment, annual income, educational level, gender of adult children, age and psychiatric diagnosis of the adult children with SMI are reported in detail in Table 2, which follows this paragraph. Six parent dyads were interviewed in the study. Five parent dyads were interviewed separately, and one parent dyad requested to be interviewed together. Two parents had more than one adult child with SMI. One parent had four adult children and a minor child with SMI, and one parent had three adult children with SMI. One parent and one parent dyad disclosed that their children were adopted. Of the participants, 73% (n = 22) were female, and 27% (n = 8) were male. The mean age of the participants was 63.1 years (range = 53–85). Ninety percent (n = 27) were Caucasian with only 10% (n = 3) of other racial or ethnic minorities. These specific racial/ethnic data were not disclosed to protect the anonymity of the participants. Eighty percent (n = 24) of participants were married, 16.6% (n = 5) were divorced, and 3.3% (n = 1) was single. Participant employment status was as follows: 36.6% (n = 11) full-time, 26.6% (n = 8) retired, 16.6% (n = 5) part-time, 16.6% (n = 5) not working, and 3% (n = 1) self-employed. The mean annual income of participants was \$91,050 with the range of \$7,500–\$250,000. Educational levels were 33.3% (n = 10) graduate/professional degree, 46.6% (n = 14) college degree, 6.6% (n = 2) some college, 6.6% (n = 2) associate degree, and 6.6% (n =

2) high school diploma. Of interest, 64% (n = 16) of the parent participants had their adult children with SMI living at home versus 36% (n = 14) of adult children who lived elsewhere (i.e., their own apartments or residential placements). Despite these children not living at home, this subgroup of parents identified themselves as their adult children's primary support system and financially assisted them.

Table 2
Participant Demographics (N = 30)

Category	Number	Percentage	Mean	Range
Age			63.1	53–85
Gender				
Female	22	73.3%		
Male	8	26.7%		
Ethnicity				
Caucasian	27	90%		
African-American				
Hispanic				
Other	3	10%		
Marital Status				
Married	24	80%		
Divorced	5	16.7%		
Single	1	3.3%		
Employment				
Full-time	11	36.7%		
Part-time	5	16.7%		
Retired	8	26.7%		
Self-employed	1	3.3%		
Not working	5	16.7%		
Annual Income	30		\$91,050	\$7,500–\$250,000
Educational Level				
Graduate/Professional Degree	10	33.3%		
College Degree	14	46.7%		
Some College	2	6.7%		
Associate Degree	2	6.7%		
High School Diploma	2	6.7%		
NAMI member				
Yes	22	73.3%		
No	8	26.7%		
Child with SMI (n = 34) living with parent				
Yes	16	47.1%		
No	18	52.9%		
Age of Child with SMI (n = 34)			31.8	22–58

Gender of Child with SMI (n = 34)		
Female	6	17.6%
Male	28	82.4%
Diagnosis of Child with SMI (n = 34)		
Schizophrenia	4	11.8%
Schizoaffective Disorder	21	61.8%
Bipolar Disorder	9	26.4%

Theme 1. “When it hits your family”: Recognition of a Problem

Theme 1 was characterized by the participants’ awareness of a problem emerging in their children. These problems presented in various ways. The majority of parents reported gradual changes in their children occurring in early to late adolescence. In addition, the majority of these children had no prior psychiatric diagnoses. Six parents reported that their child had some learning difficulties starting in elementary school. One parent dyad stated that their child was diagnosed with symptoms of Asperger’s Syndrome in early elementary school, and two parents reported that their child exhibited symptoms of Attention Deficit Disorder. Only two parents stated that their child did not exhibit symptoms of bipolar disorder until his/her early- to mid-20s. Of those children diagnosed with schizophrenia and schizoaffective disorder, half exhibited behavioral changes in their senior year of high school or first year of college, whereas the other half had behavioral changes in junior high or high school. Three subthemes emerged with this theme: *Child’s behavioral changes*, *It’s a serious problem*, and *Decision to act*.

Subtheme 1A. Child’s behavioral changes.

The child’s behavioral changes manifested in different ways. Participants talked about gradual behavioral changes in their children occurring over weeks and months. These changes included moodiness, a decline in school performance, agitation, social withdrawal, poor concentration, experimentation with drugs and alcohol, and inattention

to hygiene. Many parents attributed these behavioral changes to the physiological and psychological adjustments of adolescence and to exploring one's independence. The majority (n = 25) of parents described their child as being intelligent, being a good student, getting along with others, having friends, being well-organized, and having various talents (i.e., in sports, the arts, and writing) prior to the emergence of the behavioral changes. Parents described it being difficult to differentiate between normal adolescent hormonal changes and a mental health issue.

One parent stated, "First, in the beginning, I thought it was just like becoming a teenager and going through all the hormonal imbalances and different changes....How do you determine a kid with a mental disorder from a teenager?"

Several parents thought that a specific event may have triggered these changes in their child (i.e., changes in family dynamics or a world event such as 9/11). Three parents attributed their child's behavioral issues to their getting divorced. One mother blamed getting remarried as causing her son's behavioral changes. One mother thought that the unexpected and early death of her husband precipitated the behavioral changes in her son. All of the parents expressed concern about their children's behavioral changes. The majority of parents stated that they did not consider mental illness as the cause of their children's difficulties, and they did not seek psychiatric treatment for them during this phase. One mother described so poignantly, "Mental illness was not even on my screen." Only one parent disclosed earlier concerns about having children due to mental illness in his family of origin.

Subtheme 1B. It's a serious problem.

All of the parents reported increasing levels of concern as their children's behavioral changes persisted and reality set in. One father eloquently described this experience: "We were, at first, a little concerned and then we became worried and then became scared." The majority (n = 29) of parents noted that some of the changes their child exhibited became more disturbing, such as suicidal ideation, thought distortions, severe agitation, and aggression. Most parents (n = 28) acknowledged that something was *seriously wrong* with their child, but they could not accurately define the problem. Mothers had a tendency to blame themselves for their child's problems more so than fathers, although one father questioned whether he did something wrong in parenting his son that may have caused his behavioral changes. One mother talked about seeking counseling for herself. During the course of her treatment, she described blaming herself for her child's behaviors and asked what kind of parent she was to be raising "a lazy bum" who would not get up off the couch. Her counselor educated her, stating that she did not have a lazy bum for a child, but a child with mental illness.

Subtheme 1C. Decision to act.

The decision to act was characterized by the child's behavior escalating to beyond the parent's ability to control the situation. Parents described feeling confused, frightened, and threatened by their children's escalating behaviors, which included continued depression, psychotic thinking, self-injury, suicidal ideation, increased agitation, and aggression. Parents acted in varying ways depending on the age of the child and severity of the behaviors.

The majority of parents whose children exhibited behavioral changes in earlier adolescence sought out professional help, with variations in responses. Several parents (n = 5) sought evaluation through the child's pediatrician or primary care physician. These parents reported either receiving no help from pediatricians in evaluating psychiatric problems in their child or pediatricians recommending psychological counseling for their child with no guidance as to whom to contact. A number of parents (n = 11) sought psychological counseling for their child on their own, with only three children being referred by counselors to psychiatrists for psychiatric medication evaluations. Several parents (n = 5) used the resources within their school systems such as meeting with the school psychologist or changing schools, thinking this intervention may help reduce behavioral problems.

Parents (n = 14) with children in later adolescence or early adulthood who were in college or living away from home when they manifested behavioral problems became aware of their child's problems in a variety of ways. After having contact with their brother who lived away from home, in two separate cases, two siblings alerted their parents that something was seriously wrong with their brother. During phone conversations with their adult child in college, parents noted drastic changes in their child's presentations (i.e., bizarre, paranoid, or grandiose thinking). An employer contacted the parents of an adult child informing them their child was exhibiting problematic behaviors in the workplace. Several children (n = 4) dropped out of college and returned home to live with their parents. These parents noted disturbing behavioral changes in their children upon returning home (i.e., disorganized and delusional

thinking). Some parents (n = 5) received telephone calls stating their child had been hospitalized for psychiatric problems.

Several parents (n = 5) described dangerous and unsafe situations requiring immediate intervention. These children were exhibiting bizarre, threatening, and aggressive behaviors, forcing parents to call 911 for police intervention. The police transported these children to local hospital emergency rooms for psychiatric evaluation. One parent described driving in the car with two of her children when her son “just snapped” and grabbed the steering wheel. While the other child subdued the agitated son, the parent was able to drive to a local emergency room. Not all children brought to the emergency room were admitted for psychiatric evaluation. Some parents had to demand that their child be admitted to the hospital for psychiatric evaluation while other parents were forced to call 911 again after the child was discharged from the emergency room.

**Theme 2. “Here I am a new parent (to mental illness) with no idea what to do”:
Scrambling for a Diagnosis**

The hallmark of Theme 2 was parents being new to dealing with mental illness and the mental health system. Scrambling for a diagnosis was characterized by parents entering the mental health system, scrambling to identify the exact nature of their child’s psychiatric illness, realizing that their child had serious mental health illness that would require ongoing psychiatric interventions, and receiving minimal information from mental health professionals. The majority (n = 28) of parents described a long journey ranging from months to years to obtain accurate psychiatric diagnoses for their child. Because of their educational backgrounds in psychology, two mothers themselves diagnosed their children with bipolar disorder from the symptoms they exhibited.

Subtheme 2A. My child has what?!

This subtheme referred to the confusion, frustration, and bewilderment that parents experienced upon entering the mental health system and being informed that their children were initially diagnosed with a SMI. The participants (n = 20) described the time frame to obtain an accurate and/or final psychiatric diagnosis for their children as taking anywhere from several months to two years. The majority (n = 29) of parents were introduced to the mental health system during their children's first psychiatric hospitalization. More than half of the participants (n = 18) reported that their children were first hospitalized for only a couple of days to a week, which was not long enough to evaluate or to provide adequate treatment for them. Entering the mental health system was described as a baffling experience. The majority of parents reported having limited knowledge about SMI and no knowledge of how to navigate the system. Obtaining a diagnosis of a SMI such as schizophrenia, schizoaffective disorder, or bipolar disorder was shocking and distressing for parents (n = 25) despite their awareness of their children's struggles with serious mental health issues. Participants expressed worry about what a diagnosis of SMI would mean for their child's present and future life.

