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Diana E. Mark
Experiences of Caregivers for
Relatives with a Chronic and
Severe Mental Illness: Riding the
Roller Coaster
A Descriptive Study

ABSTRACT

This qualitative study explored the experiences of caregivers to a mentally ill family member, focusing on the needs and problems they face. The demands for families to act as caregivers to their psychiatrically ill relatives have increased; their involvement has reduced relapse rates. Understanding caretakers' perspectives in fulfilling this vital role was a goal of this study. Twelve one hour interviews were held with fourteen caregivers who were actively involved with NAMI, Rhode Island. The relatives they cared for had been diagnosed with schizophrenia, schizoaffective disorder and bipolar disorder. Open-ended questions enabled participants to provide descriptive accounts of their caregiving experiences. Questions included: the patient's diagnosis, current functioning and treatment; and their own caregiving responsibilities and its impact on them. Participants discussed their own self care, supports they were receiving, and recommendations for new caregivers. Findings emphasized caregivers' experiences in providing for: structure in patients' lives; assistance with activities of daily living; arranging/coordinating appointments and services. Caregivers noted insufficient community resources, both for patients and family members, including a lack of access to psychiatrists in community mental health centers. Caregivers experienced disruption and limitations in their daily lives, such as reduced personal freedom, and leisure time, missing work, and experiencing shame, guilt and worry. Caregivers struggled with their grief and loss, in terms of the "children" who had been, and their dashed hopes for their future.

**EXPERIENCES OF CAREGIVERS OF RELATIVES WITH CHRONIC SEVERE MENTAL ILLNESS:
RIDING THE ROLLER COASTER
A DESCRIPTIVE STUDY**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2013

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CHAPTER I

Introduction

The purpose of the present research study is to explore the care giving experience of people who serve as caretakers for mentally ill family members. The research will focus on understanding the responsibilities of caregivers, the impact this has on their lives, their use of community resources, and their suggestions about needed services. This qualitative study will be carried out with a semi-structured questionnaire, interviewing 12 individual caregivers. The subjects will be members of NAMI, Rhode Island, a community program serving the needs of the mentally ill and their families.

As the mental health care system began to move from institutionalization of psychiatric patients to outpatient community care for them, the demands for families to act as caregivers to their psychiatrically ill relatives have increased (Tan et al., 2012). These families have been providing support in many ways for their relatives, including emotional, physical and financial support. Families also take on many case management roles such as assessment of patient functioning, and identification of patient needs. They often serve as a link to the treatment team, in terms of encouraging and supporting, and monitoring patient compliance with medication and recommended activities. Caregivers also provide assistance to patients in their daily living, can

provide crisis intervention, and let the team know of early warning signs) of relapse. Many relatives also serve as advocates for patients needs and rights.(Intagliata, Willer, & Egri, 1986)

Caring for a relative with a serious mental illness often places heavy burdens upon the caregiver's shoulders; "the problems, difficulties, or adverse events that affect the lives of caregivers are the most powerful predictor of psychological distress in caregivers" (Tan et al., 2012, p. 2411). Being a caregiver can cause disruption and limitations to their daily lives in aspects such as personal freedom, reduced leisure time, missing work, challenges in interpersonal relationships with other (coworkers, friends, family) as well as induce feelings of shame, guilt and worry (Chang, Chiou, & Chen, 2010; Tan et al., 2012).

This research is important because of its focus on the needs and problems faced by caregivers, who are critical players in the treatment and rehabilitation of the mentally ill; their involvement has been shown to reduce relapse rates (Clark, 2009). Understanding their perspectives as well as their needs and problems, and resources available to them, in fulfilling this vital role can add to the knowledge of the mental health field in learning more about reducing caretaker stress. This can lead to increasing caretaker satisfactions and enhancing their valuable services to the mentally ill.

Chapter 2, the Literature Review, discusses the literature related to this research, including the impact of deinstitutionalization, a brief explanation of major mental illnesses (schizophrenia, schizoaffective disorder, bipolar disorder and major depressive disorder), caregiver responsibilities, and the impact of caregiving on the caregiver. Additionally, this chapter will discuss the National Alliance on Mental Illness and its programming for consumers and families, and ends with an overview of theories such as Bowen's Family Theory and General Systems Theory and Psychoeducation.

The third chapter presents the studies' methodology. This study was a qualitative exploratory study which utilized open ended questions to solicit the unique experience of caregivers for relatives with mental illness.

The fourth chapter presents the findings of this study, highlighting the major issues and points of concern. Many participants discussed the onset of psychiatric symptoms, their reactions to the diagnosis, their caregiving responsibilities, and the impact it has had on their personal lives. Additionally, participants discussed the need for more services, both for their relative and for themselves. Lastly, participants discussed the impact of NAMI's Family-to-Family course and gave advice for other caregivers, such as accessing support systems.

The Discussion chapter discusses the results, and implications of this study and makes recommendations for further study, and recommendations for clinical social work practice are noted. Additionally, the strengths and limitations of this study are explored.

The Literature Review is discussed next.

CHAPTER 2

Literature Review

This study explores the role of family caretakers in assisting mentally ill patients, and focuses on their perceptions of their role, the responsibilities they carry, and the impact of this experience on them. This chapter discusses the literature related to major mental illness and the importance of family serving in the role of caregiver to the mentally ill patient. In order to give a perspective to this subject, the following relevant topics are discussed in this chapter.

First, deinstitutionalization is addressed, as it has had a profound impact on the families of mentally ill patients. Then, the four major mental illnesses explored in this study, schizophrenia, schizoaffective disorder, bipolar, and major depression, are discussed with an emphasis on the symptoms experienced in each illness, the effects on patient functioning, and the impact on family members. Next is a description of the caregivers and their responsibilities in caring for a mentally ill relative. This is followed by a discussion of how the caregiving experience personally affects caregivers. As all the subjects were members of the National Alliance on Mental Illness, the programs this organization has implemented to support mentally ill patients and their families are described. The chapter concludes with a discussion of various theoretical perspectives relating to family caregivers.

The Deinstitutionalization Movement

In the years following World War II, the United States began to see the development of the deinstitutionalization movement. Prior to 1955, persons with severe and chronic mental illnesses, such as schizophrenia, were involuntarily committed to psychiatric hospitals and

institutions for long periods of time (Koyanagi & Bazelon, 2007). However, with the introduction of antipsychotic medications, such as chlorpromazine, commonly known as Thorazine, psychiatric patients could be discharged from inpatient settings and managed in outpatient care (Torrey, 1997).

There was also growing concern for the civil rights of mentally ill patients. As Dumont & Dumont, (2008) point out, public mental health hospitals were “large, overcrowded, understaffed, open to abuse and over housed in decaying structures” (p. 62). The deinstitutionalization movement pushed for psychiatric patients to be supported in the least restrictive manner (Torrey, 1997). This sentiment was further discussed in President Carter’s Commission on Mental Health in February of 1977; this reform was built with “the objective of maintaining the greatest degree of freedom, self-determination, autonomy, dignity, and integrity of body, mind, and spirit for the individual while he or she participates in treatment or receives services” (Torrey, 1997, Grob, 2012).

Furthermore, the creation of the National Alliance for the Mentally Ill in 1979 to lobby for better services also allowed the individuals with mental illnesses and their families the platform to “organize and more effectively speak for themselves. A new philosophy of recovery arose, defined not as total remission of symptoms or cure, but rather living a normal life despite having a serious mental illness” (Koyanagi & Bazelon, 2007, p. 9; Novella, 2010).

However, despite the good intentions behind the deinstitutionalization movement, there have been a variety of issues that continue to cause concern in the mental healthcare community. As the Kaiser Commission on Medicaid and the Uninsured reports, “Learning from History” (2007) points out, there are several mistakes that were made in the implementation of deinstitutionalization. Some of the largest mistakes include: First, in terms of living situations,

patients once institutionalized were moved to various facilities, such as nursing homes, or sent back to their families, adding an increased burden to both families and nursing homes. Secondly, the measurement of success for mental health was measured by length of inpatient stays, rather than by the quality of life experienced by the patient (Koyanagi & Bazelon, 2007).

The lack of housing opportunities for patients suffering from a severe mental illness is discussed extensively in the literature regarding the deinstitutionalization movement. Novella (2010) writes that “A series of studies conducted in different countries have found, for example, rates of 30-50% of homeless persons suffering from a serious mental illness having become homeless after discharge from the hospital” (p. 228). Similarly, Dumont & Dumont, (2008), report that:

From a high of over 500,000 (about 2 percent of the population) in the 1950s, the U.S. state mental hospital population dwindled to about 38,000 by the end of the 1990s. But many of the discharged patients were lost to follow-up, and high numbers of them could be found among the estimated 40 percent of homeless shelter and prison populations in the United States who suffer from a major mental illness. (Dumont & Dumont, 2008, p. 61)

Additionally, the literature highlights the increased burden faced by families who found themselves serving as caregivers for a mentally ill relative. It is reported that as many as two thirds of the population discharged from institutions returned to their families (Koyanagi & Bazelon, 2007). Those who did not return to live with their families, may still depend on them for various reasons and supports (Koyanagi & Bazelon, 2007; Novella, 2010).

In this study, the impact of deinstitutionalization on families was explored as they currently serve as the primary caregiver for a mentally ill patient.

Mental Illnesses

The majority of seriously ill psychiatric patients have been diagnosed with four major disorders: schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder. All of these disorders have a profound impact on the patient's psychological states, affecting their social and daily functioning. It is important to understand not only how these illnesses impact the patient, but also what family caregivers face as they assume responsibility for these patients. In this present study, caregivers are asked about their caregiving responsibilities and its impact on their lives. This presents the opportunity to compare their experiences with reports from the literature. The remainder of this section is a discussion of the characteristics of these four major diagnostic categories.

Schizophrenia: Schizophrenia is a severe and chronic mental illness affecting approximately 2.4 Americans over the age of 18 (NAMI, 2010). It is a brain disorder that causes individuals to struggle with their ability to think, manage emotions, make decisions, or maintain relationships (NAMI, 2010, NIMH, n.d.). A person with schizophrenia may experience hallucinations, delusions, issues with thought patterns, as well as flat affect, problems with memory, or poor decision making skills (NIMH, n.d).

Because schizophrenia is such a pervasive disorder affecting so much of everyday functioning, caregivers often face a multitude of problems such as coping with patient's hallucinations, delusional thinking, difficulty relating, flat affect, and low energy. According to McFarlane (1983), "most families attempt to support the patients by becoming intensely involved, attempting to make sense out of the nonsensical and avoiding setting limits on persons

they view as sick” (p. 105). Furthermore, Mcfarlane writes that in order to protect patients, family members have curtailed their own activities, both social and occupational. They have attempted to watch the patients to insure they did not kill themselves or hurt other people. To avoid hospitalization, families have tried to normalize the patients’ behaviors and attempted to coax them to behave according to societies rules. Sometimes, a patient has been maintained in the home only because the entire family has learned to ignore its own needs. (p. 105).

While presently there is no cure for schizophrenia, it can be managed with the use of antipsychotic medications. Additionally, patients suffering from schizophrenia may benefit from other interventions, such as learning coping skill and social skills as to maintain social relationships and even assistance with employment (NIMH, n.d).

Bipolar Disorder: Bipolar disorder is a psychiatric illness characterized by frequent oscillation between manic and depressive symptoms (NAMI, n.d.). These mood states may be intense and last anywhere from one day to months. Mania, according to NAMI, can be identified by “extreme irritability and/or euphoria, agitation, surges of energy, reduced need for sleep, talkativeness and pleasure seeking and risk taking behaviors” (p. 1). On the opposite end of the spectrum, during a depressed episode, a patient may become very sad, hopeless, and experience lack of energy. Some patients may experience psychotic symptoms as well, such as hallucinations or delusions (NAMI, n.d.). Suicide is a risk during depression and mania. Bipolar illness can cause impaired functioning in various realms such as self care, relationships, and/or academic/employment.

