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The lived experience of family members of those who suffer from chronic mental illness

Felicia Fior-Nossek

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The Lived Experience of a Family Member Who Suffers from Mental Illness

Submitted by

Felicia Fior-Nossek

In partial fulfillment of the requirements for the degree of
Master of Science in Nursing

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The Lived Experience of Family Members of Those Who Suffer From Chronic Mental Illness

Felicia Fior-Nossek

Medical University of Ohio

Summer 2005
DEDICATION

This thesis is dedicated to all family members who care for those who suffer from chronic mental illness. I would also like to dedicate this thesis to my husband, Bill, who has been patient and supportive in all of my endeavors. Finally, to my parents, who have given me the gift of faith and taught me perseverance.
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I wish to extend my appreciation to my committee chair, Dr. Joanne Ehrmin for her knowledge, inspiration and passion for qualitative research. I would like to thank my committee members, Dr. Ann Smith and Mary Kozy. Without their guidance, patience, and encouragement this thesis would not have been possible.

I would like to express eternal gratitude to my sister, Dominique Sorbo who has provided me with constant support throughout my education experience in more ways than can be expressed. I thank her for her love and support and always believing in me.
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CHAPTER I

Introduction

Over 3 decades ago, the United States began to deinstitutionalize those who were mentally ill. Prior to that time, those who had been afflicted with some form of mental illness were often institutionalized and unable to live in society. This marked the beginning of what has been a major transformation in mental health care. Today, mental health care advocates do not view deinstitutionalization as a successful solution in the treatment of those suffering from mental illness. This was depicted by Torrey (1995), who referred to deinstitutionalization as “the launching of a psychiatric Titanic, the largest failed social experiment of twentieth century America” (p. 23). One of the many consequences of deinstitutionalization is the added responsibilities that have been placed on the families of these individuals. Many patients who were once cared for in institutions by mental health professionals, now have to rely on their families to care for them.

The role of the family caregiver in mental illness becomes even more important when reviewing the prevalence of mental illness. Reports indicate that 22.1 percent of Americans aged 18 years and older suffer each year from a diagnosable mental disorder (National Institute of Mental Health, [NIMH] 2004). In other words, forty million Americans are affected by mental illness each year (U.S. Department of Health and Human Services, 2000). Of this number, 2 million were diagnosed with schizophrenia and 6.5% of all women and 3.3% of all men in the United States suffer from an affective disorder, such as Major Depressive Disorder. These disorders are considered “severe”
and “persistent” (Rose, Mallinson, and Walton-Moss, 2002). In comparison with other illnesses that are disabling, mental illness accounts for four out of the 10 causes of disability in the United States and other developed countries (NIMH, 2004).

Statement of Problem

Allowing individuals to live in the community as opposed to institutionalization could be perceived as beneficial to the quality of life for those with mental illness. This would be true provided adequate resources were available. Without adequate resources, the responsibility of caring for those with chronic mental illness falls upon their loved ones. The effects of mental illness on family members were part of Rose et al.’s (2002) study findings. Rose et al. referred to additional supporting literature and discussed how mental illness can often have a great impact on the other members of the family. For example, a patient with psychotic symptoms such as those found in someone diagnosed with schizophrenia can be perceived as frightening for family members (Rose). One can infer from Rose et al.’s discussion that the consequences of mental illness could be as challenging for family members as for the patient.

Through scientific research, symptom management of many mental disorders has greatly improved over the past decade. This is particularly evident with the development of the newer medications that have greater effectiveness in symptom management and have less toxic side effects. However, substantially less research is available on the lived experience of the family members of those suffering from chronic mental illness. As a result of the changes in the mental health care system in this country, these family members have been forced to take on many aspects of caring for their mentally ill loved
one. Family members have now become the primary caregivers and advocates for their ill family member. Family members are assuming greater responsibilities with limited resources and minimal information regarding how to deal with the mental illness. In addition, family members have become the primary source of emotional support for the mentally ill individual, “although they feel they are the least equipped to handle mental illness” (Rose et al., 2002, p. 517). If families are to assume the role of primary caregivers for their mentally ill loved ones, then the patient’s family should be a priority in the patient’s treatment planning. Since family members have become an essential aspect of treatment, it is important to understand the lived experience of these family members. Nursing research in this area could provide valuable information for many disciplines, but in particular may be most beneficial for nursing. In qualitative research, gathering data regarding the family’s lived experience adds knowledge to the discipline of nursing, which could be applied to practice, potentially improving the care of patients and their families.