All parents stated that they were in need of information from mental health professionals about their children's diagnoses, prescribed medications, outpatient treatment, and strategies to help their children after discharge. Information about their child's diagnosis, treatment, and progress was difficult for most parents to access. The majority of parents (n = 25) reported being given minimal to no information by mental health professionals regarding their child's illness, treatment, and management after discharge, especially during the first psychiatric hospitalization. One parent explained, "I

had to learn everything by myself. If you didn't know anything or know enough to ask a doctor, you didn't get to know anything. They (the mental health staff) didn't answer or come out and say 'Here's a brochure' or 'Here's what to expect.'" Seven of the parents reported being excluded from treatment team meetings despite the fact their children were returning home with them. One participant angrily stated, "So, here I am a new parent (to mental illness) with no idea what to do." This statement was made after being told by a treatment team member that he needed to find outpatient services for his child after discharge because one of the team members was out and the rest of the team was too busy to accomplish this task. Another parent talked about his child being acutely psychotic and being discharged from hospital because he refused psychiatric medication. "They (the mental health staff) did nothing for him there....Nobody would let us participate in the plan of care. Within a week (of being home), he was breaking the doors everywhere...pictures, everything."

Parents with children over age 18 (n = 14) at the time of hospitalization stated that mental health staff would not share information regarding their child's treatment due to the confidentiality and privacy laws that protect health information. Information about their child's diagnoses, treatment, and progress, once obtained, was difficult for most parents to access. Only a small number of parents (n = 5) considered themselves fortunate to have met a mental health professional on their child's treatment team who provided information on their child's diagnosis, treatment, and recovery strategies. Three parents whose children were admitted to private psychiatric units described having adequate access to information and adequate attention by mental health professionals. Twenty-two participants identified that locating the NAMI was more beneficial in providing support

and education about SMI than the mental health professionals whom they came in contact with during their child's initial hospitalization.

**Theme 3. “It’s very clear what we need to do, but not clear how to get there”:
Learning to Maneuver Family Life and the Mental Health System**

The effects of SMI on the family functioning were significant. Family life was destabilized as a result of the SMI. This theme was characterized by parents learning to move *in careful ways* to regain a sense of solidity in the family and to access appropriate mental health services for their children. Family life was in turmoil as parents were trying to learn ways to manage the care of an adult child with SMI and manage the family as a whole. Moving *in careful ways* reflected the caution parents used as they learned skills for managing their child with SMI and for working with mental health professionals. These skills included effective communication, prioritizing problem areas within the family, and evaluating appropriate mental health services. A parent described her experience with her son who had difficulty focusing and carrying out daily tasks after discharge from the hospital. ““Okay, well, how come you missed this and that?’ I would ask him. I had a hard time understanding until the people at the facility sat with me and explained to me about his illness, what it consists of, and...to break it (information) down.” Searching for information and the most appropriate and effective mental health treatments for their child became a mission for many parents. This learning process was arduous and lengthy, spanning years for the majority of parents.

Subtheme 3A. Family in turmoil.

This subtheme described some of the effects of SMI on the family and parents' attempts to manage these effects and to gain stability within the family. Parents were confronted with caring for their adult child who was now acting differently due to SMI.

Parents stated that they learned how to manage these difficult situations by trial and error, with the support of family and friends, and with education about SMI.

Many adult children who previously had been extremely bright, funny, motivated, gregarious, independent, and creative were now exhibiting worrisome, disturbing, and frightening behaviors. Most parents stated they were fearful of saying and doing things that would upset or trigger their adult child. Several parents described their lives at home as “walking on eggshells.” As one parent stated, “And, one minute I’m talking to my bright intelligent son and the next minute I’m talking to schizophrenia....It took me a long time to learn not to argue with him.” A disturbing behavioral change for most adult children with SMI was an alteration in their hygiene. Caring for their appearance (i.e., showering and changing their clothing) became unimportant as the symptoms of their SMI emerged. Parents (n = 18) expressed concern and frustration regarding their adult child who was no longer able to adequately focus on his/her self-care.

Parents expressed worry and sadness about their child’s social isolation and loneliness. Children who had many friends prior to their illness had difficulty now maintaining relationships due to odd behaviors; psychotic symptoms (i.e., paranoia, hallucinations, delusional and grandiose thinking); and social dysfunction. The majority of parents mentioned that their children’s friends “stopped coming around.” One parent reported that after friends had asked her child to attend a concert, on the night of the concert, they all refused to go with him. Another parent held back tears as he stated, “He had a lot of friends. They’re all gone....I think he’s scared of that. He doesn’t make new friends. He relies a lot on family.”

Maintaining safety at home was paramount for those parents whose children exhibited bizarre and threatening behaviors due to irrational thinking. At least half of the participants talked about dealing with unsafe behaviors by their adult children, ranging from severe agitation, self-injury, destruction of property in the home, threats of aggression, and assaultive behavior. Other safety concerns parents mentioned were careless smoking and cooking. Three parents mentioned having to lock up kitchen knives, and one parent reported having her child's B-B gun removed to prevent injury to the child himself or others in the home. One sibling told her parent that she was fearful of her ill sibling who was not taking medication: "He's going to kill us." One parent discussed considering the purchase of a gun for self-protection. After talking with his wife, he decided against this so that their child with SMI would not have access to the weapon. No other participants discussed the availability of guns in the home or the fear their child would purchase a weapon. Several parents (n = 10) were forced to call police when their adult child was acting in erratic and dangerous ways. Five of these parents reported having proactive conversations with their local police departments, explaining that they had a child with SMI, in the event that they needed to call the police for assistance in the future. One parent described what she thought was unnecessary and brutal force by police toward her son with SMI when they were called to the home. An important issue regarding safety that five parents had to confront was the decision to seek alternative housing for their child with SMI. These parents stated that they could no longer have their adult child remain in the home due to his/her threatening and aggressive behaviors. Although this decision was difficult to make, these parents expressed relief knowing that

they and their child were safe in supervised residential placements or apartments with staff monitoring.

Parents were also dealing with multiple, conflicting emotions about having an adult child with SMI. The most dramatic situations were with the two parents who had multiple adult children with SMI. Sadness, heartbreak, and grief were omnipresent in all parents whether their adult child had been dealing with SMI for a couple of years or decades. The majority of parents (n = 28) were tearful and deeply saddened during the interviews. One parent dyad who had been dealing with their child's SMI for over 40 years wept as if the child were recently diagnosed. Parents reported being angry at their situation of having a child with SMI and the effects of SMI on all of their lives. The expectations that most parents had for their children's futures were jeopardized. Several adult children were unable to finish college (n = 6), and many adult children were unable to obtain and/or sustain competitive employment (n = 18) due to the severity of their symptoms.

Parents talked about the difficulty experienced by their other family members as a result of their sibling having SMI. Several parents (n = 10) reported siblings being angry at them for focusing most of their attention on the ill child. Parents observed that siblings had a range of emotions from grief at losing their sibling to SMI to fear and embarrassment of their ill siblings' behaviors. An unfortunate situation for several parents (n = 8) was in families where siblings reported wanting little or no contact with their sibling with SMI. These parents expressed optimism that with increased information about SMI, these siblings would want to improve their relationship with their mentally ill brother or sister. Most participants described other family members such as aunts, uncles,

cousins, and grandparents as being supportive to both the adult child with SMI and their families. Only a small number of parents (n = 5) stated that they felt isolated and unsupported by other family members who had little understanding about SMI.

The financial burden of caring for adult children with SMI was discussed by all participants. All participants discussed the financial burden of caring for their adult child whether the child was living with them or living elsewhere. Of the seven adult children who were employed, parents continued to help them financially since they did not make enough money to support themselves. Five parents reported that they continued to provide financial help despite their child receiving disability benefits for his/her SMI. Several parents (n = 4) independently paid for certain mental health treatments (i.e., a therapeutic residential facility, a program for first-episode psychosis) and for private health insurance coverage for their child with SMI.

Parents' health, work schedules, and social lives were seriously affected by their adult child's SMI. Parents described needing to take time off from work, to re-arrange work times, and to change their positions in order to care for their child with SMI. One parent reported taking an enormous pay cut after leaving his full-time position to work from home. Most working parents discussed how hectic their lives became running from work to the hospital each day when their child was hospitalized. These parents reported loss of sleep, constant fatigue, and chronic stress. Eight parents retired from their jobs and had limited incomes, but they continued to provide financial support for their adult child. Social activities became limited for many parents. Meeting with friends, engaging in hobbies, going on vacations, and participating in activities outside the home other than work were restricted. One parent stated she had not been on a vacation in two years.

Three parents talked about being on vacation with family and having the vacation ruined by disruptive behaviors of their adult child with SMI.

The relationships between parents were affected in caring for their adult child with SMI. A total of 80% of the parents (n = 24) in this study were married. The majority (n = 21) agreed to “being on the same page” with their partners in terms of dealing with their child with SMI. Conflicts in their relationships usually came about because of their different styles of management. Conflict resolution evolved for these parents as they realized their goals were similar and the styles were just different. Three married parents disclosed having to deal alone with their child’s illness because their partners were too emotionally distraught. Of the five parents who were divorced, four stated that their ex-spouses blamed them for their child’s SMI and provided minimal assistance for the care of their adult child.

The stigma of mental illness had a significant influence on family life. Parents discussed their reluctance to talk with family and friends about their child’s SMI, fearing uncomfortable social ramifications. One parent stated she could not talk with her older brother about her son’s mental illness, “He would make fun of (son).” A parent talked about her ambivalence of wanting to share her situation with friends in order to get support, but her husband told her she could not talk with anyone about their son’s SMI. She said, “My husband didn’t want people to know ‘cause he was afraid it would affect our son’s job.” A parent dyad explained that in their culture the whole family is labeled and marked within their community as having mental illness. Many parents (n = 12) expressed fear of losing relationships because family and friends would not understand their situation, would judge them as bad parents, and would be frightened of their child

with SMI. A painful experience was shared by a parent who told the story of losing a long-term family friend after disclosing her son's mental illness. This parent explained that her friend was judgmental, showing no empathy for her situation and refusing to allow her adult child to have contact with the parent's adult son with SMI out of fear of violent behavior.

Subtheme 3B. Access to appropriate mental health services.