A major issue for those suffering from bipolar disorder is lack of insight. It is reported that approximately 50% of bipolar patients do not believe they are sick; “half of bipolar patients do not describe their manic symptoms, because they do not realize they are abnormal. These

patients will deny their symptoms. Additionally, when patients are depressed when they come in, they may have a hard time remembering their manic symptoms in the past” (Ghaemi, n.d.). Due to lack of insight, non compliance with medication is common for those diagnosed with bipolar disorder (Smith & Segal, 2012).

Living with a person suffering from bipolar disorder can be extremely stressful. During manic episodes, patients experience increased energy and impulsive behaviors. For example, a person might impulsively quit a job, charge up huge amounts on credit cards, engage in risky sexual behaviors, or feel rested after sleeping two hours. They may also experience hallucinations and delusions. (Smith & Segal, 2012; NAMI, n.d; Ghaemi, n.d). During a depressive episode, that same patient may experience extreme fatigue, hopelessness and sadness (Smith & Segal, 2012). These patients may be at high risk for suicide (Ghaemi, n.d.; Smith & Segal, 2012).

Family caregivers must deal with the behaviors and symptoms of a person struggling with bipolar disorder, both when the patient is manic and/or depressed. “During a manic episode, they must cope with reckless antics, outrageous demands, explosive outbursts, and irresponsible decisions. And once the whirlwind of mania has passed, it often falls on them to deal with the consequences. During episodes of depression, they may have to pick up the slack for a relative who doesn’t have the energy to meet responsibilities at home or work” (Smith & Segal, 2012).

Patients with bipolar can manage their symptoms with medication, therapy, education, and family, friends or more formal support systems (NAMI, n.d., p. 8).

Schizoaffective Disorder: Schizoaffective disorder is quite similar to schizophrenia. However the main difference is that patients diagnosed with schizoaffective disorder experience

severe mood symptoms, similar to that of bipolar disorder, in conjunction with the symptoms of schizophrenia. (Alliance, Illness, & Drive, n.d.).

Schizoaffective disorder impacts a patient's life in many ways. As with schizophrenia, a person with schizoaffective disorder may experience difficulty with thinking, managing emotions, making decisions, and even maintaining relationships. They may also experience hallucinations, delusions, issues with memory and thought pattern, as well as flat affect (NAMI, 2010, NIMH, n.d.).

Schizoaffective disorder differs from schizophrenia in that these patients may also experience manic and depressive states similar to that of bipolar disorder. During a manic episode, a person may need little sleep, feel energized and euphoric, and may engage in some risk taking and impulsive behaviors; during a depressive state, they may experience extreme depression, fatigue, hopelessness and even suicidal ideation (Smith & Segal, 2012). Families serving as caregivers to a relative suffering from schizoaffective disorder are faced with the complications of coping with symptoms of both schizophrenia and bipolar disorder.

These patients can be treated with antipsychotic drugs as well as mood stabilizers. However, NAMI also recognizes the importance of good sleep, hygiene, exercise, and diet (2010).

Major Depressive Disorder: Depression is a psychiatric illness wherein a patient experiences profound sadness, lack of motivation and energy, poor concentration, insomnia, fatigue, appetite changes, guilt, and thoughts of suicide (NAMI, n.d.). It affects approximately 25 million Americans each year and is more common in women (NAMI). People suffering with depression may find it difficult to even get out of bed; therefore, they may have trouble holding a

job, attending school, or maintain relationships. There are many treatments available for depression, ranging from medication, to therapy, to physical exercise.

For many individuals suffering from the above mentioned diagnoses, maintaining stable routines and relationships can be difficult. In this study, caregivers are asked how this illness most impacts their relatives lives and what are the biggest issues of daily living they face.

Caregivers and Their Responsibilities

In response to deinstitutionalization and the severe impact on daily living mental illness presents, including unemployment, many families have had to take on the responsibility of supporting their relatives. The word caregiver encompasses many different meanings and responsibilities for the people who take care of psychiatric patients. Some of the roles and responsibilities identified by Intagliata, Barry, & Ergi (1986) are: “assessment (provide historical and current information on client functioning and identify patient needs not apparent to the treatment team); linking (knowing the treatment plan in terms of medication or activities as well as providing encouragement and support to engage in the activities); monitoring (compliance and support patient responsibility); assistance in daily living (encouraging the patient to be as independent as possible; and, when necessary, setting limits and boundaries); crisis intervention (learn early warning signs); and advocacy” (p 702-703). Caregivers as identified by Intagliata et al., must then take responsibility for many facets of a patient’s life, not only in terms of daily living, but often financially as well.

This study explored whether the aforementioned tasks identified by Intagliata et al. were the same for the participants of this study.

Effects on Caregiver

Emotional: Acting as the primary caregiver for a relative suffering from a severe and chronic mental illness is taxing in many ways. Many caregivers struggle emotionally to cope with the stress of supporting a relative suffering from mental illness. One concept that has been frequently discussed in relation to schizophrenia is Expressed Emotion (EE). It is thought that if a patient returns home to where the EE is high, meaning “intrusive, emotionally intense exchanges, especially expressed in negative and hypercritical comments about the patient’s overtly disturbed behavior” (Goldenberg & Goldenberg, 2008), then it is likely that a patient’s symptoms might return, resulting in relapse. On the other hand, if a family has low EE, when “concerned about the disturbed behavior of their relative, they were not overly anxious in their response to the patient’s condition, allowing the individual more psychological space (Goldenberg & Goldenberg, 2008), the patient will do better.

While this idea appears to place blame on the caregiver if a patient relapses, subsequent studies have also found that “living with someone who is severely mentally ill increases the emotion level within the family” showing that the relationship may be “reversed or bidirectional” (Rosenfarb, Goldstein, Mintz, & Nuechterlein, 1995 as cited in Miliken, 2001, p. 159). Keeping in mind that living with someone with a mental illness raises the emotional level within a family, it is understandable that caregivers experience a range of emotions such as guilt, grief, exhaustion, depression, anxiety, and anger (Mcfarlane, 1983; Tan et al., 2012; Lynch & Lobo, 2012).

Guilt in caregivers stems from various causes. Outdated theories of mental illness contributed to the sense of guilt felt by caregivers, specifically mothers. As Miliken (2001) points out, the 1948 theory of Frieda Fromm-Reichmann placed the blame on

“schizophrenogenic mothers for being emotionally cold and distant, asserting that their children lack the affection necessary to develop social and psychological skills and, thus, were prone to developing schizophrenia” (p. 160; Simon et al. 1991). While this theory has been discredited, research has found that they continue to inform some professional’s treatment (Hatfield, 1987 as cited in Miliken, 2001). Furthermore, some caregiver’s guilt can stem from psychoeducation about mental illnesses. “When parents learn that early diagnosis and treatment are associated with a better outcome, they feel guilty for not recognizing the illness sooner” (Milliken, 2001). Other experiences that elicited guilt were thinking about, or moving a relative to a residential facility, becoming angry and frustrated with an ill relative, neglecting other family members, and becoming exhausted (Erlingsson, Magnusson, & Hanson, 2012; Milliken, 2001). This study explores whether caregivers experience guilt, and if it is similar to the feelings of caregivers described in the current literature.

Another emotion commonly experienced by caregivers is grief. Caregivers generally grieve various aspects of their own and their relative’s lives that are impacted by the diagnosis of a severe mental illness. Caregivers need to grieve the major changes in their mentally ill relatives (Erlingsson et al., 2012; Milliken, 2001; Tan et al., 2012). Furthermore, caregivers, and more specifically parents, must grieve the loss of their child as they knew them as well as the loss of the future they may have had (Miliken, 2001).

Caregivers can also suffer from compassion fatigue, which has been defined in different ways (Lynch & Lobo’s (2012). According to Lynch & Lobo, the most frequently used definition is from Charles Figley (1995):

“Compassion Fatigue is defined as a state of exhaustion and dysfunction—biologically, psychologically, and socially—as a result of prolonged exposure to compassion stress and all that it evokes. (p. 253). Compassion Fatigue, like any other kind of fatigue, reduces our capacity or our interest in bearing the suffering of others’ (p. 1434)” (Figley, 1995 as cited in Lynch & Lobo, 2012. p. 2127).

In the past, this concept has been applied to professionals in the health care industry such as nurses, doctors, social workers, psychologist and other mental health workers. Lynch & Lobo (2012) state that since families assume much of the responsibility of care giving, they may also experience high levels of stress. “In families, a limited number of individuals have the responsibility of providing 24-hour care. This intense experience may exceed that of the professionals and lead family caregivers to experience compassion fatigue” (p. 2126).

Caregivers may experience their own mental health issues. Rates of depression amongst caregivers are quite high, estimated between 38% and 60% (Berg-Weger, 2000, p. 162); caregiver depression may be correlated with a caregiver’s sense of competency. “As the caregiver’s perception of his/her competence improves, so does the caregiver’s ability to perform tasks to meet his/her basic needs” (p.170).

Adding to the emotional issues faced by caregivers is the impact caregiving has on one’s social outlets. Many studies have indicated that caregivers may become increasingly isolated (Mcfarlane, 1983; Erlingsson, 2012; Tan, 2012). The stigma and stress of mental illness can make it difficult for families to maintain relationships (Chang et al. 2012; Miliken, 2001). Additionally, their personal lives may be restricted due to their responsibilities. Some areas of restriction or disruption explored in Tan et al. (2010) are: “neglecting friends or other family members, friction within the family, reduced leisure time, and missed days at work or school” (p.

2412). The impact of a relative's mental illness on a caregiver's social life is explored in this study.

Physical Health: In addition to emotional struggles, caregivers may also suffer physically. There has been more research about the psychiatric and emotional effects of caregiving and less research about the physical problems experienced by caregivers. Furthermore, the majority of studies conducted about the physical effects of caregiving speak to the challenges presented for caregivers of patients with chronic illnesses, such as cancer and Alzheimer's rather than the challenges of mental health. Chang et al. (2010) cited various studies that found that "caregivers often experience several physical problems, including back injuries, arthritis, high blood pressure, gastric ulcers and headaches (Sawatzky and Fowler-Kerry, 2003 as cited in Chang et al. 2010, p. 268). Other literature suggests caregivers may experience sleep deprivation, frequent diarrhea, and weight changes (Lynch & Lobo, 2012; Mak & Cheung, 2011; Tan et al, 2012). When physical distress was discussed by subjects in this study, which they felt was related to their caregiving, this was noted.

Financial: There are also financial challenges that caregivers must cope with as well. As previously mentioned, with all the day to day responsibilities caregivers face, they may have trouble keeping a job (Miliken, 2000; Tan et al., 2012). As Miliken (2000) found in her qualitative interviews with Canadian caregivers, supporting someone with a mental illness can be very expensive. In Canada, basic health insurance is covered; however, there are certain aspects of a patient's treatment that may not be covered, such as mediations or psychotherapy (p. 156). It was anticipated that participants in this study, who live in the United States, may have even more expenses than their Canadian counterparts.

Some of the financial strains acknowledged by caregivers in Miliken's (2000) study were extra expenses due to damaged furniture and clothing, smoking and drugs, cleaning apartments, deposits on new apartments, clothing, food, insurance, telephone charges, and periodic handouts (p. 157).

National Alliance for the Mentally Ill (NAMI)

The National Alliance for the Mentally Ill, according to their website, is "the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI advocates for access to services, treatment, supports and research and is steadfast in its commitment to raise awareness and build a community for hope for all of those in need" (NAMI, n.d.).

While NAMI.org (the national website) does not credit a founder, NAMI Wisconsin does. According to their affiliate website, Harriet Shetler and Beverly Young, two mothers with schizophrenic sons, had lunch together. Tired of feeling blamed for their children's illness, they created a group for families with similar concerns. "In April 1977, 13 people met, and Mrs. Shetler suggested the name, Alliance for the Mentally Ill, partly because its acronym, AMI, meant "friend" in French. Within six months, 75 people had joined" (NAMI Wisconsin, n.d.). Eventually, "AMI" heard about a similar group in California and held a national conference in September, 1979, resulting in the creation of the National Alliance on Mental illness (NAMI Wisconsin, n.d.).