Conceptual Framework

The nursing framework used to conceptualize this study is Friedemann’s Framework of Systemic Organization FSO (1995). This framework is applicable to Fawcett’s (2000) metaparadigm of nursing, which has been widely accepted within the discipline of nursing. Fawcett’s framework included the concepts of environment, person, health and nursing. Friedemann expanded on this metaparadigm and stated, “The dynamic concepts of family and family health guide the explanation of systemic function of individuals, social and environmental systems, and the interactions between them”
Friedemann’s theory addresses working with families, individuals and other social systems. In this study, the focus is on the portion of Friedemann’s theory that relate to the concepts of “Family” and “Family Health,” as it pertains to the lived experience of family members of those who suffer from chronic mental illness. The goal in Friedemann’s theory is to manage anxiety and move toward congruence. According to Friedemann, each person and social system (family) has four interacting targets to balance. These “system targets” include: stability, growth, control and spirituality. Friedemann stated, “Each person or social system emphasizes these targets in a unique way and uses processes learned and acquired over time” (p. 60). The interactions and movement of various parts within the system and outside of the system is a desired attempt to reach a healthy state of congruence.

According to Friedemann (1995), the family (system) maintains balance through four dimensions: system change, system maintenance, coherence, and individuation. The following is a summary of Friedemann’s dimensions. In the system change dimension, the focus is on the system’s ability to adapt to change. System maintenance refers to all actions that maintain the system’s “stability and control” (p. 11). System maintenance includes all of one’s basic needs. This would include one’s coping mechanisms and defense mechanisms, which Friedemann explains occurs in rhythmic and regular patterns of the individual system. Friedemann stated, “At the base of system maintenance lies a
set of values and beliefs that concerns physical and mental health as well as orientation to
time tradition, and flexibility” (p. 11). In the coherence dimension, the focus is on
relationships that are formed between family members and all the behaviors of the
members that keep the family unified. Friedemann described that those who reach a state
of coherence feel a sense of security and peace (Friedemann).

The last dimension in Friedemann’s FSO (1995) theory is individuation. The
process dimension of coherence is necessary for individuation. In the dimension of
individuation, the individual must connect to other parts of the system in order to fully
develop and experience growth. The individual feels comfortable within him or herself,
and feels safe to move out and explore their environment. Behaviors included in this
dimension include those activities that enhance and develop one’s potential and give one
a sense of purpose. According to Friedemann, one must have a balance of behaviors
within each of the dimensions to be able to manage anxiety, which can surface when
tension builds within the system. The ultimate goal in Friedemann’s theory is to attain
congruence and ultimately health. The goal in the current study was to explore the lived
experience of family members of those who suffer from chronic mental illness
(Friedemann).

Friedemann’s Framework of Systemic Organization FSO (1995) was selected for
its focus on the family system. Within Friedemann’s FSO, there are dimensions of
adaptation to change and relationships, which ultimately lead to health. This is
compatible with the phenomenon of interest in this study, the lived experience of family
members who are forced to adapt to the changes that occur as a result of a family member suffering from mental illness.

Statement of Purpose

The purpose of this study is to increase nursing’s knowledge base regarding the experiences of individuals with a family member who suffers from a chronic mental illness. The phenomenological research method was used to conduct the study. Using this method assists the researcher in discovering the “essence” of the phenomenon of the lived experience of the family members of those who suffer from chronic mental illness. Van Manen (1990) has elaborated further on the meaning of the “essence,” of the phenomenon,

The essence of a phenomenon is a universal, which can be described through a study of the structure that governs the instances or particular manifestations of the essence of that phenomenon. In other words, phenomenology is the systematic attempt to uncover and describe the structures, the internal meaning structures, of lived experience. A universal or essence may only be intuited or grasped through a study of the particulars or instances as they are encountered in lived experience (p. 10).