This subtheme addressed the fact that mental health services were not easily accessible for most adult children with SMI. Parents talked about the multiple gatekeepers in the mental health system making the process of accessing services complicated, long, and uncertain. As one parent aptly described this process, "It's very clear what we need to do, but not clear how to get there." Many parents reported that once mental services were obtained, they were not always the appropriate services for their adult child. A crucial factor identified by many of the parents that made accessing mental health services difficult was their adult children's own lack of awareness of their SMI and their ambivalence regarding treatment. Another important factor influencing access to appropriate mental health services was a previous negative experience with the mental health system. A parent described difficulty finding a psychiatrist for his child. "We went from one psychiatrist to another and maybe talked to eight before meeting the one who our daughter's been dealing with ever since. Once we got him... he suggested Clozaril and it worked." Parents proceeded in their search for appropriate services with anger, mistrust, and caution. Another participant expressed her frustration with her child's current medication regiment. "I don't know what's making him so tired...if he's

still overmedicated or it's a combination. I don't have any faith in the doctor that he has right now....Our task is to find a meds doctor that will agree to see him and be available.”

Parents discussed their struggles with their adult child's anosognosia, or lack of insight into their SMI. The symptoms of SMI caused functional disturbances in their child's abilities to work, relate to others, and provide self-care. Due to the thought disturbance that accompanies SMI, many children did not believe they were suffering from SMI or that they were in need of long-term psychiatric treatment. Parents recognized the behavioral changes in their children and the need for mental health treatment, whereas many of these adult children did not. A total of 66% of parents (n = 20) reported problems with psychiatric medication nonadherence among their children. These differences in opinion caused problems in the relationships between parents and their adult child. Disagreements between parents and their adult child with SMI placed the parents in difficult positions. The children were now adults in the eyes of the legal system, but they continued to depend on their parents for social and financial support and advocacy.

Parents described varying experiences with psychiatric hospitalizations. All parents stated that their adult child was hospitalized psychiatrically from one to multiple (20+) times. Four parents reported having no difficulty getting their child hospitalized when needed and receiving satisfactory care. Getting their child admitted for a psychiatric hospitalization was difficult for the majority of parents (n = 20). These parents reported making multiple trips to hospital emergency rooms with their children who were acutely psychotic, exhibiting bizarre and dangerous behaviors in the home or community, only to have them discharged after mental health providers deemed them not

ill enough to be admitted to a psychiatric unit. These parents reported not being asked any questions about their child's symptoms by evaluating mental health staff in the emergency room. Six parents stated that privacy laws protecting adult children's confidentiality prevented their child from getting hospitalized because mental health providers did not have an accurate picture of the acuity at home. Parents talked about their anger and frustration at not being able to get in-patient treatment for their ill child. They also described fearing for their safety after their child was discharged from the emergency room in an acute phase of his/her illness. One parent dyad described their desperation at not being able to get their child hospitalized after their household had been taken over by the adult son who refused to take his psychiatric medication: "What do we do? I had to call 911 again to step in because he started becoming a bit more violent. He has gone to the ER a number of times. We sat there the whole day... in the waiting room. Then the... 'I'm discharged.' We come home. The cycles continue."

Short lengths of stay on psychiatric units were another problem that parents discussed. They characterized these short hospitalizations as lasting several days to two weeks, which did not provide enough time for their child's symptoms to be stabilized. Several parents (n = 8) reported that their children were overmedicated and their symptoms were no better managed upon discharge. This situation contributed to recidivism and rehospitalizations. Thirteen parents had to involve the legal system by going to court for commitments to psychiatric hospitals for longer admissions and for guardianships for adult children who refused psychiatric medications while hospitalized and/or who proved unable to manage their money. During court proceeding for commitments and guardianships, eight parents described having to persistently advocate

and “fight” with judges and lawyers in order to get appropriate treatment (hospitalizations and medication) for their adult child. One parent stated she had to make phone calls to her state senator for assistance in keeping her child in the hospital when he was acutely ill. A parent dyad reported having to pay an inordinate amount of their savings for an attorney and independent psychiatrist in order to evaluate their child for a medication guardianship because their child was acutely psychotic and continuously refused psychiatric medication.

Finding appropriate outpatient mental health treatment for adult children with SMI was another issue reported by parents. Several factors influenced this issue. The most problematic of these factors was adult children who did not believe they needed outpatient mental health services especially for psychiatric medication. Medication nonadherence, which is a common problem for people with SMI and leads to exacerbation of symptoms and rehospitalization, was identified by participants as an ongoing issue. The majority of parents (n = 25) reported their children struggling with medication nonadherence during the course of their illness. At the time of the interviews, 63% (n = 19) of parents stated that their children were taking their psychiatric medications as prescribed. These parents reported that their child’s psychiatric symptoms were better managed when taking psychiatric medications consistently.

Another factor identified by participants was deciding how to select mental health providers. One parent stated, “It’s impossible to know how to pick a doctor. When you finally get a good name, there’s an 80% chance they’re not taking any new patients.” Parents cited the following problems: having to wait months to obtain appointments for psychiatrists and therapists, having difficulty reaching mental health providers when their

child was in crisis, and finding mental health professionals whose care they felt comfortable with and confident in. One parent described going through a lengthy and difficult process in order to get an appointment for her newly diagnosed child with a mental health professional running a first-episode psychosis program. After waiting several months for the appointment, the parent was informed by the professional that her child was “too sick” to participate in the program. Many participants (n = 12) reported that their child saw multiple mental health providers before finding one with whom they were able to develop a therapeutic relationship.

Only eight participants discussed their children’s involvement with the Massachusetts Department of Mental Health (DMH) for services in the community. These parents stated their children had varying experiences with DMH. Three parents reported that their child had to apply several times for DMH eligibility before obtaining these services. Three parents stated that the case managers sent to provide support services to their child at home were not helpful in promoting their child’s recovery. Three parents reported positive outcomes with DMH services (i.e., residential placement and case management). Several parents (n = 6) reported not wanting their child to apply for DMH services due to the lack of adequate resources within DMH and the stigma attached to being a DMH client and accepting public assistance.

All parents expressed concern about their adult children having access to appropriate outpatient mental health services for the stabilization of their psychiatric symptoms. Parents discussed the importance of their child’s long-term prognoses being dependent on outpatient services that promote recovery. A parent described a goal she has for her child: “I would love to see him hook up...with some kind of peer

counselor...one of those people that goes around...to say ‘I have lived with mental illness’ ... to give him hope.” Parents with adult children who refused outpatient mental health services expressed their concerns for their children’s long-term outcomes (i.e., obtaining employment, establishing meaningful relationships, and living independently).

Theme 4. “It’s not a sprint...It’s Heartbreak Hill”: Enduring the Illness

Parents continued their journeys in caring for their children with SMI. Theme 4 was characterized by parents’ persistence and perseverance as they endured the physical and emotional burdens of their child’s mental illness on the family and worked continuously to re-establish stability within the family. Enduring the illness was described by participants as marked by moments ranging in emotion from deep sadness to joy. All participants continued to grieve the loss of their child who had been previously intelligent, gifted, social, and motivated and to adjust to their child with SMI. Parents described continually needing to readjust to the disturbing symptoms and behavioral changes associated with SMI. When a friend of a parent said, “It’s not a sprint. It’s a marathon,” the parent replied, “It’s Heartbreak Hill, you know?” Parents started out not realizing the severity of their child’s problem and struggling to obtain a diagnosis and treatment. They then hit the toughest stretch of their journey, which was managing and redefining day-to-day family life with SMI. Parents focused on gaining the latest knowledge about SMI, learning strategies to manage their child’s illness and family life more effectively, sharpening their skills to navigate the mental health system, identifying community resources, and establishing social supports for their child and themselves. The majority of participants took on advocacy roles to increase awareness about SMI and to confront the stigma of mental illness.

Subtheme 4A. Family life redefined.

This subtheme reflected parents' efforts to redefine family life that was severely disrupted as a result of caring for an adult child with SMI. Parents talked about re-evaluating and reformulating family life in the context of managing an adult child with SMI. All participants acknowledged that their child's SMI dominated family life, especially when the symptoms were acute and untreated. They described their focus shifting from managing the family as a whole to managing the chaos created by SMI whether the adult child lived at home or away. One participant described, "It's the defining thing that's happened...in our family...is that illness. The stress level in our family was very, very high." Gaining knowledge about SMI, recognizing their child's symptoms and patterns of behavior, accessing treatment and other resources, and obtaining social support allowed families to find periods of equilibrium in their lives. Participants whose child consistently refused treatment experienced more instability within the family.

Parental roles were redefined in many families. In 17 households, the primary caregivers for their adult child with SMI were mothers. Seven mothers were in single-parent homes, stating they received little or no help from their children's fathers. Ten mothers in two-parent households were the primary caregivers. In several situations, fathers identified themselves as the primary caregivers. Two fathers in two-parent households were the primary caregivers. One father explained that his wife "outsourced" the care of their child to him because of his firm decision-making ability. In five two-parent households, parents discussed sharing the caregiving role based on their different abilities. As one father described it, he and his wife each have different personalities and

expertise, “She’s a teacher....She’s uncommonly empathetic. I had the good luck to read books that were really helpful...I mean, I’m a scientist, so that’s what I did.” Ten parents reported that other family members (i.e., siblings, aunts and uncles, cousins, and grandparents) provided support and assistance in caregiving.

Family life was also redefined by how much independence and autonomy the adult children with SMI were able to regain. All participants discussed their attempts to foster their child’s abilities to be independent and autonomous. Participants realized that the severity of their child’s symptoms and whether these symptoms could be effectively managed with treatment dictated their child’s abilities to be independent and autonomous as well as the amount of control parents needed to take as caregivers. The use of alcohol and illicit drugs was reported by participants (n = 10) to worsen the symptoms of their children’s SMI. A parent sobbed as she told the story of her son who refused any prescribed treatment for SMI and died of a drug overdose. Parents (n = 16) whose adult child was not abusing substance and whose psychiatric symptoms were able to be stabilized with treatment reported more periods of equilibrium within their family life. One parent whose child’s psychiatric symptoms were stabilized on medication after years of refusing treatment stated, “I’m in a nice spot now where I can sit back and just be supportive.” After years of hospitalizations and medication refusal, another parent remarked, “I was just happy that I had my son back because he was gone for so long.” Parents (n = 8) who talked about their adult child refusing treatment stated that their child was more dependent on them for day-to-day caregiving. When asked what a day was like at home, a mother replied, “It’s like I’m babysitting him...uh...I’m *babysitting* him.”