NAMI's mission includes, support, education, awareness, advocacy and research (NAMI, n.d.). NAMI chapters across the county have support groups for both individuals diagnosed with mental illness and their families. Their 'peer to peer' course is "an experiential learning program for people with any serious mental illness who are interested in establishing and maintaining

their wellness and recovery” (NAMI RI, n.d.). The ‘family to family’ course, discussed in detail in the following section, is a psychoeducational program for families and close friends of those suffering from a mental illness (NAMI, n.d.). NAMI also offers weekly and monthly support groups for both members suffering from a mental illness and their families.

Education about mental illness and recovery is also a major component of NAMI’s mission. NAMI has created nine educational programs, which include courses for mental health providers and teachers. These courses contain information about many issues, including mental illness, recovery, support, and medication. NAMI also has a toll free helpline available for people across the country, both patients and families, to call for information (NAMI, n.d.).

NAMI seeks to raise awareness through local walks, Mental Health Awareness Week, responding to current events, and other programs and efforts to raise awareness in our communities (NAMI, n.d.).

NAMI also supports research in the mental health field. According to the NAMI national website: Research is vital to advancing our understanding of mental illness and, eventually, finding a cure. Research is the ultimate source of hope for people living with mental illness and their families. And research is imperative if we are to understand early intervention strategies as well as all we can about the mental illness continuum including medication side-effects, nutrition, recovery and more (NAMI, n.d.).

While NAMI membership is open to the general public, it may not mirror the general population, and it also may not represent the full population of people with serious mental illness. According to Hatfield et al. “the NAMI membership is known to differ from the general

population; the membership has a higher educational level, higher-than-average income, and a lower proportion of racial and ethnic minorities” (1996, p. 826).

As all the participants in this study are NAMI members, which of NAMI’s programs they utilize and what they have found to be most helpful was explored. Additionally, the demographic make-up of participants and how this reflects the population of NAMI members as well as the general public was considered.

Family –to-Family Course

Family-to-Family is a led by NAMI members who “have completed a three day, 26 hour intensive teaching training workshop” (Family-to-Family Education Program, n.d.). While providing psycho education about various mental illnesses, treatment and medication,-this program also promotes emotional understanding and healing, as well as encouraging members to take action and to become empowered (Family-to-Family, n.d.).

Family- to-Family seeks to provide a safe environment for family members and friends to discuss their experiences with mental illness, where they "can debrief the traumatic events and feelings they have” (Family-to-Family, n.d.). One goal is to normalize the experience of mental illness and recovery.–Additionally, the course-helps families identify coping skills, self care, empathy and understanding (Family-to-Family, n.d.).

This course “encourages family members to recognize and express their anger at discrimination and stigma” against the mentally ill (Family-to-Family, n.d.), and to acquire biomedical knowledge about mental illness. Families are encouraged to become involved with activism both on a local and national level (Family-to-Family, n.d.).

This course has had a major impact; approximately 200,000 family members have graduated from the course and it is currently taught in 49 states (some states also offer the course in Spanish), and in Canada, Puerto Rico, Mexico and Italy (Family-to-Family, n.d).

In this present study, some participants who were graduates of Family to Family, were asked about the impact that this course has had on their ability to understand and cope with serious mental illness.

Theory

There are many theories regarding families and mental illness. Over the years, theories regarding family systems have evolved. Once blaming and stigmatizing families, especially mothers, (so-called "schizophrenogenic mothers", discussed earlier), the field has moved to a more accepting and strengths based perspective. Below is a brief discussion of family systems theory, psychoeducational approach and the strengths based approach.

Bowen's Family Systems Theory: Murray Bowen, the pioneer of Family systems theory focused his interest on family relationships, particularly families in which a member was suffering from schizophrenia (Goldenberg & Goldenberg, 2008. Through his research, Bowen developed "Family Systems Theory." Bowen "believed the driving force underlying all human behavior came from the submerged ebb and flow of family life, the simultaneous push and pull between family members for both distance and togetherness (Goldenberg & Goldenberg, 2008, p.175).

According to Kaplan et al. (1994), "it's hallmark is personal differentiation from the family of origin, the ability to be one's true self in the face of the familial or other pressures that threaten the loss of love or social position" (p. 846). The goal, in terms of families, is for members to function as individuals, think and feel independently and also maintain relationships

with other members (Goldenberg & Goldenberg, 2008). This goal, as we shall see shortly, is also relevant in the Psychoeducational approach.

Although this theory discusses multilevels of assessing family organization, Bowlby emphasizes two main issues: "(1) the degree of their enmeshment versus the degree of their ability to differentiate, and (2) an analysis of emotional triangles in the presenting problem" (Kaplan et al. 1994, p.846). Triangulation refers to the way couples, especially when stressed, "one or both partners will involve a third person" (Goldberg & Goldenberg, 2008, p. 184).

Family systems theory takes into consideration the various aspects of a family communication and relationships to understand their dynamics. The goal of family systems therapy is "changing the relational system including helping family members manage their anxiety, helping them detriangulate from three person systems, and more important, aiding each family member to increase his or her basic differentiation of self" (Goldenberg & Goldenberg, 2008, p. 190). However, this theory does still hold an aspect of blame on parents for children suffering from mental illness. According to Simon et al (1991):

Bowen and the family systems theorist (1961) hypothesized that schizophrenia is a manifestation of a process that involved the entire family and that the client is merely the person who displays the family psychosis. Bowen agreed that the child who developed schizophrenia was intimately involved in stabilizing his or her parent's marriage (Fallon, Boyd, & McGill, 1984 as cited in Simon et al, 1991. p. 324).

Thus, while this theory does take into consideration the communication and behavioral patterns within a family, it does, in fact, still place large amounts of blame on patients' relatives. This raises a controversial point: If there are unconscious mental processes, and high levels of

anxiety in a parent, and the child reacts to this, does this mean we are “blaming” the parent if we focus on helping them reduce their anxiety?

The emphasis on the psychoeducational approach with its focus on interaction, education and behavioral methods, does not incorporate a psychodynamic viewpoint. It would be of interest to explore the subjective, experiences of relatives, including their own baseline levels of comfort and security. However, this is not within the scope of this research, and therefore will not be broached with these families.

General Systems Theory: General systems theory states that the family is a system and that every action will subsequently produce a reaction (Kaplan et al. 1994, p. 846). Each member “plays a role (ex: spokesperson, persecutory, victim), which is relatively stable. However, the member who fills each role may change” (Kaplan et al. 1994, p. 847). Kaplan et al. (1994) add that some families “try to scapegoat one member by blaming him or her for the family’s problems (the identified patient) (p. 845).

Mara Selvini- Palazzoli, a child psychoanalyst, worked with a team in the 1960’s to treat the families of “severely disturbed children” (Goldenberg & Goldenberg, 2008, p. 289), later forming the Milan Center for the Study of the family, and creating the “Milan approach” (p. 289). They “conceptualized the family as ‘a self-regulating system which controls itself according to the rules formed over a period of time through a process of trial and error’” (Selvini-Palazzoli et al. 1978, p. 3 as cited in Goldenberg & Goldenberg, 2008, p. 290). Selvini-Palazzoli felt that;

The schizophrenic family, trapped by rules of the game, is powerless to effect change. That is, the rules of the game, rather than any individual input, define and sustain its member’s relationships. What remained paradoxical was that all family members,

presumably seeking therapy in order to change, nevertheless continued to behave in ways that prevented any change from taking place. Thus, the goal of the therapist is to use “therapeutic counterparadoxes- to warn the family against premature change, allow members to feel more acceptable and unblamed for how they are, and then attempt to discover and counter the families paradoxical patterns, thus interrupting repetitive, unproductive games” (Goldenberg & Goldenberg, 2008, p. 291).

The families behavior patterns were given a positive connotation—positive motives were ascribed to all family transactions, which were reframed to appear to be carried out in the frame of family cohesion. At the same time, each family members behavior was connoted as related to the identified patients symptoms, thereby tactically getting their acknowledgement of overall implication in ‘the family game’ (Goldenberg & Goldenberg, 2008, p. 291).

Like Bowen, general systems theory asserts that all of the family member’s actions influence the symptoms of the identified patient. However, it continues to place blame on family members for the psychiatric symptoms in their relatives.

Psychoeducational Approach: The psychoeducational approach was conceived in response to newer research that shed light on the biological factors that cause mental illness; “In response to these developments and other research concerning schizophrenia and the family, the psychoeducational approach to family treatment emerged”(Simon, McNeil, Franklin, & Cooperman, 1991, p. 326). However, while families may not cause mental illness, research also found that patients returning home to environments with high EE (i.e. Expressed Emotion), were found to have higher relapse rates (Simon et al., 1991; McFarlane, 1983). Thus, providing psychoeducation to families was created as an attempt to lower relapse rates.

This approach is particularly useful to families following the deinstitutionalization movement, as now families “need much more concrete assistance from mental health professionals” (Simon et al., 1991, p. 327). Psychoeducation seeks to reduce relapse rates by increasing “the stability and predictability of the family environment by increasing families' self confidence and knowledge about the illness and thus decreasing family anxiety about the patients and increasing their ability to react helpfully to them” (McFarlane, 1983. p. 102).

McFarlane (1983) explains that this approach takes place in four phases. Phase one is “connecting with the family”; that is establishing an alliance with the family. Phase two is “survival skills workshop,” where families are educated about their relative’s mental illness, illness management, and encouraged to feel less stigmatized. Phase three is the “reentry and application of survival skills”—families are supported as they learn to implement their newly learned coping skills. Finally, phase four involves continued treatment (p. 102-109).

Goldenberg & Goldenberg (2008) report that research (Anderson, Reiss, & Hogarty, 1986) has confirmed that using a psychoeducational approach alongside family therapy “is much more effective in staving off a psychotic relapse in the year following hospital discharge (0% relapse), than family therapy alone (19% relapse), individual behavior therapy (20% relapse), or treatment involving chemotherapy and social support” (p.384).

Another major difference from family systems therapy is the focus in a psychoeducational approach on the impact of a mentally ill patient on the family. Historically, families dysfunctional patterns have been seen as the cause of a patients psychosis (Saleebey, 1996; Simon et al., 1991). However, the focus of this perspective is rather “the schizophrenics impact on family functioning, not the other way around” (Goldenberg & Goldenberg, 2008. p. 384). While it is important to focus on "the schizophrenics’ impact on family functioning", it is

not inconceivable that the family's own problems and anxieties can also be affecting the person. However, this will not be addressed.

In my study, all participants are members of NAMI, an organization that utilizes the psychoeducational approach, how this approach has or has not helped them cope with their relative's illness will be explored.

Strengths Based Approach: Another recent approach to individual and family therapy is the strengths based approach. Historically, various theories have focused on the pathology of individuals and families, rather than the unique strengths and talents of each (Early & GlenMaye, 2000; Saleebey, 1996; Turcotte, Pouliot, & Saint-Jaques, 2009).

“In part the impetus for the evolution of a more strengths-based view of social work practice comes from the awareness that U.S. culture and helping professions are saturated with psychosocial approaches based on individual, family, and community pathology, deficits, problems, abnormality, victimization and disorder” (Saleebey, 1996, p. 296)

The strengths based approach looks at multiple facets of a family's life including member characteristics, environmental factors and other influences (Turcotte et al., 2009) and stresses the point that “people who seek help with problems are more than the problem” (Saleebey, 1996; Turcotte et al., 2009). Families are comprised of members with unique talents and strengths. Families have their own traditions, rituals, and resources (such as extended family and community) (Early & GlenMaye, 2000). The underlying assumption is that families have the “capacity to grow, change, and adapt” (Early & GlenMaye, 2000).

The application of strengths based approach with families is helpful for families where one member suffers from a chronic and severe mental illness. According to Hartman (1981), families “are the primary social service agency in meeting the social educational and health care

needs of its members” (cited in Early & GlenMaye, 2000, p. 10). As the primary “social service agency,” it is important to empower families especially in time of crisis.

The strengths based approach emphasizes that families are the experts of their situation; “people have knowledge that is important in defining their situations—the problematic aspects as well as potential and actual solutions” (Early & GlenMaye, 2000, p. 119; Saleebey, 1996). The clients know that is best for them. Practitioners have theoretical and technical knowledge that can help others act rather than hinder them” (Turcotte et al., 2009, p. 455).