Research Question

The research question in this study was: “What is the lived experience of family members of those who suffer from chronic mental illness?”

Definition of Terms

This section includes the conceptual and operational definition of the following terms that were used throughout this study, lived experience, family member and mental
illness. By providing the conceptual definition of a concept, one gains a deeper understanding of the theoretical meaning of the concept. Whereas, the operational definition provides an explanation as to how the concept was observed in this study. Concepts in qualitative studies tend to be abstract in order to prevent restrictions and limitations being imposed on the study and the study findings (Burns & Grove, 2001). Overall, these definitions provide a more accurate understanding of the concepts that were studied.

**Lived Experience**

**Conceptual Definition:** The “lived experience” was conceptually defined as “every day life” (Carpenter & Speziale, 2003, p. 53). The lived experience provides meaning to how each individual perceives a particular phenomenon (Carpenter & Speziale). Carpenter and Speziale stated, “It is the lived experience that presents to the individual what is true or real in his or her life” (p. 53). Each experience of the individual family member can be viewed from their subjective perspective (Friedemann, 1995).

**Operational Definition:** The operational definition of the “lived experience” in this study was the responses provided by the participants during tape-recorded interviews. The participants were asked to respond to the following question: “Tell me about your experience of having a family member who suffers from chronic mental illness.”

**Family Member**

**Conceptual Definition:** Family member in this study is conceptually defined within the context of Friedemann’s (1995) theory. The family is viewed as an
element that is inseparable from what is going on within the environment. Within this theory, when reference is made to family, biological family should not be assumed. According to Friedemann, “The family is a system with interpersonal subsystems of dyads, triads and larger units defined by emotional bonds and common responsibilities…” (p. 18). Whom the individual considers family, are those with whom the individual bears an emotional significance and whose behavior mirrors that of a family member (Friedemann).

**Operational Definition:** The operational definition of family member in this study could include but was not limited to, one who self identifies as having a family member who suffers from chronic mental illness.

**Mental Illness**

**Conceptual Definition:** Chronic mental illness was conceptually defined as one’s maladaptation to internal or external stressors that are evident through altered behaviors, thoughts and feelings, which are incongruent with cultural norms. This maladaptation contributes to social, physical and occupational dysfunction and disability (Townsend, 2003).

**Operational Definition:** Mental illness in this study was operationally defined as a diagnosed mental disorder that was documented in the *Diagnostic and Statistical Manual of Mental Disorders IV-TR* as a mental disorder and was chronic and persistent.
Significance

The National Institute of Mental Health (NIMH) reported on the results of the Global Burden of Disease study, conducted by the World Health Organization. According to this report, the burden of mental illness and suicide account for 15% of disease in the market economies. This number exceeds disease burden for all cancers (NIMH, 2001). Mental illness is also the number one cause of disability and is responsible for 25% of all disability in the world. In addition to morbidity, mental illness accounts for significant mortality. For example, of the 30,000 Americans who commit suicide, 90% have a mental illness (NIMH, 2004). Such significantly high numbers reflect the mental health care needs of this population. The transformation of mental health care has had dramatic consequences for this population. For example, long-term provisions in a mental health facility are no longer an option for those who suffer from chronic mental illness. When a patient’s condition warrants an acute hospitalization, their stay is brief and they are often discharged from the hospital before they are completely stabilized (Jubb & Shanley, 2002). Talbot reports that 25% of those hospitalized return home to live with their families (Rose, 1998). With such short-term care for a long-term illness, families are taking on the role of mental health professionals, without the education, credentials or resources.

Including families in the care of patients has become essential, since families have increasingly served as the primary caregivers of those with mental illness and community resources are extremely limited. The responsibilities involved in the care giving experience are influenced by the meaning that family members give to their experience
(Rose, 1998). To be able to provide effective nursing care to family members, such as facilitating the acceptance of the mental illness, nurses must gain the knowledge and understanding of what this experience means to these family members. Allen and Jenson (1990) emphasized the importance of phenomenological research in nursing and stated, “knowledge in nursing is, in part, determined by its relevance to the significance for an understanding of the human experience” (p. 241).