Developing a support system was one of the most important strategies for parents managing family life with an adult child with SMI. The majority of parents (n = 22) talked about the importance of joining NAMI and the impact NAMI had on their lives. These parents stated that NAMI provided them education, support, and advocacy that they had not received from the mental health system. Several parents (n = 12) explained that taking NAMI's 12-week "Family to Family" course was an invaluable resource that provided education about SMI, information about available community service, and ways to navigate the mental health system. Five parents moved on to teaching the "Family to Family" course to other parents. Parents stated that they continue to attend and/or run the monthly NAMI support groups throughout Massachusetts. A parent dyad explained that they were part of the initial grassroots organization supporting families with SMI that later became NAMI. The majority of parents discussed how NAMI influenced them to take on advocacy roles for families affected by and people suffering from SMI within the community.

Subtheme 4B. Expectations and goals redefined.

All parents stated that they want their children to have happy, satisfying relationships and to live up to their potential. The majority of participants acknowledged making adjustments in the expectations and goals they had for their adult child after being diagnosed with SMI. Parents discussed not wanting to lose hope for their child's future while wanting to be realistic. A parent sadly commented, "Eventually, we realized that this vision that we had of a person who could be, literally, anything she would choose...uh...we realized that was gone by the boards and wasn't going to happen." Another parent stated, "So, my expectation is just that he find his way to a life that he

wants. It doesn't have to be prestigious or anything like that. I want him to find something that gives him satisfaction.” Only two parents commented that their expectation for their child's future had not changed greatly because they believed their child had a milder form of SMI.

Parents whose adult child's symptoms were well managed by treatment expressed more optimism about their child's future. Parents reported that seven of these children graduated from college, and two went on to graduate school. Five of these children were working full-time jobs, and four of the five were living in their own apartments. One parent expressed his pride that his child had published a collection of poetry. In contrast, several parents (n = 7) acknowledged that their adult child was unable to obtain or sustain a job in the competitive workforce. One parent described her child obtaining seven positions over the past year and being able to tolerate only 1 day at each job before quitting. Four of these children received disability benefits. Due to the functional impairments caused by SMI including the inability to manage money, 12 parents reported that their adult children were unable to live independently in their own apartments, thus requiring supervised living situations (i.e., home, staff-supervised residential placement, or supervised apartment settings).

Parents discussed the goal of their children being able to develop loving relationships and to find partners to share their lives with. Because of the social dysfunction associated with SMI, several parents questioned their child's ability to develop satisfying and long-term relationships. Eight parents also expressed concern about sexual dysfunction and severe weight gain their children were experiencing as side effects from psychiatric medication. One parent was extremely angry, stating, “Nobody

works with those mentally ill men, specifically, talking to them that...those medications make them impotent.” Five parents commented on trying to help their children with weight reduction by educating them about health food choices, food preparation, and obtaining gym memberships.

Subtheme 4C. Fears for the future.

Parents of adult children with SMI expressed specific fears for their children’s futures. Certain symptoms caused particular worry for parents (i.e., history of violence toward others and suicidal and self-destructive behaviors). Seven parents talked about their child’s chronic suicidal ideation and prior suicide attempts that caused them to worry about their child’s future. Of these parents, three stated that, with adequate psychiatric treatment, their child had a reduction in suicidal thoughts and attempts. The majority of parents (n = 21) reported history of violent behavior when their child was acutely ill. These parents expressed fear of violence in the future if their child relapsed and had an exacerbation of psychiatric symptoms. When asking a parent what her fears were, she stated, “Um...that he’ll lose his job. That he’ll...he’ll do something really awful at work and frighten the children. I’m also afraid he might hurt someone again...I tell them about his...his...um...two episodes where he has hurt people.”

The greatest fears for the future of parents caring for their adult children with SMI were aging and death. Parents expressed worry of who would manage the care of their child when they were no longer able to. Four parents obtained DMH services and disability benefits for their adult child. Three children lived in DMH-supervised residential settings, and one child lived in his own apartment with DMH-supported services. Several parents (n = 3) mentioned the possibility of their child applying for

DMH eligibility in the future. Two parent dyads had already established living trusts for their child. These parents stated they felt more comfortable with the future having made these decisions and knowing their child with SMI will be cared for. Another 10 parents discussed looking into the process of obtaining living trusts. Five parents obtained representative payees to manage the finances of their children who were unable to manage their finances independently. A parent stated that she made an agreement with another one of her children, who agreed to live with and manage the care of her sibling with SMI after the mother dies. Two parents expressed confidence that siblings would be helpful and supportive of their child with SMI when they were no longer able. Three parents questioned whether other children in the family would be supportive of their sibling with SMI due to current problematic family relationships.

Participants’ Recommendations for Improving Community-Based Mental Health Services

Participants were asked to make recommendations for improving community-based mental health interventions that would support and/or enhance overall family functioning. These recommendations are organized in Table 3.

Table 3

Participants’ Recommendations for Improving Community-Based Mental Health Interventions

Number	Recommendations
11	Develop a central statewide program providing information about SMI, including symptoms, what to look for, types of treatment, where to call for help, what to do in a crisis, where to locate various services (outpatient mental health provider, inpatient hospitalization, legal advice, social services, primary and mental healthcare, respite care), available provider list, insurance issues.
6	Changes in Health Insurance Portability and Accountability Act (HIPAA) so that parents caring for adult children with SMI can have reasonable access to information about their children’s care.

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- 6 Increase public awareness about NAMI and services it provides to people with SMI and families.
 - 4 Increase public awareness about SMI, treatment, and where to access mental health services through the media.
 - 4 Increase the number of support groups for parents and children with SMI.
 - 4 Increase beginner psychoeducation groups/first-episode psychosis programs (inpatient and outpatient) for parents and adult children newly diagnosed with SMI.
 - 3 Increase lengths of stay on psychiatric units to support stabilization of people's psychiatric symptoms.
 - 3 Increase number of mental health hospital beds in MA.
 - 3 Develop mental health home care services for both adult children with SMI and parent caregivers to provide education and support.
 - 2 Provide more Program of Assertive Community Treatment (PACT) services in the home for adult children and their families.
 - 2 Develop outreach programs for mental health staff to go into the home to evaluate adult children for hospitalization and provide follow-up services after hospitalization to assess mental health needs and to provide support and education as needed.
 - 2 Provide more education to police department regarding working with people with SMI and their families.
 - 2 Increase the number of psychiatrists and mental health professionals in MA to increase access to care.
 - 2 Increasing the amount of entry level education and continuing education mental health staff are required to improve communication skills and increase sensitivity to the needs of people with SMI and their families.
 - 1 Routine mental health screening for children throughout elementary and secondary school.
 - 1 Increase mental health screening in court clinics to reduce the number of people with SMI going to jail.
 - 1 Have mental health providers who provide life-coaching skills to adult children with SMI to promote recovery and autonomy.
 - 1 Develop state-run programs to engage people with SMI in community activities.
 - 1 Develop all-inclusive clinics that provide holistic care to people with SMI including psychiatric care, primary care, social services, and employment opportunities.
 - 1 Allocate more state funding for Recovery Learning Centers to provide education, recovery skills, employment assistance, and support.
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Summary

Thirty parents were interviewed to examine the management styles and associated management components of caring for their adult children with SMI. Four major themes emerged from the data: Theme 1. “When it hits your family”: *Recognition of a Problem*; Theme 2. “Here I am a new parent (to mental illness) with no idea what to do”: *Scrambling for a Diagnosis*; Theme 3. “It’s very clear what we need to do, but not clear how to get there”: *Learning to Maneuver Family Life and the Mental Health System*; and Theme 4. “It’s not a sprint...It’s Heartbreak Hill”: *Enduring the Illness*. These themes reflect parents’ descriptions of their management styles in parenting and caring for adult children with SMI. Caring and managing their adult children with SMI was described by participants as lengthy, difficult, and perplexing.

Theme 1, “When it hits your family”: *Recognition of a Problem*, was comprised of three subthemes: *Child’s behavioral changes*, *It’s a serious problem*, and *Decision to act*. Parents are confronted with behavioral changes that are uncharacteristic of their children. Confusion set in as parents questioned whether this was normal adolescent behavior or something more serious. When their children’s behaviors became more bizarre and disturbing, parents became aware of the seriousness of the situation. Parents were forced to act in search of help for their children. From Theme 2, “Here I am a new parent (to mental illness) with no idea what to do”: *Scrambling for a Diagnosis*, one subtheme was identified: *My child has what?!* Now aware that their children were exhibiting psychiatric symptoms, parents were befuddled regarding where to go for proper diagnosis and treatment for their children in a convoluted mental health system.

Theme 3, “It’s very clear what we need to do, but not clear how to get there”:
Learning to Maneuver Family Life and the Mental Health System, encompassed two subthemes: *Family in turmoil* and *Access to appropriate mental health services*. Families described chaos after their children were diagnosed with SMI. All aspects of day-to-day family life were disrupted. Parents had to learn how to adjust to family life that had been severely changed by SMI. Parents also learned ways to maneuver a complicated mental health system with no clear path to get to the appropriate services their children needed.

Theme 4, “It’s not a sprint...It’s Heartbreak Hill”:
Enduring the Illness, was comprised of three subthemes: *Family life redefined*, *Expectation and goals redefined*, and *Fears for the future*. Parents described regaining equilibrium within the family, albeit lengthy, arduous, and emotion-laden. Family life was re-evaluated and reformulated in the context of managing an adult child with SMI. Parents acknowledged making adjustments in the expectations and goals for their children’s lives after the SMI diagnosis. Parents’ fears for the future included worry about who will care for their children as they age and die and about their children relapsing and harming themselves or others. Parents offered recommendations for community-based mental health interventions that would support and enhance overall family functioning.

CHAPTER 5

DISCUSSION

Introduction

The purpose of this study was to examine parents' management styles and associated management components in caring for adult children with SMI. All participants described distinct phases that were lengthy, arduous, and emotion-laden as they learned to manage the impact of SMI on the lives of their adult children and the family. Four main themes emerged from examining parents' experiences in caring for adult children with SMI. The majority of participants expressed the importance of telling their unique stories in order to help other parents dealing with similar circumstances.