Saleebey (1996) writes, “certain words are key to the strengths perspective” (p. 298). They include: “empowerment, resilience, and membership,” which are major aspects of this approach (Saleebey, 1996). The goal is to empower families to identify their tools and resources, recognize their resilience (skills, abilities, knowledge and insight that helps families rise to challenge), and help families recognize they are responsible and valued members in their group.

While this perspective removes the historic blame on parents and families for causing mental illness, it is not without criticism, such as the strengths perspective ignores the difficult and painful aspects of reality and does not look at the severity and complexity of a family's issues (Saleebey, 1996). Saleebey argues that in fact, the strength perspective explores how a family has been able to survive its crisis, and builds on these traits for strength. Thus, it acknowledges a major issue but focuses on how a family has survived despite its issues (Saleebey, 1996, p. 303).

Summary

This literature review encompassed an overview of the deinstitutionalization movement, which led to the serious crisis of inadequacy of care for the mentally ill; this also produced homelessness as well the movement for their relatives to care caring for them, primarily their

own homes. The history and mission of NAMI, a supportive and advocacy group for patients and their families was reviewed, and finally relevant theories and approaches to family theory/therapy involving mentally ill patients was presented.

Caretakers, in this study were involved with patients diagnosed with the following four severe mental illnesses: Schizophrenia; Bi-polar Disorder; Depression; and Schizoaffective Disorder. This chapter discussed these illnesses, with an emphasis on how they impact patients' social functioning, and what burdens, in turn, this placed on their caregivers.

Literature was also reviewed about the responsibilities and emotional, physical and financial responsibilities of caregivers. This qualitative study is designed to understand how caregiving is experienced by relatives of seriously mentally ill patients, and to better understand how they cope with stresses inherent in this role. Participants were also asked for suggestions they have for further assistance for themselves and their relatives.

The following chapter discusses the methodology used in exploring these issues.

CHAPTER 3

Methodology

This study explores the care giving experience of people who serve as caretakers for mentally ill family members. A qualitative, exploratory method was conducted using flexible methods through interviews with family members who serve as caregivers for a relative suffering from a chronic and severe mental illness. Semi-structured, open ended questions were used to encourage responses that described the unique experiences, challenges of concerns of each caregiver.

Sample

Twelve interviews were conducted with fourteen family members. While interviews were scheduled with twelve participants, two participants were accompanied by a family member, who was included in the interview. There were 13 females, and one male participant, who ranged in age from 26 to 78. Many of the subjects were mothers of the patients (7), 1 was a father, 1 a wife, and 1 a fiancé; there were also 3 were sisters and one aunt.

All participants were members of the National Alliance on Mental Illness, Rhode Island Chapter (NAMI-RI). NAMI encourages its members to discuss their experiences with each other as a way to gain support, reduce guilt, shame and stigma (NAMI, n.d.). Qualitative methods were chosen for this study because it complements the open nature of NAMI. Members, in most cases, are used to discussing their experiences with others so it is presumably within their comfort zone to participate in semi-structured interviews. All interviews took place at the NAMI-RI

Providence office for two reasons. First, it is a safe place for both the participants of the study and myself. Secondly, this setting is familiar to NAMI members, which may have helped participants feel more comfortable and open. Semi-structured, open ended interview questions were used to elicit responses that discuss the unique complexity of the caregiving experience.

Fourteen members of NAMI-RI were interviewed. This sample is a nonprobability sample with a reliance on available subjects (Rubin & Babbie, 2013, pg. 171). This is naturally occurring group of individuals who are seeking out support groups as they care and interact with a mentally ill family member. However, it is not without its limitations. It is important to note that many family caretakers may not be NAMI members; therefore this study will not discuss the experiences of caretakers who are not NAMI members. Additionally, the NAMI population differs from the general population in a number of ways. According to Hatfield et al. “the NAMI membership is known to differ from the general population [of family caretakers who are not members]; the membership has a higher educational level, higher-than-average income, and a lower proportion of racial and ethnic minorities” (1996, p. 826). According to Rubin and Babbie (2013), “even if bias is evident (as it is in this proposed sample), some convenience samples can produce useful tentative findings, especially when care is taken not to over generalize their findings” (p. 171).

Data Collection

Chaz Gross, Executive Director of NAMI-RI, and Jennifer McCarthy, Assistant Director of NAMI-RI, were instrumental in facilitating this study. They assisted me in recruitment by sending out my recruitment letter to NAMI members via email, newsletters and flyers. Additionally, they helped to coordinate interviews and allowed me to conduct each interview in their offices. All participants allowed me to audio record our interview.

As stated, open ended interview questions were used to explore the unique experiences of each caregiver. The questions explored various aspects of caregiving. The first part of the interview explored the psychiatric care of each participant's family member. For example, participants were asked "When and how did you learn of your relatives diagnosis?" and "Have providers communicated with you about treatment?"

The second part of the interview explored how participants defined "caregiver," what their responsibilities are, and if participants have any sources of support. Participants were asked to describe their caregiving responsibilities and how this has impacted their life.

The third part of the interview explored available and needed resources in the community. Furthermore, this part of the interview explored how families had been introduced to NAMI and the impact it has had on their lives.

Lastly, participants were asked to discuss any satisfying aspects of caregiving as well as any coping skills, approaches, and procedures that have proven helpful.

Risks of Participation

The risks to participants were minimal, considering they had already sought support, and discussed their situation with NAMI-RI. However, participants were told that it was possible that they could experience strong emotional reactions when discussing their care giving experience. If they did, this could be discussed in the interview, and resources for further help would be suggested.

Benefits of Participation

Participants were told that the opportunity to share their experiences as caregivers may be beneficial to them and other caregivers within the community. Additionally, participation in this study may allow them to gain a new perspective on the personal impact their relative's mental

illness has on them. In a broader sense, participants may benefit caregivers as a whole by giving voice to their experiences, which may affect future services.

Informed Consent Procedures

This study was undertaken with the approval of the Human Subjects Review Board of Smith College (APPENDIX C). Once an interview was scheduled with a potential participant, they received a copy of the informed consent document to review. At the interview, I explained the informed consent document, reiterating that participation is voluntary and they may choose not to answer any questions and could end the interview at any time. Participants were told they could withdraw from the study before April 1, 2013, and if they did, their data would not be included in the study and would be destroyed. Participants were asked if they had any questions and then signed the form in my presence. Two copies were signed, one for my records and one for theirs.

Precautions to Safeguard Confidentiality and Identifiable Information

Each participant was assigned a number and their names and other identifying information was removed from each transcript. Participants signed informed consent forms which were placed in a locked drawer and kept separate from any data collected during the interview. After collecting demographic information (which was also kept separate from interview materials), the interview began and lasted between 45 -60 minutes. All interviews were audio recorded.

All interviews were transcribed by the researcher and all identifying information about participants, their relative, and any other individuals mentioned were disguised or removed. The audio recordings of each interview were kept separately from any forms containing identifiable

information. Transcriptions were kept in a password protected file on the researcher's computer and were backed up onto a flash drive that was kept in a secure location when not in use.

I informed participants that in accordance with Federal Guidelines, their data would be stored securely for 3 years. After this time, the data will be destroyed. If the data is still needed for research purposes, it will continue to be stored securely until it is no longer needed. Data was not collected until the HSR approval letter was received.

Data Analysis

Participant interviews were recorded by a digital voice recorder and interviews were transcribed into work documents by the researcher. After all interviews were transcribed, the data was coded by content. This was done by organizing responses to each interview question in word documents, noting similarities, differences, and other important content areas in participant's responses.

The analysis of this data exposed general themes as a result of serving as the caregiver for a relative with a serious mental illness. Due to a small sample size and limited cultural diversity among participants, the results of this study are not generalizable. However, the findings of this study can provide some insight into the challenges and experiences of caregivers. The findings of this study will be discussed in the following chapter.

Chapter 4

Findings

Introduction

This chapter contains the findings from twelve interviews conducted with 14 participants who serve as caregivers to relatives with a serious and chronic mental illness. This exploratory study asked participants to discuss their experiences as caregivers, as well as focusing on the impact that this experience has had on their own lives. The interview questions were structured to learn about their relatives' diagnosis and treatment, their involvement in this treatment, their actual caregiving responsibilities and the impact this had on them. They were also asked their opinion about mental health services in the community and their recommendations to other caretakers.

Demographic Information

The subjects in this study were caregivers for relatives with four severe mental illnesses: schizophrenia, schizoaffective disorder, bipolar disorder and major depressive disorder. Two of the 12 subjects, were accompanied by a family member, who were included in the interview, (at the request of both), which increased the number of subjects to 14. Although the companions spoke little, they sometimes made significant contributions, which are noted. There were 13 females, and one male participant, who ranged in age from 26 to 78 with an average age of 54. Twelve participants identified as Caucasian, 1 as African American and 1 as Cape Verdean.

Seven subjects were mothers of the patients, 1 was a father, 1 a wife, and 1 a fiancé; there were also 3 were sisters and one aunt. Eight participants live with the patient, 5 do not, and one

lives with the patient “off and on.” Of the 8 subjects who live with their relative, 7 stated other family members also lived in their home including their husbands and other children. Of the 14 participants, 4 are retired, 4 are in the health/mental health field, one is a legal professional, 2 are laborers, 1 is a volunteer, 2 are in a spiritual field, one is in commerce, and 1 is a writer.

Demographics of the Patients.

The patients' ages ranged from 18 to 64 with an average age of 31.14; 8 are male and 4 are female; 12 were identified as white, 1 as African American and 1 as Cape Verdean. The highest levels of education completed by the patients were: 4 college graduates: (1 “attempted a master’s program”); currently in college or completed some college work: 4; completed high school:3; received GED: 1. Currently 7 patients are unemployed, 3 are students, 1 is a temp, and 1 works in sales.

Diagnosis

The most frequent current diagnosis of the patients, given by their relatives was: schizophrenia (5); schizoaffective disorder, (3), and 2 were diagnosed with bipolar 1; none were diagnosed with major depressive disorder. Two had no determined diagnosis at the present time. Although 2 of the caretakers talked of the diagnosis changing over time, only the current diagnosis was recorded. Of the two subjects who were uncertain about diagnosis, one reported the patient was being currently evaluated (diagnosis in record is schizophrenia). The second commented: "No one has really talked to us but its schizophrenia. She’s Paranoid and all that."

The onset of mental illness for most of the patients was in adolescence or early adulthood; two women started having symptoms as teenagers: one in the 8th grade and the other in the 10th grade. The average age for the onset of schizophrenia was 21.5, for schizoaffective disorder -17.5 and for bipolar disorder- 22.5.

For patients with schizophrenia and schizoaffective disorder, there is a lag time between patient's the age of what appeared to be the first psychotic break and the observation of "strange behaviors," and the actual psychiatric diagnosis. This length of time varies from 1.5 to 4 years. One subject noted: "She had her first breakdown in her 20s; in the 10th grade she was home schooled for weird behavior."

Participants were asked how and when they learned of their relative's diagnosis. Generally, the subjects observed the patient's decline, such a sleep problems and disturbed thoughts and behavior, which escalated. "And it just got out of control". One woman commented:

I didn't have a clue for a very long time except that he walked to the beat of a different drummer sort of. At the end of high school, he couldn't decide on a college, he had become somewhat withdrawn although he did have friends.

In two instances, the patient had disappeared for long periods of time. One woman stated:

He was gone for 5 years and I didn't know where he was. One day he just knocked on my door and said I have schizophrenia." In the second example, the mother stated that "One day, he didn't come home. I didn't know what really happened.

Interestingly, three participants were on vacation without their relative when they were alerted to the patient's strange behaviors and hospitalizations. "My husband and I were out of the country, and she went into psychosis. Her older sister called us immediately and said something is wrong." Two participants noted significant deaths within the family prior to their relatives' psychotic break.

Five participants noted the need for police involvement in securing hospitalization during their relative's psychotic break.