As previously stated, obtaining research data would provide nursing with greater knowledge and a better understanding of the phenomenon of the lived experience of family members of those who suffer chronic mental illness. The knowledge gained from this study and further research in this phenomenon could be beneficial if applied to nursing practice. Applying this knowledge in practice could potentially facilitate better nursing care for these patients and their families, helping them to accept and adapt to the illness. Friedemann (1995) supported the importance of nursing’s knowledge of the family’s experience by stating, “A nurse needs to fully grasp the wealth and depth of each family’s experience before being able to enhance its health (p. 33). Greater efficacy in nursing care of these patients and their families could potentially result in improved patient outcomes, reduced recidivism, and a decrease in the overall cost of mental health care. It is evident through the literature, such as in Rose’s (1998) study, that the “complexities of the care giving role need to be investigated if effective interventions are to be realized” (Rose, p. 363). This study of the lived experience of family members of those who suffer from chronic mental illness would not only add to the foundation of
knowledge in nursing, but could potentially benefit other mental health professionals who are involved with treating the chronically mentally ill and their family members.

Assumptions

Assumptions in research studies refer to statements that are presumed to be true, although there may not be evidence to support them. Identifying assumptions within a study is considered introspective and positive (Burns & Grove, 2001). For example, when conducting a phenomenological study, to accurately understand the lived experience the way it really is, it is critical to liberate one’s own perceptions and judgments of the phenomenon being studied (Speziale & Carpenter, 2003). One assumption in this study was that the participants would express their experience as accurately and honestly as they perceive the experience. A second assumption, based on the literature reviewed and this researcher’s many years of providing nursing care for people with mental health disorders, is the profound affect that mental illness has on the family members of those who are mentally ill. Having a loved one who suffers from mental illness can profoundly affect the quality of life and the relationships within the family. Third, since this study was conceptualized within Friedemann’s FSO (1995), an underlying assumption can be made that if one part of the system (family) is affected, consequently other parts of the system (family) will also be affected.

Summary

Family health was equated to “congruence” in the family (Friedemann, 1995). Mental illness within the family can have a profound impact on “congruence,” within the family system. It is the hope of this researcher that from the findings of this study,
nursing will gain knowledge and a better understanding of the meaning of this experience for these family members to promote better patient outcomes. The following topics were discussed in this chapter: statement of the problem, the purpose, the theoretical framework, the research question, conceptual and operational definitions of terms, significance, and assumptions of the study.
CHAPTER II

Conceptual Framework

The purpose of this research study is to explore the lived experience of family members of those who suffer from chronic mental illness. First in this chapter, will be a discussion of Friedemann’s FSO (1995), used to conceptualize this study. Secondly, a review of literature is presented related to the lived experience of family members of those suffering from chronic mental illness. The review of literature was organized according to the most common themes found in the literature reviewed. These themes include caregiver burden, emotional response, resilience, and the unmet needs of families. The chapter concludes with a summary of previous research studies and the gaps of knowledge relevant to this study.

Friedemann’s FSO (1995) is an open systems model that provides a holistic approach and perspective that includes the world, environment, people and families. This model is a conceptual approach that integrates the nursing profession and families. The overall theme in Friedemann’s FSO is that all elements within the system strive for congruence. Friedemann explained the role of nursing in promoting health, which included involving the client’s family (system). Friedemann stated, “Although the goal of health belongs to the client system, nursing’s goal is the life process itself that encompasses both nurse and client as active participants” (p. 35). Friedemann’s model encompasses Fawcett’s (2000) nursing metaparadigm, which integrates the environment, person, health, and nursing, but expanded on these concepts. Friedemann’s model emphasizes the concepts of the family system and family health (Friedemann). This study
was conceptualized within Friedemann’s theory as the lived experience of family members of those who suffer from mental illness.