The findings are examined in relation to the theoretical framework used to undergird the study, the FMSF (Knafl & Deatricks, 1990, 2003; Knafl et al., 2012). Three major findings emerged in this study specific to the family management of caring for an adult child with SMI: (a) the adjustments in caregiving that families undergo in confronting SMI and in providing the day-to-day management of an adult child with SMI, (b) the stigma of mental illness that families must face, and (c) the differences in day-to-day management that families experience. These findings will be explored in relation to previous empirical studies of parents caring for adult children with SMI. An adaptation of the FMSF is presented in the next section as Table 4, comparing and contrasting the use of the FMSF to guide the management of families caring for children with chronic medical illness with parents caring for adult children with SMI. This discussion will include appraising similarities and differences between the themes and subthemes of this study and the conceptual components and dimensions of the FMSF.

Lastly, this discussion presents implications for practice, future research, and health policy as well as summarizes the limitations of the study.

Adaptation of the Family Management Style Framework

The results of this study support the use and adaptation of the FMSF for examining the management style of parents caring for adult children with SMI. The major components of the FMSF aligned well with the four major themes identified in this study. Examination of the subthemes from the study and the dimensions within the FMSF revealed several differences between the use of the FMSF for families caring for a pediatric population with chronic illness versus an adult child population with SMI. Overall, the use of the FMSF to undergird this study provided a greater understanding of how parents manage the day-to-day care of their adult children with SMI and family life. This insight is important to guide further research and the clinical care of families caring for adult children with SMI.

Comparing the components of the FMSF with the major themes of this study highlights a similar adjustment that parents go through when their child becomes ill whether the illness is a chronic medical illness or a SMI. See Table 4. Parents recognize a problem developing in the family when the child becomes symptomatic, and they define what the illness means for the family and the child. Parents are then faced with obtaining an accurate diagnosis of the child's illness and making alterations to incorporate illness management into daily family life. Parents of children with chronic medical illness as well as SMI need to make behavioral adjustments (i.e., gaining information and skills, learning to maneuver healthcare systems) in order to manage the illness on a day-to-day basis. Whether the child's illness is in the foreground or background of family life is

dependent on multiple factors. For parents of adult children with SMI, the severity of the child's symptoms, the long, arduous process of obtaining an accurate diagnosis and appropriate treatment, and the treatment adherence of the adult child influence whether the illness remains in the foreground of family life.

When examining the findings of this study within the context of the FMSF, differences emerged in how parents of adult children with SMI view the child's identity and illness. The dramatic behavioral manifestations of SMI severely impact how parents view their children and their futures. Regaining a sense of normalcy and assessing the adult child's capabilities after being diagnosed with SMI reek with uncertainty for parents who are trying to define their situation. Another difference noted is in the adjustments parents make to manage their child's SMI on a daily basis. Daily routines take on different characteristics due to the unpredictability of the course of SMI and of adult children who may or may not agree to treatment for their SMI.

Table 4

Adaptation of the Revised FMSF for Parents Caring for Adult Children With SMI

Revised FMSF Components	Revised FMSF Dimensions	Adapted FMSF Components	Adapted FMSF Dimensions	Adaptations & Comparisons Between Pediatric and Adult Child Populations
<p>Definition of the Situation: Subjective meaning family members attribute to important elements of their situation related to the child’s illness.</p>	<p>Child’s Identity: Parents’ views of the child and the extent to which these views focus on illness, normalcy, and capabilities or vulnerabilities.</p> <p>Illness View: Parents’ beliefs about the causes, seriousness, and predictability, and course of the illness.</p>	<p>Definition of the Situation: Subjective meaning parents attribute to the important elements of their situation related to SMI.</p>	<p>Adult Child’s Identity: Parents’ view of their child with SMI related to severity of symptoms and response to treatment compared with past personality, function, activities, and interests.</p> <p>Illness View: Parents’ beliefs about the causes of SMI being a biological dysfunction in the brain. As parents learned about SMI, they realized its seriousness and its symptoms were unpredictable when left untreated. Parents’ beliefs about the course of illness being dependent on severity of symptoms, treatment adherence, effectiveness of treatment, and support.</p>	<p>Adaptation: As the adult child becomes more impaired without treatment/with ineffective treatment or the adult child’s symptoms stabilize with treatment, his or her identity may change.</p> <p>Adaptation: Parents come to realize the seriousness of SMI. The earlier the adult child gets treatment and the more effectively the treatment stabilizes symptoms are factors that can improve function and outcomes.</p> <p>Comparison: Pediatric: Parents maintain hope that their child can maintain some function, become more independent, and compensate for the illness.</p>

	<p>Management Mindset: Parents' views on the ease or difficulty in carrying out treatment regimens and ability to manage effectively.</p> <p>Parent Mutuality: Parents' beliefs regarding the extent that they have similar or differing views of the child, illness, parenting philosophy, and approach to illness management.</p>		<p>Management Mindset: Parents viewed that getting accurate diagnosis and effective treatment as difficult. Managing SMI was difficult depending on symptom severity and effectiveness of treatment.</p> <p>Parent Mutuality: Married parents viewed being "on the same page" with their spouses regarding the adult child, illness, parenting philosophy, and approach to illness management. Divorced parents dealt with the daily care of the adult child alone.</p>	<p>adult children with SMI had difficulty managing a daily routine when the symptoms were more severe and when adult children were nonadherent with treatment. Managing was done by trial and error. Tried to focus on increasing functioning and independence.</p> <p>Comparison: Pediatric: Parents' mindset was to foster stability and independence for the future.</p> <p>Adaptation: Married parents worked together for the same goal of caring for the adult child to manage illness symptoms, improve function, and increase independence.</p> <p>Comparison: Pediatric: Parents combined their efforts to care for the child to improve health outcomes.</p>
<p>Management Behaviors: Specific behavioral adjustment that family members make to manage the illness on a daily basis.</p>	<p>Parenting Philosophy: Parents' goals, priorities, and values guiding overall approaches and specific strategies for illness management.</p>	<p>Management Behaviors: Specific behaviors used to manage the day-to-day care of their adult child with SMI.</p>	<p>Parenting Philosophy: Parents' major priority was to maintain safety in the home when adult children exhibited bizarre and dangerous behaviors.</p>	<p>Adaptation: Parents have to closely monitor adult children whose symptoms are more severe or not treated effectively. When symptoms of SMI are</p>

	<p>Management Approach: Parents' assessment and strategies for managing the illness and incorporating it into family life.</p>		<p>Searching for information on SMI and obtaining effective treatment for adult children were parents' goals.</p> <p>Management Approach: Developing a daily routine was challenging for parents because the family was in chaos due to SMI. Parents moved "in careful ways" to regain solidity/stability in the family.</p>	<p>effectively managed, adult children are able to manage more independently.</p> <p>Comparison: Pediatric: Parents monitor younger children more closely when the illness is less stable. Parents focus illness management and increasing functional ability and independence.</p>
<p>Perceived Consequences: The extent to which parents experience the illness in the foreground or background in family life.</p>	<p>Family Focus: Parents' assessment of balance between illness management and other aspects of family life.</p>	<p>Perceived Consequences: The extent to which parents view the illness as in the foreground or background of family life.</p>	<p>Family Focus: Parents view SMI as being in the foreground of family especially early on in the course of illness. Only a few parents acknowledged when SMI is effectively managed for a significant period of time does the illness move to the background of family life.</p>	<p>Adaptation: Parents describe SMI as being in the foreground of the family functioning during the times when symptoms of SMI are acute, poorly treated, or untreated. When there is a period of stabilization of the illness, SMI can go into the background of family functioning. Parents can focus on the family as a whole and focus on self-</p>

	<p>Future Expectations: Parents' assessment of the implications of illness for the child's and family future.</p>		<p>Future Expectations: Parents' redefine family life as well as the goals and expectations they have for their adult child's future due to SMI.</p>	<p>needs.</p> <p>Comparison: Pediatric: Illness management remains in the foreground of family functioning when the child's illness is acute and/or difficult to manage. The illness can move to the background of family functioning when the child's condition is stable.</p> <p>Adaptation: Due to the impact of SMI on family life, parents redefine what family life is and redefine the expectations/goals for their adult child. Factors affecting parents' expectations/goals for the future are the child's response to treatment, child's acceptance of treatment, parents' knowledge of SMI and recognition of symptoms, and parents' confidence in their abilities to manage situations with their children. Parents have more optimism when the adult child's illness is effectively managed and the child becomes more like his/her "old self" before the</p>
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				<p>illness. Parents face fears of the future as they age and are unable to care for their adult child at home.</p> <p>Comparison: Pediatric: Parents of younger children have to redefine family life and their expectation for their children based also on the seriousness of the illness and the ability to manage the illness effectively. Parents of younger children, too, must fear and develop plans if they are unable to care for an ill child in the home.</p>
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Adapted with permission from K. A. Knafel et al. (2012) and A. S. Beeber and S. Zimmerman (2012).

Relationship of Findings to Prior Empirical Literature

The parental role has been identified as vital to the care and recovery of adult children with SMI. Several researchers examined the experiences of families managing the care of adult children with SMI (Chan 2011; Chang & Horrocks, 2006; Chesla, 1991; Doornbos, 2001, 2002; Drapalski et al., 2008; Karnieli-Miller et al., 2013; Levine & Ligenza, 2002; Muhlbauer, 2002; Rungreangkulkij & Gilliss, 2000). This study revealed three major findings specific to families caring for adult children with SMI. The first major finding revealed progressive and distinct phases that parents went through in managing the care of their adult children with SMI. These phases became apparent after reviewing the main themes and subthemes identified in the study. Secondly, the role of stigma of mental illness had a significant influence on parents' management styles. Lastly, the third major finding was the differences in management behaviors that parents experience in the daily care of an adult child with SMI. These major findings will be examined in relation to previous research studies on parents caring for adult children with SMI.

The Adjustments to Caregiving

A limited number of studies have been conducted that address caregiving in families with relatives struggling with SMI. The present study added important information about adjustments parents make in caring for adult children with SMI. The parents described distinct phases that were lengthy and burdensome as they learned to manage the profound effects of SMI on their children and the family. The main themes of this study reflected phases with specific characteristics moving from one phase to the next as knowledge about SMI and skills for managing their child's illness were obtained.