Hospitalizations

There were generally a high number of hospitalizations for the patients; relatives couldn't always be precise. 4 patients had between one and 3 hospitalizations; 3 patients had between 4 and 5; and four had between 6 and 11. One relative commented: "I don't know I lost count. She has been to many hospitals". Patients with a diagnosis of schizophrenia had an average of about 3 hospitalizations, 1.5 for schizoaffective disorder, and 11 for bipolar disorder.

Current Treatment and Functioning

Nine patients are receiving treatment from various community mental health centers throughout the state. Of these, four participants commented on difficulties they were having with the psychiatrist at the community mental health centers. One stated:

The thing is with the doctor; they keep canceling the appointments so if it's supposed to be like 6 weeks or 2 months (between appointments) it's usually its closer to 3 months before we see the doctor.

Similarly, another stated; "It's difficult to see the psychiatrist because he is overworked. She [the patient] sees him one time every few months."

Three participants reported that their relatives see a case manager or nurse weekly at the community mental health center.

Four participants reported using private pay providers, mainly psychiatrists. One caregiver's son is currently refusing all psychiatric treatment.

Patient's Current Functioning

Six caregivers stated their relative was doing good/great. One reported; “Now he is back on meds with the support of a private pay recovery organization, he is doing great.” Another stated; “He hasn’t been hospitalized in well over 10 years- maybe 15. He has done very well with the services at the community mental health center. They helped him and the family.”

Three participants were more reserved about their relative’s progress stating the patient is “doing okay.” One stated, “He manages ok, but when he comes home, it’s the talking to himself in the middle of the night. He wakes me up. He’s outside having an argument with the voices.”

Two participants reported relatives not doing well. One stated: “The past couple weeks have been tough. He kind of has these weeks where he is really good then just boom, total psychotic state. He goes in and out kind of.”

One subject has had very little contact with her sister for years, does not know how she is currently doing:

I think she isn’t in good physical condition because she smoked all her life. I know she isn’t consistent with her meds. When she would stop she would be living on the street.

I’m assuming at this point in time her physical health isn’t good. I’d like to be somewhat prepared if she is dying but I’m not allowed to know that. I don’t know if they

(community mental health center) would even tell me she dies.

Involvement in Relative’s Treatment

Nine participants were involved in their relative’s treatment; however two, although not actively involved, commented that the patient's treatment team was responsive if they reached out and contacted the team. One caregiver stated:

I will call his nurse, if I see something [concerning] I’ll say, be aware of this. She is responsive, she is much more responsive than the last one he had.

Another participant also talked about her needing to reach out to the staff.

Yes but only if I contact them they are responsive, her case manager has been good about that. They know that I am her family and “the caretaker” in her family. There isn’t anyone else.

Other types of involvement in their relatives care, included going to the patient’s appointments. One stated: “Yes, I feel like I am his case manager. I try to make it to all of his appointments; I coordinate, set up everything, do the research, and make the calls.”

Three participants are not currently involved in their relative’s treatment for various reasons, such as their relative not receiving treatment or refusing to sign a release of information.

One woman said, “Right now, I do not have a release to speak with his psychiatrist. It’s a bone of contention right now. I am involved in that I ask about his meds and sometimes count his pills. By since that’s the only treatment he is getting, I would say no. In the hospital though, I am extremely involved.” This participant noted that her husband had signed a release while in the hospital. However, he will not sign a release for his current psychiatrist because she had filed a restraining order against him as a way to encourage him to get help.

Communication with Providers

Participants were asked if providers had communicated with them about treatment, and when applicable, discharge plans. Five participants reported that providers did communicate with them, but only if they contact the providers. One stated: “No, I have to ask.” Another caregiver responded, “Not voluntarily... But if I call, there is no problem.”

Three participants stated that hospitals did communicate with them regarding discharge plans; one observed:

Well, yes and no. The discharge plan from the hospital was to return to community with support. I did not find I had a lot of support after the hospital like I thought. The new doctor and therapist do help me feel more in control in the conversation about what is happening with her.

Additionally, two participants discussed the necessary releases that are required to allow any providers to speak with family members. Participant stated, “He has to sign that release every year. I don’t know if he did this year. They can’t tell me anything without that. But if I call, there is no problem.” Another noted, “He has been pretty good about signing all the releases and everything else. That’s really hard once they are over 18 because they don’t have to involve you

Six participants responded that they do know the signs of potential relapse, two of whom were educated by the community mental health center-

A number of participants do know the signs of relapse, but this was not communicated to them by providers. One participant explained; “I don’t think I got a lot of information from them. I did a lot of research online and from NAMI. But I don’t remember doctors, especially in the beginning, explaining it.” Another participant stated, “They haven’t told me anything. I know his mom, who did most of this before me, has never received any thing. We are just now taking the family to family course together but before she had no resources or anyone to go to.”

Only one participant stated that she did not know the signs of relapse.

Length of Time as Caregiver

Participants have been caregiving for a wide range of time, anywhere from 9 months to 40 years. Four participants were caregivers for seven years.

Nine participants stated they are the primary caregiver for their relative, while two specified that they are the only caregiver. One mother stated; “Only. His father isn’t in his life anymore. He will call and see how he is doing, but he won’t talk to him.” Other participants who were the primary caregivers cited family and friends as helping as well. One woman stated; “I would say primary, but his mom helps a lot.”

One couple reported that the duties are split between them; “but she is an amazing nurturer. Not everyone is as lucky to have a mom like he does.”

One participant stated that she was not the primary or the only-“No, my family does a lot more because he lives with them.”

Caregiving Responsibilities

Many themes emerged during these in terms of what participants stated were their caregiving responsibilities, such as monitoring medications and assisting with activities of daily living. One participant stated, “... prompting her to shower, dress, eat, take her medications.” Three other participants also discussed prompting their relative to maintain their hygiene and take their medications.

Another common responsibility is coordinating services and appointments. One participant stated that she “took him to his appointments when he wasn’t safe to drive,” and another, “Coordinating service is one big thing.”

Four participants discussed helping their relative maintain structure. One participant said, “I try to make sure he has some structure in his life. I try to facilitate him doing something other than just sitting in front of the T.V.” Another noted:

But because right now he doesn’t have any structured activity and does nothing all day, I feel responsible to rush home and try to get him out and get active. So I am constantly

like let's go work out. It's for my own benefit too, but I try not to let it bombard our lives but when he is sick like this, I think all of my time is taken up with how to get him the care he needs.

Two participants felt that they had little to no caregiving responsibilities at the time of their interview because their relatives were currently not residing with them. However, both noted that when their relative is home, they do have some responsibilities such as "making sure he is eating, washing, and doing his laundry."

Caregiving and its Impact

Responses to this question varied but many contained similar themes which will be discussed in the following order; physical and psychological, social and loss of future.

Physical and Psychological: Many participants discussed the "incredible stress" involved in caregiving, stating that it is "overwhelming" and "devastating." One participant noted, "I put on like 20 pounds after I had just lost a bunch because it's just so stressful."

Another participant discussed stopping a hobby, "I used to play hockey, but I just didn't want to do it anymore."

Due to the amount of stress involved in caregiving, three participants reported a loss in functioning and seeking out their own therapy. As one participant noted, "I started seeing a therapist to help myself manage how I am feeling." Another echoed a similar idea;

I wasn't handling the stress very well. I took some time off, my doctor gave me a few weeks, and I got myself a therapist. I've been just trying to remember what it means to take care of me. It's had a major impact because on a daily basis, I am constantly stressed.

One participant described yoga as therapeutic for her stating, “I just couldn’t function anymore. And then a yoga studio opened right near me. It completely changed my life.”

Social: Six participants found that their social life had been impacted by their caregiving responsibilities. One woman reported:

It has impacted my life, it is more restrictive socially more than anything because sometimes it’s just not possible. And I am outliving friends. When they were alive, they weren’t judgmental, but more like, detached. You don’t want be talking about it if you are our socially. The only place you can really open up is at the NAMI support groups. I didn’t want to bring this to my friends, they have their own problems.

Another reported feeling “so disheartened that it was really hard to be with people for a long time,” while another simply said, “We have no leisure activities.”

Loss of a Future: Loss of a future refers to both the future of the participant and/or the future of the patient. This theme was discussed by five participants during this question, but was discussed by almost all of the participants throughout their interview (this will be discussed in greater detail later). One participant stated:

The biggest issue for him and for me is the loss of a predictable future. That just hits the nail right on the head because I am very concerned about him. He is very bright. You know you have a child, he is handsome. You have this son and you have all these ideas for him but one day you wake up and realize none of it is going to come true. Not only that you realize he is going to need some level of caretaker for his life and if it’s not me, it will be his sister. It has certainly impacted her life as well.

Another mother stated,

You have to learn to be happy with what you have. It does make it complicated because you are on a different journey than other people. It is complicated because, when you have kids that are so called “normal” that graduate and go off to college and get married, it’s difficult to put yourself in the shoes of someone else. So when people say what do your kids do? You can’t say, “I have one in a wheelchair one with mental health issues and one that passed away” because they look at you like what’s your problem.

One woman said, “I felt like my brother died and was replaced by someone I don’t know.” Another stated, “our marriage has suffered a great deal just because I’m either learning to love the man he is now or have to figure out whether I can do that.”

The oldest of the participants, stated that while she does not currently feel greatly impacted by her caregiving responsibilities, she remembers a time when it was incredibly difficult; “There are times, I remember when I first got the diagnosis, schizophrenia, and I thought oh my God. I’ll be honest if they told me he had a terminal illness I could have taken it better.”

Biggest Change in Caregiver’s Life

In discussing the biggest change in their lives since being a caregiver, the theme of loss of future emerged. Seven participants discussed the loss of their future plans and/or the loss of their relative’s future. As one mother stated,

Losing my independence. Because I really thought, I had this mindset of the child I was going to have and now I almost feel that I am mourning the death of a child because it is not what I thought it was going to be. I have had to reevaluate my life in terms of long term care giving instead of her going to college.

Another woman addressed “mourning” when she said, “I think that I used to like depend on my husband [now the patient] to be there to support me. And I don’t do that anymore. So I, feel like, on some level, I’m in mourning a lot. Like he’s there but he’s not there the way he used to be.”

Three participants discussed the challenges of navigating the mental health system. One participant noted; “Probably just like how many appointments there are and honestly, it was like a slap in the face how poor services are.” Another caregiver stated, “The worst part even more than my son having an illness was just the frustration of being able to find anybody that could offer any help or assistance or know what to do or treat you like you knew anything.”

Constant worrying and anxiety was also a common answer; four participants disclosed increased levels of anxiety and worry. One participant stated “I think the hardest thing is that it created anxiety in an already anxious person.” Another stated,

I worry about him all the time. He doesn’t have a fixed place to live so he is here and there and I worry where he is. It’s a big city that worries me. I don’t worry that he will harm anyone but I worry someone will harm him, misunderstand him. The biggest thing is that it is constantly on my mind.

Supports for Caregivers

The majority of participants (10) identified family as a support. Siblings were most commonly mentioned; “My siblings have been amazing. They congregated around me”; another participant stated, “My sister who is a medical professional is supportive but she just moved far away. My brother is supportive in terms of money, he’s very generous.”

Some participants mentioned their children as a source of support; one participant spoke about her daughter, with whom "I share a lot of this- I have probably put a big burden on her

because she does hear about things.” Similarly, another participant stated “our third son comes around too.”

After family, friends were named as another source of support by 6 participants. One stated that she can call her “best friend, if there is a bad crisis” and another stated “I have friends and family that listen and try to support me.”

Three participants listed their own therapist as a source of support. As one woman said,

And I recently got a therapist who is really good, it’s hard sometimes to find a therapist who you click with, but it’s nice to be able to go and talk and make it about me because she is helping me to remember what it means to take care of yourself.

Church was reported as a place of support for two participants, as well as the support groups at NAMI,

But my biggest support, and it’s going to sound like I like I am tooting NAMI’S horn but to be honest, the support group which is once a month and I wish it was once a week because you get to be with people who know exactly what it is to live with someone with a mental illness.

Similarly, another participant stated “People here at NAMI, getting involved with NAMI makes me feel more in control.”

One participant did not respond to this question verbally, instead, just shook her head no.

Caregiver Self Care

Participants mentioned multiple outlets and activities that they do to take care of themselves. Most commonly, (7) participants stated that they “took time away” as a way to take care of themselves. One mother stated, “I just like to go in the car and drive by myself to have a

sense of independence.” Another echoed, “I take an hour a day with my headphones to give myself a break.” Other participants talked about taking time to see a movie, go out to lunch, or other activities with friends.

Six participants stated that they use exercise and nutrition as a form of self care. One woman noted that she, “mediates every day, walk[s] every day, [does] yoga every day. My mindset changed to taking control over whether I was going to ride her rollercoaster. Eating properly and trying to balance my time and energy amongst all my kids.”

Another stated “I have to eat good and work out, even if he doesn’t want too.”

Finally, five participants stated they relied on therapy; one participant enthusiastically exclaimed: “Therapy!” in response to the question. Many others also stated that therapy was important; “seeing my own therapist to have someone to say whatever I want to and not feel like a bad parent if I have a bad day where I don’t want to be a caregiver.”

Helpful Community Services

Six participants found that NAMI was a particularly helpful service. One stated: “NAMI [helped me] to connect and hear what others are going through.” Another participant agreed, “The support groups at NAMI. The big thing was family to family. That was a big eye opener.”

Three women mentioned that the community mental health centers were helpful; one woman said, “I am very thankful for the mental health center for being there.” Another reported:

I think the mental health center has been great for her. There are a lot of pros and cons but I think so much of it is if the client is willing to be a part of their own recovery the help is there. If she reaches out to them they are very supportive and helpful. If she doesn’t, they don’t pursue her.

Two participants stated that there have been helpful services; however, their relatives are unwilling to engage. One woman said “there are things in the community I was made aware of, support groups, but she doesn’t want to go.” Another woman agreed:

It’s hard because I think they were helpful for me because he was connected to a system but they weren’t helpful for him. It just wasn’t helpful because he fights any connection to the system.

Three participants have found no services helpful. One reported that “so far no, it’s very disappointing. I wanted to get her connected to a service that I liked their mission statement, but they won’t call me back.” The other two participants, however, noted that there were services that might be helpful for their relative, but none for them, “not together. Everything has been just for him.”

Desired Services

Most commonly, participants wished they had access to services; not only to access to service agencies and providers, but also learning how to access services. One participant stated:

There needs to be a transitional liaison, not just you’re sick, here is your meds. And for the family too because his mom knew nothing. I just think it’s terrible especially with a serious diagnosis and its going to impact your life or change the entire outcome of your life. No one sat down with him and explained anything.

Another, stressing economic problems, noted:

We had a really tough time getting support from unemployment and TDI. I wish there was an easier or better way for certain types of families to get help because we just didn’t qualify because I had a job and was making a decent salary but we were still struggling but we were in limbo like we weren’t poor enough. The system was so

ridiculous and it took so long to get help. We could never speak to anyone. It was awful trying to navigate that part of it.

Four participants spoke to the need for more family involvement and support. One stated: “I think it would have been nice if they [the treatment team] had taken the time to talk to the family and get insight through our perspective.” Another noted, “He went to a recovery thing and I don’t even know what it was. It would have been nice if they would have called me to explain it.” A third participant said:

Besides NAMI, the community mental health centers offered nothing for caretakers or families that I was made aware of. NAMI did have some groups a couple times but then they stopped. But somebody who can hold the space that something better is possible was pretty missing.

Finally, two others discussed wanting more services that provide structure and/or life skills for people struggling with mental illness. One participant said:

You can’t force an adult to do something, but they wanted him to go to a program for life skills- I really wish that we could make him go. My brother is smart and not violent. I wish that they would have tried to work more on vocational stuff. Not that he has to work full time or do something super important- I think it would help him to feel productive.

NAMI and Family-to-Family

All participants are members of NAMI. Five participants report finding NAMI themselves, either through internet research or seeing flyers/advertisements for the NAMI walk. Four participants found NAMI through friends or family who are connected to NAMI. Finally,

three participants found NAMI through a health care professional, such as a therapist or psychiatrist.

Eleven participants (which include the two family members that came to support their family member had taken NAMI's Family- to -Family course. Two participants have not taken it and one participant was taking the course at the time of the interview. Of the two participants who had not taken the course, one reported that she had "never heard of it" and the other reports that "I was registered, but I had no one to stay with my daughter."

One participant was previously a facilitator of the course, and another is training to become a facilitator.

Of those taking the course, seven found the course had a positive impact for them. Two reported that the course was "just okay" and one reported "it was not helpful."

Eight caretakers reported that a benefit of the course was connecting with others in a similar situation. One said: "it's nice to talk to people that get it." Another stated: "meeting other people in similar situation, they are people dealing with the same things you are."

Three participants valued the education provided in the course; one woman noted, "that's the biggest impact, going home and educating my family about it. Myself understanding his illness helped me become more compassionate." Another reported, "the education of it, the reading of it, seeing scientific information about the drugs and side effects, seeing some of the skills, I am a lifelong learner so that was wonderful for me."

Three participants also reported that the course helped them gain perspective. One stated "it put things in perspective, things aren't so hopeless." Another noted "I felt like maybe my sister wasn't that bad off and was making some progress."

Advice for New Caregivers

Most participants (7) suggested that caregivers “get their own supports.” As one caregiver put it, “I would say to put your oxygen mask on first. Absolutely take care of yourself and other family members first or at least simultaneously.” Another also said “try to get as much support on the outside as possible.”

Five participants recommend that a new caregiver “call NAMI and take the Family-to-Family course.” One woman said “run to your nearest NAMI office because no one else gets it” while another stated, “take the Family-to –Family course. It’s so important so that you can understand and know how to treat [your] child. It’s a must.”

Five participants felt that caregivers should become advocates. One stated: “if they allow you to be involved, do it.” Another said:

You have to learn how to be an advocate for your loved one and also for yourself. And you have to be able to communicate a level of knowledge and interest to get them on board and to recognize you as a good support even though someone might think, and I could see where they could have thought this about me, that I was over involved.

Similarly, five participants recommend that caregivers read about their relative’s illness and to do their own research. One participant said; “Find out as much as you can about the illness, don’t take the first diagnosis as the bible.” Another said “Read everything and anything. I like to read a lot of things written by people with schizophrenia. I like their point of view.”

Other responses included “finding a good doctor is essential that you can communicate with and that is willing to communicate with you.” Additionally, others spoke of the importance of educating others and reducing the stigma surrounding mental illness.

Satisfying Aspects of Caregiving

Four participants directly answered no when asked about satisfying aspects of caregiving.

As one mother reported:

If anything, seeing the progress is exciting to me. Just watching her stabilize and get it and being proactive is rewarding. But other than that, satisfying? No. I wouldn't wish it on anyone.

Another agreed: "satisfying is not a word I would use" and another-said, "How can it be satisfying if it's always a failure?"

Six participants discussed the relationship with their relative and family, primarily in a positive light. As one woman said, "It's nice to know what whatever the outcome; I think I've had a positive impact on his life. I have showed him he is just a normal guy and deserve[s] what everyone else deserves." Another said: "in some ways it made out family closer but I don't know, we were already pretty close."

Other positives mentioned included: witnessing the progress of their relative is rewarding; "I think that on some level, I've been able to see some progress in all this." Two participants noted that they were grateful for their relatives "good behavior." One mother stated, "There have been times at meetings I leave and I think how lucky I am because he's not a problem behaviorally."

Finally, two participants discussed how caregiving gave them, as one participant said, "a higher sense of purpose."

Helpful Approaches

Four participants stated that it is important to "meet them where they are at." One mother stated,

Going along with what's happening in the moment is effective. Resisting it for so long, the doctors we initially saw said we can't feed into the fantasy and we need to redirect.

But the latest info we got is that it's not right because it's real to her. Fighting against her is damaging the relationship and building a wall.

Another reported: "One of the things that took me awhile to understand is meeting them where they are at. It is really hard for me because I am a go and do it person."

Similarly, another said;

He calls me a tornado because I say "you need to do this and that." He told me I need to be calmer and not so bossy. Little things like "we are going to do something different today." I can be bossy and pushy with him and he's gotten used to it but being flexible and kind, definitely flexible.

Four participants discussed various ways of communicating with their relatives that they felt were helpful. This includes techniques to keep their relative engaged. One mother reported: "Working together to get him to take his medications, like saying 'if you do this you can have this.' We do that all the time now." Another participant stated;

Boundary setting has helped. I try to encourage him and to make things equal between us. I just try to help him see it's not a "him" thing, like that I think it's cool too. Positive reinforcement and trying to just be as understanding and empathetic as possible.

Remaining Thoughts

Five participants discussed issues with treatment, ranging from addressing issues in the services that already exist to the creation of further needed services. One participant stated: "My biggest concern is the horrible mental health system in this country." Another said that "there isn't enough information and services out there for children with these illnesses."

In a similar vein, two participants discussed hoping for political change, one said:

. . . People have to lobby and write their congressman, but who has the time when you are writing a dissertation and are taking care of someone with mental illness. I hope that in twenty years from now, there is less stigma and more support because it is just sad.

Three participants discussed the desire for their relative to have a “functioning life.”

Another participant questioned her son’s possibilities, “I want someone to talk about possibilities or impossibilities. I’d like to know if there is something else I could do and what about his future?”

Another echoed:

“. . . If it was lined up, he could have a good life. People have a right to a good live, not just go live in a group home, but a good life.”

Interview Experience

Six participants responded that they hope they are and/or this project will effect change. One participant stated “I was excited when I got the email (for your study) because it’s important we talk about things and change things.” Another echoed, “I hope this will start more research and lead to more support and programs for families.”

Five responded that it was “cathartic or therapeutic” and five participants also responded that it was “good to be able to get stuff out.” One participant said, “It’s very cathartic, put it that way. Get things out that I don’t always get to talk about.” Another said, “Therapeutic. It was good to feel like someone is hearting what is actually going on from my perspective.”

Four participants responded that the interview was “good/great” and three reported it helped them “focus.” One woman reported, “I think it’s helpful. It helps me to focus in a positive

way.” Similarly, another participant stated. “Good, I feel like for the first time in all this time, I have a better way to hold it and understand it.”

Summary

This study explored the challenges faced by people who serve as a caregiver for a relative with mental illness. Twelve interviews were conducted with fourteen participants who considered themselves to be the primary caregiver. Schizophrenia was the most common diagnosis for relatives, followed by schizoaffective disorder and bipolar disorder. While the study included a diagnosis of major depressive disorder, none of the participant’s relatives had this diagnosis. Participants were asked questions regarding their relative’s diagnosis, their caregiving responsibilities, the impact of caregiving, and the availability or limited availability of community services. The findings of this study highlighted the unique experiences and challenges of their caregiving role. Participants noted a variety of practical and emotional struggles.

In terms of practical struggles, participants discussed the assistance they provide with activities of daily living, which included: monitoring medications, prompting relatives to shower, eat, dress, and maintain their personal hygiene. Additional responsibilities included arranging appointments and coordinating services as well as providing structure to their relative. While participants discussed the responsibility of coordinating care, they also noted a lack of community resources, both for their relative and for families. Additionally, they described “treatment issues,” such as lack of access to psychiatrists in community mental health centers and lack of communication with providers.

Perhaps more significantly, participants described the emotional struggles of caregiving. Several participants discussed feelings of grief, loss and mourning, including a feeling of “the

loss of a predictable future,” both for themselves and for their relative. Participants mourned the loss of what they envisioned both of their lives to look like.

The following chapter contains a discussion of the findings, strengths and limitations of this study. Additionally, it discusses the implications for clinical social work as well as implications for future research.

Chapter 5

Discussion

This study explored the challenges faced by people who serve as a caregiver for a relative with mental illness. Participants were asked questions regarding their relative's diagnosis, their caregiving responsibilities, the impact of caregiving, and the availability or limited availability of community services. The findings of this study highlighted the unique experiences and challenges of their caregiving role. Participants noted a variety of practical and emotional struggles. Participants discussed the lack of community resources and other treatment issues. Additionally, participants discussed the feelings of grief and mourning of a "predictable future," both for themselves and their relatives.

In the following section, the study's findings are discussed in relation to the existing literature. Then, the strengths and limitations of this study will be discussed followed by implications for clinical social work practice, as well as implications for future research.