Chesla conducted two studies (1989, 1991) examining parents caring for adult children with schizophrenia. In the earlier study, Chesla (1989) interviewed parents (N = 21) who described their lived experience caring for adult children with schizophrenia. Chesla noted that parents' caregiving patterns were dependent on the type of illness model they prescribed to. Parents identified four distinct illness models in the day-to-day lived experience of caring for their adult children with schizophrenia including strong biologic, rational control, normalizing, and survival-through-symptoms (Chesla, 1989). In the second qualitative study, Chesla (1991) identified distinct forms of caregiving practices in parents (N = 21) caring for adult children with schizophrenia including engaged care, conflicted care, managed care, and distanced care. Both studies discussed caregiving in terms of separate and distinct parental coping styles. These studies did not support a lengthy, progressive, caregiving process similar to what the parents of adult children with SMI in the current study experienced.

In a critical analysis of conceptual frameworks used to study family caregivers of persons with SMI, Rungreangkulkij and Gilliss (2000) examined the use of the Family Resiliency Model with families caring for a family member with SMI. This model described an adaptation process where families caring for family members with SMI attempt to manage crisis situations and balance the needs of the individual with SMI and the family as well as the social demands of the family within the community (Rungreangkulkij & Gilliss, 2000). This conceptual analysis supported a complex process involved in caring for a family member with SMI (i.e., managing crisis situations, family demands, available resources, family values and beliefs). These findings are similar to factors impacting parent caregiving in the current study (i.e., managing crises, social

influences, available resources, and parental definitions of child identity and illness view). The results did not address the lengthy, emotion-laden, and difficult management process parents in this study experienced to obtain information about SMI, accurate diagnoses, and appropriate treatment for their adult children in the complicated maze of the mental health system.

In a qualitative study, Doornbos (2001) interviewed caregivers (N = 76) focusing on family caregiving for young adults with SMI. Five separate caregiving processes that operated simultaneously emerged. These processes included monitoring, managing the illness, maintaining the home, supporting/encouraging, and socializing (Doornbos, 2001). The results of the Doornbos study differed from the findings of this current study by identifying five separate management processes going on at the same time. In contrast, this current study described a lengthy management process encompassing four phases that built upon each other, from recognizing that a problem existed in the family, scrambling to diagnose what the problem was, learning how to live with SMI, maneuvering a complicated mental health system, to enduring the illness. Muhlbauer (2002) conducted a qualitative study of 26 family caregivers' perspectives on the development and process of SMI as they cared for relatives (adult children, spouses, and a sibling) with SMI. The interview data revealed a progression of six phases with specific characteristics that the majority of family caregivers went through. These phases compared mental illness to navigating a storm: Phase 1—Development of Awareness: Storm Warnings; Phase 2—Crisis: Confronting the Storm; Phase 3—Cycle of Instability and Recurrent Crises: Adrift on Perilous Seas; Phase 4—Movement Toward Stability: Realigning the Internal Compass; Phase 5—Continuum of Stability: Mastering

Navigation Skills; and Phase 6—Growth and Advocacy: Sailing Existential Seas. These phases described the various situations that family members confront as they try to manage the care of relatives with SMI. Two similarities were noted in comparing the results of Muhlbauer study with the findings of this current study. Both studies described a long, progressive management process of caregiving that can last for years, and both identified multiple phases in the caregiving process that require the acquisition of information, skills, experience, and support to move on to the subsequent phase. These present study findings were most similar to the results of the Muhlbauer study.

Stigma

The stigma of mental illness had a significant impact on the parent participants of this study. Parents discussed their discomfort and reluctance to talk with family and friends about their child's SMI for fear of being judged and discriminated against. Many parents reported feeling embarrassed and shameful as a result of disclosing about having an adult child with SMI. The literature has documented that the family burden of caring for persons with schizophrenia is an enormous challenge throughout the world (Chan, 2011). The stigma of mental illness has been noted to adversely impact and add to caregiver burden (Chan, 2011). Muhlbauer (2002) noted that parental concerns related to stigma increased from the earlier phases of family caregiving. The results of Muhlbauer's study reported family caregivers having negative encounters when disclosing information about their children having SMI (Muhlbauer, 2002). These negative encounters included having to face institutional stigma within agencies and regulations (i.e., discriminatory employment and insurance regulations; Muhlbauer, 2002). Chang and Horrocks (2006) explored the meaning of the lived experiences of Chinese families caring for family

members with mental illness. Family caregivers reported confining information about their family members' mental illness to their immediate family only to avoid "losing face" and to protect the family name (Chang & Horrocks, 2006). They also reported feeling shame and embarrassment.

The concept of "family stigma" was explored by Larson and Corrigan (2008). Family caregivers experience stigma by their association with persons with SMI, which Goffman (1963) referred to as courtesy stigma. Family or courtesy stigma is the discrimination experienced by parents, siblings, spouses, and children of a family member with SMI (Goffman, 1963). Family stigma can lead to shame and avoidance of social situations. Karnieli-Miller et al. (2013) conducted a study to explore family members of persons with SMI experiences with and efforts to cope with mental health stigma. Family members reported feeling blamed, rejected, and betrayed when disclosing having a relative with SMI (Karnieli-Miller et al., 2013). Similar findings were noted in the current study regarding several parents who reported losing the support of family and friends after disclosing that their adult child had SMI. In a cross-sectional study exploring mental health stigma in family caregivers of people with bipolar disorder, Gonzalez et al. (2007) found that mental health stigma was more prevalent among caregivers of family members who were exhibiting active symptoms versus family members whose symptoms were stable. The results of this current study did not differentiate stigma experienced by family caregivers according to symptoms, but agreed with the findings of the negative impact of stigma on family caregivers.

Differences in Management Behaviors

The findings of this study showed that the care of adult children with SMI required families to use different management behaviors than those families managing the care of children with chronic medical conditions. Parents caring for an adult child with SMI and parents caring for a child with chronic medical illness engage in similar caregiving activities such as providing a living situation, financial assistance, assistance with household chores, meal preparation, transportation to appointments, medication administration and monitoring, and emotional support. Symptoms of SMI can include disturbing and bizarre behaviors. At least half of the parent participants in this study talked about dealing with unsafe and frightening behaviors by their adult children ranging from severe agitation, hallucinations, paranoia, self-injury, destruction of property in the home, threats of aggression, and assaultive behavior. Parents described having to engage in other management behaviors (i.e., locking up kitchen knives to prevent a child's self-injury, calling the police for assistance with a child's dangerous behaviors, taking the child to the emergency room for a psychiatric evaluation, deciding to seek alternative living arrangements for a child) and going to court to file for guardianship when adult children refuse psychiatric treatment.

Rose et al. (2004) conducted a qualitative study to identify barriers to family care in psychiatric settings and to describe family and provider perspectives about what is needed to provide effective family care for caregivers of people with SMI. Parents reported a lack of provider support to deal with emotional crises (i.e., being forced to call police for assistance, getting the ill family member committed to a hospital, dealing with the verbal and physical abuse of the family member with SMI (Rose et al., 2004). In Doornbos's study (2001) of family caregivers (N = 76) of young adults with SMI, family

caregivers stated that they needed more information to develop interventions for dealing with their children's difficult symptoms (i.e., paranoia, hallucinations, anger, delusional thinking). Levine and Ligenza (2002) conducted a qualitative study using focus groups to gain greater knowledge about the needs of family caregivers of persons with SMI, in which 55 family caregivers participated. A key finding of the study was that family caregivers were most challenged by the bizarre symptoms and behaviors exhibited by family members with SMI including problems with health and appearance, self-abuse, violence, and problems with the legal system (Levine & Ligenza, 2002). The results of these studies underscore the fact that family caregivers of adult children with SMI need to develop management behaviors to deal specifically with problematic symptoms of SMI.

Kaufman et al. (2010) conducted a pilot study using a pre/post treatment/control design to test a home-delivered, problem-solving intervention for parents caring for adult children with SMI. The intervention consisted of ten 90-minute sessions presented in family caregivers' homes. A major component in the intervention was a problem-solving approach to help caregivers gain knowledge and skills for dealing specifically with the adult child's challenging symptoms as these symptoms were identified as causing increased distress and burden for caregivers (Kaufman et al., 2010). Caregiver burden was measured in both the treatment group (N = 5) and the control group (N = 10) before and after the intervention. Caregiver burden using the Zarit Burden Interview in the treatment group decreased from 43.6 (s.d. = 12.4) to 28.0 (s.d. = 9.7) and decreased in the control group 46.1 (s.d. = 12.7) to 42.7 (s.d. = 13.0). This interaction was statistically significant ($p = .02$). The results regarding caregiver burden from this study provided

support for acknowledging that a different set of management behaviors is needed by family members caring for adult children with SMI.

Implications for Practice

Our parent participants offered multiple recommendations for mental health services needed to enhance family functioning in caring for an adult child with SMI. The findings suggest that parental needs differ at various points in the management process. See Table 5 at the end of this section. Improving screening procedures for mental health issues when parents “recognize a problem” in their children is a valuable strategy for early detection and prevention. Having a central statewide program for obtaining information about mental illness and available mental health resources is important for ongoing education, access to services, and support. Access to home-based psychiatric services is another need parents identified. Several parents recommended that more Program of Assertive Community Treatment or PACT Teams be developed to provide psychiatric services in families’ homes.

Parents reported that resources about mental illness and services are available in the community and on the Internet (i.e., Massachusetts Child Psychiatry Access Project, NAMI, and the Department of Mental Health Resource Guides). Many parents stated that they had difficulty accessing the appropriate information because there was not a central agency where they could talk to a mental health professional who could direct them to the correct place to address their needs. A central location and bridge system linking these various mental health resources is sorely needed. Mental health resources need to be connected to primary care providers, elementary and secondary school systems, college mental health services, community mental health centers, mental health hospitals, legal

advocacy groups, police departments, and social services organizations. This is a vital intervention to increase public awareness of available services, reduce fragmentation of services in the community, and minimize the number of people from falling through the holes within the mental health system. Psychiatric healthcare teams going into homes could provide outreach services to those families whose adult children are nonadherent with outpatient follow-up services. These psychiatric healthcare teams could also provide assessment of the person with SMI and the family in order to identify needs and potential problems.