Comparison of Study Findings to Existing Literature

This study was undertaken as there is currently little research on the impact of caregiving on relatives of patients with psychiatric illness. Most of the current literature regarding caregiving focuses on caregivers for patients with terminal illness, such as cancer or Alzheimer's. However, this study, focused on giving to the explored the needs and experiences of caretakers for the mentally ill, presents the opportunity to highlight the similarities and differences between this population, and with those caretakers working with the medically ill.

Deinstitutionalization Movement: As previously discussed, the deinstitutionalization movement was meant to be beneficial for those struggling with mental illness. However, it is not without its faults. As the Kaiser Commission on Medicaid and the Uninsured reports, “Learning from History” (2007) points out, there are several mistakes that were made in the implementation of deinstitutionalization, which include: First, in terms of living situations, patients once institutionalized were moved to various facilities, such as nursing homes, or sent back to their families, adding an increased burden to both nursing homes and families. Secondly, the measurement of success for mental health treatment was measured by length of inpatient stays, rather than by the quality of life experienced by the patient (Koyanagi & Bazelon, 2007).

These “mistakes” were addressed by participants in this study. Housing remains an issue, both for those who live with their relatives and those who are trying to find alternative living arrangements. As one participant noted, “I would like to have more support in trying to find appropriate housing for her. I just feel like there is not enough support there. And that is a really serious issue right now. “

Additionally, participant responses seemed in agreement with the Kaiser report regarding the measurement of mental health. Many participants discussed wanting a “better life” for their relatives; as one woman said:

I feel like no one wants to help but I just feel like in my view he [the patient] is a great person with potential and if it was lined up, he could have a good life. People have a right to a good life, not just go live in a group home, but a good life.

This sentiment was echoed by other participants who wanted their relatives to have a “great life” but did not feel that the mental health services were fostering a productive life. One

mother said “There is no one saying what is best for this person to give them a functioning life. It is so frustrating.”

Caregiving Responsibilities: Intagliata, Barry, & Ergi (1986) identified some core aspects of caregiving for someone with mental illness. The main areas identified are: “assessment (provide historical and current information on client functioning and identify patient needs not apparent to the treatment team); linking (knowing the treatment plan in terms of medication or activities as well as providing encouragement and support to engage in the activities); monitoring (compliance and support patient responsibility); assistance in daily living (encouraging the patient to be as independent as possible; and, when necessary, setting limits and boundaries); crisis intervention (learn early warning signs); and advocacy” (p 702-703).

The participants of this study noted similar caregiving responsibilities. Most commonly, participants discussed assistance with activities of daily living. For participants, this includes monitoring medications, prompting their relatives to shower, dress, eat, and maintain their hygiene.

Additionally, participants noted that a major responsibility is coordinating services and appointments, as well as helping their relative maintain structure. As one woman said;

But because right now he doesn't have any structured activity and does nothing all day, I feel responsible to rush home and try to get him out and get active. So I am constantly like let's go work out. It's for my own benefit too, but I try not to let it bombard our lives but when he is sick like this, I think all of my time is taken up with how to get him the care he needs.

When asked directly about their caregiving responsibilities, participants mainly discussed assistance with activities daily living and monitoring relative's compliance with medication as

well as insuring they are engaged in treatment. However, some of the other areas identified by Intagliata et al (1986), were discussed throughout the interviews, such as assessment, crisis intervention, and advocacy.

Some participants discussed their communication with treatment providers. One participant stated that the community mental health center does not contact her, but that she will contact his nurse “if I see something, I’ll say ‘be aware of this, this is what’s going on or he’s short tempered’ and I’ll let her know my concerns that way.” According to Intagliata, assessment involves providing historical and current information on client functioning, thus caregivers are doing this every time they speak with treatment providers.

Participants also engaged in crisis intervention and advocacy. A component of crisis intervention is knowing the signs of relapse. When participants were asked if they knew the signs of relapse, 8 participants stated they did.

In terms of advocacy, four participants stated that they advocate for their relatives in various ways. Mainly, this was discussed in terms of treatment. As one participant, while talking about issues in securing psychiatric treatment for her relative stated, “I am like an advocate-make –it- better kind of person, so I’m trying to get things in place”

Impact of Caregiving: As discussed in the literature review, caregiving impacts many different facets of life, discussed in the following order; emotional, physical and financial.

Emotional: The emotional impact of caring for a relative with a severe and chronic mental illness can be great. Caregivers may experience a range of emotions such as guilt, grief, exhaustion, depression, anxiety, anger and many more (Mcfarlane, 1983; Tan et al., 2012; Lynch & Lobo, 2012). Some participants expressed feelings of guilt for various reasons. One participant stated, “I used to always feel guilty about just taking time for me to do things that I

enjoy; I forgot what those things were;” another stated: “I think when a sibling gets diagnosed there is a sense of guilt that I struggled with, like why did he have to get sick and not me? Why if we grew up in the same house? Why does he have to have a hard life and I don’t?” The findings of this study were similar to that of Mcfarlane (1983), Tan et al. (2012) and Lynch & Lobo (2012).

In this study, participants felt guilt for being healthy, or for taking time for their own self care. Interestingly, when asked what advice they might give a new caregiver, one participant specifically stated, “Don’t let them run your life, don’t let them hold you hostage or feel guilty.”

Many studies cited grief as a commonly experienced emotion (Erlingsson et al., 2012; Milliken, 2001; Tan et al., 2012). Additionally, Miliken (2001), reported that caregivers need to grieve the loss of their children as they knew them as well as the loss of the future they may have had (Miliken, 2001). Grief, mourning and loss of a predictable future were common themes identified by participants in this study. More than half participants discussed feelings of grief related to the loss of the person they knew before they became ill, and the loss of their own future. As one mother said, “I almost feel that I am mourning the death of a child because it is not what I thought it was going to be. I have had to reevaluate my life in terms of long term care giving instead of her going to college.”

Berg-Weger (2000), found that rates of depression amongst caregivers are quite high, estimated between 38% and 60% (p. 162). Many participants of this study discussed increased anxiety and depression following their relative’s diagnosis and some participants disclosed seeking out their own therapist to better cope with the added stress.

Included in the emotional impact of caregiving is the effect it has on one’s social life. Many studies discussed issues of isolation among caregivers (Mcfarlane, 1983; Erlingsson, 2012;

Tan, 2012). The stigma and stress of mental illness can make it difficult for families to maintain relationships and responsibilities, such as work. (Chang et al. 2012; Miliken, 2001; Tan et al. 2012).

Six participants in this study reported that their social life had been impacted by their caregiving responsibilities. One participant stated, “It’s more restrictive, I guess, more socially than anything because sometimes it’s not possible.” Another said, “Mainly we were so disheartened it was really hard to be around people.” One participant reported that she lost her job “because of her constant need for me to be there. My employer felt I was taking too much time when she was hospitalized.” Thus, the findings of this study mirrored that of Chang et al. (2012), Miliken (2001) and Tan et al. (2012).

Physical Impact: Much of the current literature regarding caregiving focuses more on the psychiatric and emotional impacts of caregiving, and has not addressed the physical impact. However, Chang et al. (2010) cited various studies that found that “caregivers often experience several physical problems, including back injuries, arthritis, high blood pressure, gastric ulcers and headaches (Sawatzky and Fowler-Kerry, 2003 as cited in Chang et al. 2010, p. 268).

In this study, caregivers focused more on the emotional impact of caregiving, although some participants did mention physical symptoms. One participant stated she had gained approximately 25 lbs due to the stress. Others talked about needing to take care of themselves physically, by eating well and exercising.

Financial Impact: I anticipated that participants would address financial impacts and burdens of caregiving based on Miliken’s (2000) study which discussed potential expenses of caregiving such as housing, clothing, food, insurance and periodic handouts (p.157). However, this issue was rarely addressed by participants in this study. As stated, one participant reported

losing her job due to her caregiving responsibilities. Another reported that when her husband became ill, they struggled to receive support from unemployment and TDI (which is Rhode Island's Temporary Disability Insurance).

NAMI and Family-to-Family

As previously reported, all participants are members of NAMI Rhode Island, and nine had completed Family-to-Family (one participant was taking the course at the time of the interview). NAMI (n.d.) states that for Family-to Family, "our primary mission in education involved orchestrating a transformation from personal devastation to action and power." In terms of emotional understanding, Family to Family seeks to provide a safe environment for family members and friends to discuss their experiences with mental illness. "Family members can debrief the traumatic events and feelings they have" (Family to Family, n.d.). One goal is to normalize the experience of mental illness and recovery as well as encouraging families to speak openly about their experience.

The majority of participants in this study who had completed Family-to-Family found it to have been a positive experience. Even those who did not enjoy the course overall stated that it was "nice to connect with others."

Psychoeducational Approach

NAMI and the Family-to-Family utilize the psychoeducational approach to coping with mental illness. Psychoeducation seeks to reduce relapse rates by increasing "the stability and predictability of the family environment by increasing families' self confidence and knowledge about the illness and thus decreasing family anxiety about the patients and increasing their ability to react helpfully to them" (McFarlane, 1983. p. 102). Additionally, the psychoeducational approach focuses on the impact of a mentally ill patient on the family (Saleebey, 1996; Simon et

al., 1991). However, the focus of this perspective is rather “the schizophrenics impact on family functioning, not the other way around” (Goldenberg & Goldenberg, 2008. p. 384).

Some participant responses aligned with the goals of the psychoeducational approach. One participant stated, “the education of it, the reading, seeing scientific information, learning about the drugs and side effects, seeing some of the skills. I am a lifelong learner so this was wonderful for me.” Another stated, “It was a really great thing because we realized, look at all the people we met and they have the same issues we have. We aren’t bad parents, we are good parents and these things happen.” For participants in this study, the psychoeducational approach helped them to better understand their relative’s illness, and reduce blame and stigma.

Strengths

This study’s strengths include that it was a qualitative, exploratory study which was able to capture the narrative and descriptive accounts of serving as a caregiver for a relative with mental illness that could not be found in a quantitative study. Additionally, due to the lack research on caregivers of a relative struggling with mental illness, this study gave voice to a population of caregivers who have been missing from current literature. Most literature has focused on caregivers of terminally ill patients, such as those struggling with cancer or Alzheimer’s disease.

Limitations

This study also has a few limitations. One limitation is the small sample size, as 14 people participated in this study. Additionally, all participants are members of the Rhode Island chapter of the National Alliance on Mental illness. Although NAMI strives to serve a diverse population, its membership tends to be white, middle class women, which impacts their caregiving experience (Hatfield et al. 1996, p. 826).

Therefore, the lack of diversity in this study should be noted. Twelve participants identified as Caucasian, one as African American, and one as Cape Verdean. Thirteen participants were women. Additionally, while participants sexual orientation was not specifically asked, many participants referred to their heterosexual relationship (discussed their husbands or boyfriends), and those who were single did not disclose any information regarding their sexual orientation.

This study interviewed caregivers for relatives suffering from schizophrenia, schizoaffective disorder, bipolar disorder and major depressive disorder. Therefore, the caregiving experience of those whose relatives suffer from other mental health diagnoses such as Obsessive Compulsive Disorder or Borderline Personality Disorder, were not included.

Implications for Clinical Social Work Practice

This study's findings provided valuable information for the field of clinical social work as it speaks to the unique challenges of caring for a relative with mental illness. Caregivers struggle financially, physically and emotionally in their role. Clinicians should focus on continuing to support the family caregivers and keep in mind their daily challenges.

Furthermore, many participants stated that attending support groups and meeting other family caregivers in the NAMI Family to Family course was helpful. It may be helpful for clinicians recommend support groups as an option for family caregivers to provide a supportive environment.

This study also highlights the importance of family involvement in treating a patient with severe and chronic mental illness. Clinicians can only talk to family when a patient has signed a release. It is important to remember to ask patients to sign a release and once done, keep family caregivers involved in communication. This goal can present complications, as some patients

may refuse to sign these releases, for various reasons, including general suspiciousness as well as anger at the family. The husband of one of our subjects refused to sign a release because he was angry at his wife for taking out a restraining order on him, which she had done to facilitate his hospitalization. Attention needs to be focused on helping both family caregivers as well as mental health caregivers, work out techniques for working with resistant and uncooperative patients, including "wandering patients", discussed below.