Families who are the primary caregivers and support system for adult children with SMI need to be included in the mental health treatment of their children. Gaining access to mental health information about adult children can be problematic because these children are adults in charge of their treatment. Several adult parents commented on their children refusing to give permission for their health information to be shared with them. Parents talked about the need for legislative changes in the privacy laws protecting health information especially for parent caregivers. Parents belonging to NAMI have been advocating for changes in the current privacy laws. NAMI is currently supporting Bill S-1945 that is currently before the House of Representatives asking for greater access to health information for parent caregivers. Mental health providers need to contact their legislators to support Bill S-1945 because assisting family caregivers' access to health information can help improve intervention and outcomes for adult children with SMI.

Parents talked about the need for mental health professionals to find ways of working with both the adult children and their parents especially if the adult children are

returning home with parents and/or the parents are the adult children's primary support system. Exclusion of family caregivers can sometimes lead to poor patient outcomes. Mental health professionals are an invaluable resource for families who are caring for an adult child with SMI. Providing general information to parent caregivers about SMI, psychiatric medications including side-effect profiles, available community-based resources, and management strategies for dealing with problematic behaviors is a way for mental health professionals in both inpatient and community settings to help family functioning without giving specific patient information and without violating the therapeutic relationship between patient and clinician.

The current U.S. mental health system is under scrutiny with the multiple recent incidents in gun-related violence across our country and the questions regarding the mental health of the perpetrators. Concerns about the parents of perpetrators and access to mental health screening have been examined in the media as a result of the violence. The numbers of veterans from the armed forces coming home and in need of appropriate mental health services for posttraumatic stress disorder and brain-related injuries have also been flooding the media. The role of advance practice mental health nurses is an invaluable and cost-effective measure to help in these situations. Advance practice psychiatric nurses work in a variety of settings (i.e., health clinics, schools, public health agencies, hospitals, private practice, and homecare).

The U.S. is faced with a shortage of psychiatrists, especially child psychiatrists. Increasing the numbers of advance practice mental health nurses can help provide services especially in those areas of the country where numbers of psychiatrists are limited. Advance practice mental health nurses can provide greater access to mental

health screening and treatment for people with SMI and their families by consulting to school systems, going into people's homes as part of a psychiatric health team, accompanying police to people's homes to assess mental health crises, and collaborating with primary care providers.

Parent participants reported a great need to tell the stories of their experiences of caring for an adult child with SMI. During the interview process for this study, every parent participant expressed such gratitude for the opportunity to discuss his/her journey. The majority of parents had met with so many obstacles in managing their child's illnesses and in trying to maneuver through a mental health system that is confusing and unwelcoming. Joining NAMI became a lifeline for many parents who needed information and support. The need of parent and family caregivers to "tell the stories" is an important issue for mental health professionals working with adults with SMI. Hearing the stories becomes an invaluable part of the mental health assessment of the persons with SMI and the families who care for them. Hearing the stories of parents and families gives mental health professionals a window into the adult child's symptom patterns, responses to treatment, medical issues, and functional and cognitive deficits that could be addressed in treatment. Evaluating and addressing families' needs in managing the care of their adult child with SMI can promote more positive health outcomes for the whole family.

Table 5

Practice Implications in Various Phases of the Management Process

Phases of the Management Process	Practice Implications
Recognition of the Problem	<ul style="list-style-type: none"> • Improving screening procedures for mental health issues for early detection and prevention • Increasing access to home-based psychiatric services • Creating a central statewide program for obtaining information about mental health and available resources with links to access these resources • Connecting mental health resources with PCPs, school systems, college mental health centers, police departments, community mental health centers, inpatient mental health facilities, legal advocacy groups, and social service organizations
Scrambling for a Diagnosis	<ul style="list-style-type: none"> • Increasing the numbers and access to First-Episode Psychosis programs for adult children and parents • Providing psychoeducation to parents as they first enter the mental health system
Learning to Maneuver Family Life and the Mental Health System	<ul style="list-style-type: none"> • Creating central agency with access to mental health professionals to triage mental health problems • Increasing publicity for NAMI • Changing health privacy laws to include parent caregivers of adult children with SMI • Increasing numbers of advance practice mental health nurses to deal with shortage of psychiatrists • Increasing access to psychoeducation for families by mental health providers
Enduring the Illness	<ul style="list-style-type: none"> • Increasing media coverage about SMI to break down the stigma • Addressing the needs of the whole family in managing the care of adult children with SMI to improve patient and family outcomes

Implications for Research

The results of this study can inform healthcare providers of the lengthy and difficult adjustments in caregiving that parents undergo in the daily management of adult children with SMI. Parent participants reported that the management of their adult child with SMI monopolized family life. Having SMI in the foreground of family life had negative effects on many siblings. Parents reported siblings feeling ignored because so much attention was given to their ill child. Siblings expressed to parents their feelings of embarrassment, anger, and sadness as a result of having a brother or sister with SMI. Exploring siblings' experience with SMI within the family could provide valuable information about siblings' definition of their situation, their specific needs for managing and functioning within the family, and strategies that would help support their role within the family.

Cultural and ethnic differences in families managing the care of adult children with SMI are important areas that require further inquiry. Various cultures view mental health and mental illness differently from Western culture. The cultural meanings of illness, not just mental illness, impact people's motivation to seek treatment, how people cope with symptoms, and how people are perceived within their families and communities. With the worldwide immigration of people to the U.S., healthcare professionals, in order to provide respectful and effective treatment for mental health issues, need to have some understanding of people's belief systems and customs.

Several parent participants made the recommendation of using more home-based mental health services to assist the families and the adult child with SMI. Research in this area would be beneficial to address the needs of people with SMI and their families who care for them. Medicaid in Massachusetts offers Home and Community-Based Service

waivers for long-term community services for individuals with disabilities. Individuals who meet the requirements for this waiver become eligible for home-based services. Developing a home-based psychoeducational series (i.e., 4–6 sessions) to provide education and skill building to families caring for adult children with SMI may be a useful strategy for improving patient and family outcomes such as reducing the number of symptom relapses and hospitalizations, increasing medication adherence, and reducing the stress of caregiving among family members.

Implications for Health Policy

Mental health promotion is an important issue in the U.S. and throughout the world. The World Health Organization (WHO) recognized that promoting mental health is a global health priority since it is the key to optimal health and development in every country (http://www.who.int/mental_health/policy/services/en/). The WHO has initiated an international action plan to promote mental health through public health and social interventions and to further research evidence-based mental health practices that are culturally appropriate (http://www.who.int/mental_health/policy/services/en/).

The U.S. is faced with a broken mental health system in need of reform. Approximately \$130 billion are spent annually in the U.S. for mental health. Ten times as many people with SMI are incarcerated in prisons and jails than in psychiatric hospitals for treatment (<http://www.nationalreview.com/article/416391/federal-mental-health-policy-needs-reforming-now>). Across the country, increasing incidences of violence, abuse of vulnerable populations, and addictions make the daily media headlines.

Two important pieces of mental health legislation have been introduced in Congress: The Mental Health Reform Act of 2015 and the Helping Families in Mental

Health Crisis Act of 2015. The Mental Health Reform Act of 2015 (HR 2646) includes enhancing the enforcement of the Mental Health Parity Law, the integration of mental health and physical health care services through Medicaid in each state, promoting early intervention for the treatment of psychosis, and integration and program coordination across federal agencies that care for people with SMI (<http://www.nami.org/healthcare>). The Helping Families in Mental Health Crisis Act of 2015 (S 1945) is asking to provide resources for suicide prevention, improving the use of health information technology for mental health care, removing the 190-day limit on inpatient psychiatric units through Medicaid, increasing funding for research on SMI through the National Institute of Mental Health, and ensuring that caregivers of individuals with SMI have access to protected health information regarding those individuals to aid in their care (<http://www.govtrack.us/congress/bills/114/hr2646/text/ih>; <http://www.nami.org/healthcare>). The National Alliance on Mental Illness is advocating strongly for the passages of these bills.

Nurses in all areas of healthcare confront mental health issues daily in their patients. Nurses are in a unique position to advocate and support mental health reform for people with SMI and the families who care for them. Nurses are trained to think of their patients as part of an interactive system, such as families, communities, and society. Sometimes, the treatment of a patient means treating the whole system to bring about positive health outcomes. The time for collective political action by nurses is now more crucial than ever to support and advocate for mental healthcare reform in our country.

Limitations

This study is limited by the fact that the majority (73%, n = 22) of participants were members of NAMI, the national organization that provides education, support, and advocacy to people and families living with SMI. These participants were members of NAMI Massachusetts in several chapters throughout the state. Members of NAMI exhibited more awareness and knowledge of mental health issues and more experience in dealing with SMI than people not confronted with day-to-day mental health issues. Therefore, the transferability of the findings may be limited. The lack of ethnic and cultural diversity of the participants is a limitation of the study. Caregiver gender is another limitation, as 73% (n = 22) of the parent caregivers were female. Although this factor supports the current literature regarding the burden of caregiving for people with SMI falling on female caregivers, this study does not reflect potential differences in caregiving by gender.

Conclusions

The management styles and associated management components of parents caring for adult children with SMI were examined in this qualitative descriptive study. The FMSF, a well-established framework for families caring for children with chronic medical illness, guided the specific aims and interview questions. Four main themes emerged from the data. These themes described prolonged, difficult, and confusing adjustments that parents and family undergo in caring for an adult child with SMI.

Three major findings specific to parents in the care of an adult child with SMI were also identified. The first major finding was the process that described the long and difficult journey parents traveled—from recognizing their adult child had a serious problem, scrambling to get the problem diagnosed, dealing with the turmoil created in the

family due to SMI, maneuvering a complicated mental health system—to redefining family life and the expectations and goals for their adult child. The role of the stigma of mental illness was the second major finding, placing a significant impact on parents managing the care of their adult child with SMI. The third major finding was the differences in management behaviors specific to mental illness that are experienced by parents caring for their adult child. The previous literature that was examined provided support for these three major findings.

Despite (and no doubt because of) the trials parents experienced to regain stability within their families, they expressed much gratitude to this researcher for the opportunity to share their stories. By sharing their stories, they hoped to provide support and education to other parents who face the same difficult situation and to increase the awareness of mental health professionals to the needs of all parents who are engaged in the caregiving of an adult child with SMI. Understanding the unique situation of these parents has implications for both practice and policy. Focus on evidence-based practices that can provide more effective mental health prevention, treatment, and recovery strategies for families who are caring for an adult child with SMI is needed. These practices must include increasing access to mental health information, mental health screening, early interventions, violence prevention, and various treatment options for adult children and their families. Mental health policy will need to address the increasing numbers in our society of aging parents caring for their adult child with SMI and examine ways to reallocate finite resources to assist this growing population.