Implications for Future Research

A limitation of this study was the lack of diversity, both culturally and socioeconomically. Additionally, all participants were members of NAMI. Further research is needed so that the experiences of caregivers from various groups can be examined and compared.

Additionally, thirteen out of fourteen participants were female. It would be beneficial to understand the experiences of male caregivers and how this is similar or different than that of female caregivers.

While participants of this study brought up the idea of grief and mourning the loss of a predictable future-- both their own and that of their relative-- this researcher failed to ask questions that specifically addressed themes of grief and loss. It would be both interesting and beneficial to examine the experience of grief and loss in family caregivers of the mentally ill.

Lastly, this researcher failed to take into consideration the concept of the "wandering patient." Many participants noted that their relative has and/or still does cycle in and out of their lives. One participant discussed how her son, who still refuses all psychiatric treatment, lives in another city. She reports that he comes home, occasionally, when he is in trouble. Her caregiving duties while he is home involve attending to activities of daily living, such as encouraging his

hygiene. While he is away, she remains “constantly worried. When he calls, I talk to him on the phone, try to calm him down, tell him the voices aren’t real.” Therefore, her caregiving duties are often from a distance, when her son is in need.

Another participant reported that her sister had stopped signing releases so that providers could speak with her. This pattern has occurred repeatedly over time. In the past, she has had many caregiving duties. However, when her sister does not sign a release, her involvement is almost nonexistent. This does not mean she is not a caregiver, as the stress and worry experienced by other caregivers. Research regarding the experience of caregivers of “wandering patients” should be explored.

Another area for research is the "safety" of the caretaker and family members. In this study, five participants noted the need for police involvement in securing hospitalization for their relatives. It is not known, whether violence was a factor in necessitating police action, or whether violence of the patient is an ongoing danger for the caregiver or other members of the family. Violence (or threats of violence) were not explored in this study, but could be an important area for future research. This raises an ancillary question: could there be caretaker concerns about anti-social or illegal behaviors, such as substance abuse, gambling, stealing, etc.?

Although many aspects of the stresses affecting caregivers were explored, one aspect that was omitted was the quality of the relationship between the caregiver and the patient, as this was beyond the scope of this study. However, future research could shed light on the baseline of the relationship of the two (prior to the onset of mental illness); how does the baseline affect the present relationship?

Furthermore, this relationship can affect the adaptation and emotional well being of both partners; e.g. does the caregiver feel appreciated and/or resented by the patient? Does the patient

evoke ongoing guilt in the caretaker- e.g. by demands and complaints? What is it that motivates caretakers to seek their own therapy- is it multiple demands on their time, earlier conflicts, personal or marital issues, or something emotionally triggered by their present caregiving roles?

Summary

This study examined the effects of caring for a relative with a chronic and severe mental illness. Participants provided personal and narrative accounts of their experience which addressed diagnosis, responsibilities, impacts and community services. The personal experiences of people serving as caregivers for someone with mental illness are missing from the current literature. However, it became clear through this study that a relative's psychiatric diagnosis has a profound impact on families, namely those who provide daily care.

As described in the literature, the burden of caregiving can place limitations on caregivers independence and personal lives (Chang, Chiou, & Chen, 2010; Tan et al., 2012). The participants of this study noted various burdens and limitations, such as restricted social lives. The constrictions of their own independence is due in part to emotional struggles, such as depression, guilt and shame (Chang, Chiou, & Chen, 2010; Tan et al., 2012), but also due to the many responsibilities of caretaking. Participants in this study described a variety of responsibilities, such as assistance with daily living, medication monitoring, securing and coordinating services and appointments, and advocating for their relative.

Obtaining services for their relative was common issue amongst caregivers. Most noted that even when their family member is connected to services, such as a community mental health center, there is a lack of communication between provider and family. While many participants stated that the community mental health center was responsive if they (the caregiver) contacted them, they stated that providers did not initiate conversations.

As discussed throughout this study, the deinstitutionalization study placed a heavy burden on the families of those who suffer from mental illness. Research has shown that positive family involvement can help reduce relapse rates in major psychiatric illnesses (Clark, 2009). However, despite this information, the narrative accounts collected in this study suggests that families are still not actively included in treatment. While it is important to take into consideration how the large number of patients connected to community mental health centers, budget cuts, and the high case load for providers at the center might impact communication, it is also important to value and support families and family involvement. Perhaps the current functioning of community mental health center is not optimal for promoting family involvement, which helps to keep patients stable and reduce relapse rates.

This study was important because of its focus on the needs and challenges faced by family caregivers. The experiences of family caregivers can provide valuable insight into how the mental health field can better support mentally ill patients and their families. By valuing their perspective and understanding their challenges, the mental health field can move towards increasing caretaker satisfaction and enhance services for the mentally ill and their families.

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Appendix A

Recruitment Letter

Dear NAMI-RI Member,

My name is Diana Mark and I am a Master's student at Smith College School for Social Work. I am doing a research study of the experiences of family members who serve as caretakers for relatives with a mental illness. I am interested in learning about how taking care of your relative suffering from mental illness has impacted your life.

The only time requirement for your participation would be a one hour interview in which I will ask you a series of questions about caretaking experiences. This interview would take place at NAMI Rhode Island in a private space. I will be audio recording the interview and transcribing it, disguising all identifying information. This study and data will be used for my Master's Degree in Social Work thesis, and possible presentation and publication.

In order to participate in this study, you must be a family member (parent, spouse, partner, significant other, sibling, cousin, aunt/uncle, grandparent, grandchild) of a patient with one (or more) of the following mental illness diagnoses: schizophrenia, bipolar disorder, schizoaffective disorder, and major depressive disorder. You must be 18 or older and be able to speak and read in English.

If you are interested in participating in this study, or would like more information, please feel free to contact me by phone or email listed below

I look forward to hearing from you and learning about your unique experiences.

Sincerely,
Diana Mark
Smith College School for Social Work

Appendix B
Informed Consent

Dear Participant,

My name is Diana Mark and I am a Master's student at Smith College School for Social Work. I am doing a research study of the experiences of family members who serve as caregivers for relatives with a mental illness. I would like to have the opportunity to interview you, as a member of NAMI, to understand how your life has been impacted by being a caregiver. This study will be presented as a thesis and may be used in possible future presentations, publications or dissertations.

Your participation in this study is entirely voluntary. You will be asked to complete a one hour interview with me regarding your experiences as a caregiver. In order to participate, you must be 18 or older, be able to read and speak in English, and be a caregiver for a family member with a mental illness (ex: parent, spouse/partner). If you agree to participate, I will ask that you complete a one hour interview with me about your experience and thoughts as a caregiver. In order to participate in this study, you must be 18 or older, be able to read and write in English, be a caregiver for a family member with a mental illness (parent, spouse/partner/significant other, sibling, cousin, aunt/uncle, or grandparent/grandchild). Your relative must have a diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, or major depressive disorder. I will be audio recording our interview and transcribing the interviews, disguising all identifying information.

Participation in this study may bring up difficult feelings in regards to your experience as a caregiver. If you feel that you would like additional support relating to your participation, I

encourage you to utilize the NAMI-RI support groups. Additionally, I have provided a list of mental health resources at the end of this letter that you may use at your convenience.

Your participation is voluntary. Although there is no financial benefit for participating in this study, this interview will give you the opportunity to share your personal and unique experiences of perspective on being a caregiver. Your responses will provide insight about this experience, and your thoughts and suggestions about needed services will be useful for other caregivers and for mental health providers. Hopefully, this will lead to increased access to services, and to further research.

Your anonymity cannot be guaranteed because the interviews will take place in a private space at the NAMI-RI office. It is possible that staff or other members of NAMI could see us meet and therefore know that you participated in this study. However, the confidentiality of your interview will be maintained as far as is reasonably possible. When using brief illustrative quotes or vignettes, for example, no identifying information will be presented. In any publications or presentations, the data collected will be presented as a whole. All data will be kept in a secure, password protected, location for a period of three years as required by Federal guidelines. After that time, if the data is no longer needed for research purposes, it will be destroyed. If it is needed for research purposes, the data will continue to be kept secured in for as long as it is needed and when it is no longer needed, it will be destroyed.

If you choose to participate, you may withdraw from the interview at any point and you may choose not to answer any or all of the questions, by stating you do not want to answer. Once you have completed the interview, you will have until April 1, 2013 to withdraw from the study. Should you choose to withdraw before this date; your data will be destroyed and will not be used in the study.

If you have any questions or concerns about your rights or about any aspect of the study, you can contact me at or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

Thank you for your interest in the study.

Sincerely,
Diana Mark
Smith College School for Social Work.

Referral List

NAMI-RI Family Support Group
(<http://www.namirhodeisland.org/support/index.htm>)

Ralph Lord, MA, CSP of Harbor House
12 Bassett Street Providence, RI 02903
(401) 273-5100

Elizabeth Aloisio, M.Ed., LCMHC
1090 New London Ave
Cranston, RI 02920
(401) 463-5778

Ruth Wartenberg, MSW
55 Hope St
Providence, RI 02906
(401) 331-1350

Appendix C

HSR Approval Letter

School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

January 29, 2013

Dear Diana,

You have done an excellent job incorporating the requested changes. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your very interesting study.

Sincerely,



Marsha Kline Pruett, M.S., Ph.D., M.S.L.
Vice Chair, Human Subjects Review Committee

CC: Esther Urdang, Research Advisor

Appendix D

Interview Guide

Demographics of caretakers

1. Age
2. Gender
3. Race/ethnicity
4. Occupation
5. Relationship to patient
6. Does the patient live with you?
 - a. if so, does anyone else live in the household?
 - b. If, yes, please specify.

Demographics of patients

1. Age
2. Gender
3. Race/ethnicity
4. Occupation
5. Educational status

Psychiatric Care

6. Diagnosis
7. When was the patient first diagnosed with mental illness?
8. When and how did you learn of the diagnosis?
9. Has the patient been hospitalized for mental illness?
 - a. if so, how many times?
10. What type of care is the patient receiving now?
11. How is the patient doing now?
12. Are you involved in their treatment?
 - a. If so, how?
13. Have Providers communicated with you about treatment and discharge plans?
14. Do you know the signs of potential relapses?

Caregiving Role

15. How long have you been in the caregiving role?
16. Are you the primary or only caregiver?
17. What are your caregiving responsibilities? About how much time do you spend doing this?
18. Has caregiving impacted your life?
 - a. If so, how? (e.g. increased stress, employment, social, leisure, health etc.)
19. What has been the biggest change for you been in your life since you've been a caretaker? .
20. Do you have support in your caretaking role now?
 - a. if you do, please describe
21. What sort of things do you do to take care of yourself?

Available and Needed Services

20. Have you received community and mental health services which you have found helpful?
 - a. If so, please describe.
21. Are there services you did not receive, which would have been helpful for you?
 - a. if so, please describe
22. What brought you to NAMI?
23. Have you completed Family to Family?
 - a. if yes, what impact has it had for you?
24. What advice would you give to another caregiver of patient with a recent diagnosis of a serious mental illness?

Conclusion

25. Are there aspects of caretaking that are satisfying to you?
26. Have you discovered any approaches or procedures that you feel are helpful?
27. Is there anything we have left out which you feel is important?
28. How did you find the interview today?

Appendix E
Agency Approval Letter

November 7, 2012

Smith College
School for Social Work
Lilly Hall
Northampton, MA 01063

To Whom It May Concern:

National Alliance on Mental Illness of Rhode Island (NAMI-RI) gives permission for Diana Mark to locate her research in this agency. We do not have a Human Subjects Review Board and, therefore, request that Smith College School for Social Work's (SSW) Human Subject Review Committee (HSR) perform a review of the research proposed by Diana Mark. NAMI-RI will abide by the standards related to the protection of all participants in the research approved by SSW HSR Committee.

Sincerely,



Chaz Gross, CAGS
Executive Director
National Alliance on Mental Illness of Rhode Island