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APPENDIX A
IRB DOCUMENTS

(APPROVAL, MODIFIED APPROVAL, AND VERBAL INFORMED CONSENT AGREEMENT)



February 25, 2015

Kathryn Raymond, MS
University of Massachusetts
Graduate School of Nursing

Dear Ms. Raymond:
The IRB reviewed the following:

Type of Submission:	Study
Review Type:	Non-Committee
Project Title:	Parents Caring for Adult Children with Serious Mental Illness
Investigator:	Kathryn Raymond, MS
IRB ID:	H00006155
Funding Agency:	Departmental
Grant Title:	None
Grant ID:	None
IND or IDE:	None
IRB Review Date:	2/20/2015
Documents Reviewed:	ISP.docx FinalInformedConsentIRB.docx InterviewGuideUpdate2015.docx UpdatedStudyFlyer2015.docx

The IRB approved the research from 2/20/2015 to 2/19/2016 inclusive. Before 1/5/2016 or within 30 days of closing the study, whichever is earlier, you are required to submit a completed Continuing Review Progress Report and necessary attachments to request continuing approval or study closure.

If continuing review approval is not granted before the expiration date of 2/19/2016, approval of this research expires on that date.

Stamped consent documents are included with this approval. Use these to document consent.

In conducting this research, you are required to follow the requirements listed in the INVESTIGATOR MANUAL.

Sincerely,
Joann Jean-Baptiste IRB Coordinator

cc: Bova Carol, Sullivan-Bolyai Susan



May 13, 2015

Kathryn Raymond, MS
University of Massachusetts
Graduate School of Nursing

Dear Ms. Raymond:

The IRB reviewed the following:

Type of Submission:	Modification
Review Type:	Non-Committee
Project Title:	Parents Caring for Adult Children with Serious Mental Illness
Investigator:	Kathryn Raymond, MS
IRB ID:	H00006155_3
Funding Agency:	Departmental
Grant Title:	None
Grant ID:	None
IND or IDE:	None
IRB Review Date:	5/13/2015
Documents Reviewed:	ISP.docx FinalInformedConsentIRB.docx

The IRB approved the modification effective on 5/13/2015.

In conducting this research, you are required to follow the requirements listed in the INVESTIGATOR MANUAL.

Sincerely,
Sharon Wang, CIP, CIM
Protocol Specialist, IRB

cc: Bova, Carol
Sullivan-Bolyai, Susan

**UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL
COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH
CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

Title of research study: Parents Caring for Adult Children with Serious Mental Illness

Investigator: Kathryn Raymond, MS, RN

Why are you being invited to take part in a research study?

You are being asked to participate because you are a parent caring for an adult child age 18 or over with a serious mental illness specifically schizophrenia, schizoaffective disorder, or bipolar disorder.

What should you know about a research study?

Your participation is entirely voluntary.

You do not have to be in this research study. If you join the study, you can stop or leave at any time with no changes in the quality of the health care you receive.

You will be told about any new information or changes in the study that could affect you. You can ask all the questions you want before deciding if you want to be in this study.

Why are we doing this research?

The purpose of this study is to describe how parents manage the day-to-day care of their adult children with serious mental illness (SMI) specifically schizophrenia, schizoaffective disorder and bipolar disorder. This information may be helpful to health care providers and guide interventions in working more effectively with adult children with SMI.

How long will the research last?

We expect that you will be in this study for one in-person interview that will last 60–90 minutes. There is also the possibility that you will receive one telephone call after the interview to clarify some of the findings from this study. This interview will last no longer than 30 minutes.

How many people will be studied?

Up to 30 people will be in this study at UMass Memorial HealthCare

What happens if I say yes, I want to be in this research?

You will be asked to meet one on one with the researcher for an interview. The interview will take place at a time that is convenient for you and in a place that is comfortable and private; for example, at your home or in an office at UMassMemorial. If we meet at UMassMemorial campus, your parking fee will be paid for. The interview will be audio recorded. You will be

asked about your role in caring for your adult child with serious mental illness and how you manage your child's care on a day to day basis. You will also be asked for your opinion about what type of community based services could be most helpful to support you and your family. You will be asked for permission to contact you by telephone after the interview if the researcher needs to review or clarify some of the information that you provided in the interview.

What are the risks of being in this study?

There are no physical risks associated with this study. However, you may become uncomfortable when discussing the care of your adult child with serious mental illness. If you become upset discussing your experience as a caregiver for your adult child with SMI, the researcher will support you as she is a psychiatric nurse with 34 years of experience. If you remain upset and want to talk to a mental health provider at another time, you will be referred to an experienced psychiatric social worker who can meet with you for up to two fifty minutes sessions at no cost.

One of the risks of being in this study is that your personal information could be lost or exposed. This is very unlikely to happen, and we will do everything we can to make sure that your information is protected.

What are my responsibilities if I take part in this research?

N/A.

Will being in this study help me in any way?

There are no direct benefits to you.

Will being in this study cost me any money?

This study will not cost you any money.

What happens to information about me?

We will try to limit access to your personal information, including research study and medical records, to people who have a need to review this information. We cannot promise complete privacy. The UMMS Institutional Review Board (the committee that reviews, approves, and monitors research on human subjects) and other representatives of UMMS may need to review your records. As a result, they may see your name, but they are required not to reveal your identity to others. Your identity will remain confidential in any study results that are made public.

If we learn that you plan to hurt yourself or others, we will break confidentiality to help you.

If we learn of any child or elder abuse, we are required to break confidentiality and report this to state authorities.

What happens if I am injured because I took part in this research?

If you are injured while on study, seek treatment and contact the study doctor as soon as you are able.

The University of Massachusetts Medical School does not provide funds for the treatment of research-related injury. If you are injured as a result of your participation in this study, treatment will be provided. You or your insurance carrier will be expected to pay the costs of this treatment. No additional financial compensation for injury or lost wages is available.

You do not give up any of your legal rights by signing this form.

Will I be given any money or other compensation for being in this study?

After the interview is completed, you will receive a \$20 gift card for your participation in the study. If you have your interview at UMassMemorial, a parking voucher will be provided for you as well.

What are my other options?

You do not have to be in this study.

What happens if I say yes, but I change my mind later?

You are free to leave the study at any time. There are no penalties and you do not lose any benefits to which you are otherwise entitled. You can ask us to destroy any information that identifies you so that no one can tell the data belonged to you. Contact information: Kathryn Raymond at (774)757-8005.

Can I be removed from the research without my OK?

N/A.

Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt you, you can talk to Kathryn Raymond at (774) 757-8005.

This research has been reviewed and approved by an Institutional Review Board. You may talk to them at (508) 856-4261 or irb@umassmed.edu for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get information or provide input about this research.

APPENDIX B

PARTICIPANT DEMOGRAPHIC DATA SHEET

Participant Demographic Data:

Your Age	
Gender	Male Female
Ethnicity	Caucasian African American Hispanic Asian Other
Educational Level	Did not graduate high school High school graduate College Graduate Graduate/Professional Degree
Current Employment Status	Do not work Part-time employment Full-time employment
Annual Income	
Do you rent or own your home?	Rent Own Home
Age of your adult child with SMI	
Does your adult child with SMI live with you?	Yes No
How long has your adult child with SMI lived with you?	
Are you a member of the National Alliance for the Mentally Ill (NAMI)?	Yes No

APPENDIX C
INTERVIEW GUIDE

Specific Aim #1: To describe parents' perspectives of their unique and complex roles in managing the care of their child with SMI.

Conceptual Area	Main Question	Probes
Role as caregiver	Can you tell me about your experience when your child first became ill?	<ol style="list-style-type: none"> 1. How old was your child when he/she became ill? 2. What events occurred leading up to your child being diagnosed with a SMI? 3. What psychiatric illness was your child diagnosed with? 4. How did you obtain treatment for your child? 5. Do you have more than one child with SMI?

Specific Aim #2: To explore parents' views on the definition of the situation, management behaviors, and perceived consequences that make up family management styles.

Conceptual Area:	Main Question	Probes
Major Components of Family Management Style Framework:		
Definition of the Situation Dimensions: Adult Child's Identity; Illness View/Management Mindset; Family Mutuality	Can you describe your experiences in caring for your adult child with SMI?	<ol style="list-style-type: none"> 1. How do you view your adult child now compared with how he/she was prior to being diagnosed with SMI? 2. How do you manage the day-to-day care of your adult child? 3. Do you think you effectively manage your adult child's daily care and foster his/her stability and independence? 4. Do you share similar

		views with other family members regarding how to care for your adult child? How about with other healthcare providers?
Management Behaviors Dimensions: Caregiving Philosophy; Management Approach	Can you tell me about the adjustments you have made to provide daily care to your adult child at home?	<ol style="list-style-type: none"> 1. What are your goals and priorities that guide your caregiving approach to your adult child? 2. Have you developed a daily routine for caring for your adult child that helps to avoid behavioral problems and/or relapse of symptoms?
Perceived Consequences Dimensions: Family Focus; Family Expectations	<p>Can you talk about the outcomes or expectations that you see for your child?</p> <p>Can you describe how your expectations might affect the kind of management behaviors you choose?</p> <p>Can you talk about how you view your situation of caring for your adult child?</p> <p>Can you talk about any concerns and/or fears you may have regarding your child's future?</p>	<ol style="list-style-type: none"> 1. How do you balance between caring for your adult child and other areas of family life? 2. What do you think the effects of your adult child's SMI will have on you, your child, and family over time? 3. Have you thought about what your child will do when you are no longer able to care for him/her?

Specific Aim #3: To explore parents' perspectives of what types of community-based mental health interventions (including contextual) would support and/or enhance overall family functioning.

Conceptual Area	Main Question	Probes
Community-Based Mental Health Interventions including Contextual Influences: Social Network, Care Providers and System; Resources	<p>What community-based mental health services support you and your child at present?</p> <p>Can you describe the type of community-based mental health services you think would provide more support and improve your family functioning?</p>	1. Are you satisfied/dissatisfied with your current services?