There are five major concepts in Friedemann’s FSO (1995), the environment, person, health, family and family health. Since this framework was based on interrelated systems and the fact that all parts are influenced by change, it is difficult to discuss only portions of this theory. However, for the purposes of this study, an explanation of the family and family health concepts are the concepts primarily discussed. In each of these concepts (e.g. family and family health), Friedemann provided what she identified as “propositions” which explain the characteristics of family, family health and the dynamics of how each concept relates to other parts of the system. For example, one of Friedemann’s propositions for family was, “The family satisfies its members’ needs for control over their environment and guides them in finding their place in the network of systems through spirituality” (p. 17). Other propositions of “family” include that the family is structured, organized and interacts with the environment. The family concept includes subsystems, emotional bonds and common responsibilities that define the structure. The propositions of the family concept can be contrasted with the propositions identified for the concept of family health, which includes satisfaction of all family members, positive environmental feedback and roles in the community and low levels of anxiety within the family (Friedemann). Friedemann’s family and family health concepts were conceptualized within this study as the researcher identified themes found in the participant interviews, as they described their lived experience of having a family member who suffers from mental illness.
Friedemann (1995) explained that systems are defined by their characteristic rhythms and patterns. The goal for the system is to interact in a rhythm to obtain the state of congruence. According to Friedemann, each system evolves from the environment and interacts with its surrounding environment. Specific to this study, the community support group (NAMI) was considered the surrounding environment of the family system, which has helped the family system to develop and adapt to the change required when someone in the family has mental illness.

In Friedemann’s FSO (1995) theory, humans derive their sense of purpose from their values, which serve as a foundation for emotional and intellectual experiences. When there is incongruence within the system, such as an individual with mental illness, anxiety increases in the remaining parts of the system. This increase in anxiety can obstruct the path to congruence. Congruence refers to the state in which energy flows between systems in a compatible, rhythmic pattern. The state of congruence is a desire of all systems. According to Friedemann, “a state of congruence among people and social systems on earth is Utopia” (Friedemann, p. 6).

According to Friedemann (1995), in order to reach congruence, the human system organization uses various strategies to decrease anxiety within the system. In Friedemann’s theory, there are four “system targets.” They include: stability, growth, control and spirituality. According to Friedemann, these four targets “interact with each other along the system periphery to form a dynamic equilibrium through which the health system continuously adjusts to find congruence between its own order and that of its environment” (p. 7). How each individual learns behaviors to reach these targets is unique.
and occurs over time. The behaviors learned were included in Friedemann’s theoretical domains, referring to them as the process dimensions. These process dimensions include system maintenance, system change, coherence and individuation (Friedemann).

Friedemann (1995) has defined these process dimensions. In system maintenance, the primary focus involves the targets of “stability and control” (p. 10). System maintenance includes those behaviors that keep the system together and attempt to protect the system from change. This dimension involves the roles, rules, organizational patterns, rituals, decision-making, power structure, division of labor within the family system and the family’s ability to cope with stressors (Friedemann). The dimension of system change refers to the changes resulting from shifts in the usual value systems. System change targets growth and control. System change is the process dimension that incorporates new patterns of behavior. The third process dimension, “coherence” represents the relationships within the system. Coherence targets spirituality and stability. The dimension of “individuation” focuses on altering attitudes and learning of new information. This includes exchanging information with others. Individuation targets spirituality and growth. Both family and individuals explore new values through communication, which initiates a system change (Friedemann, 1995).

Friedemann’s FSO (1995) empowers the individual within the family system to set goals, focusing on their strengths and congruency within the family system process. The model, like nursing, supports a holistic approach in attaining congruence and health for the individual and the family. Friedemann emphasized the need for systems (families) to maintain a balance, with lower levels of anxiety, within the system otherwise there is
incongruence. Values and belief systems of the individual can influence of the system’s ability to reach congruence. Friedemann stated that, “Humans involved with systems that fail to reflect their own values and beliefs experience incongruence” (p. 6). Applied to this study, the researcher explored, how and if, family members of those who suffer from mental illness are able to buffer the anxieties of chronic mental illness in the family.

Friedemann conceptualized her theory in the following model (Figure 1).

![Figure 1-Friedemann’s Life Process of Human System](image)

Depicted in Figure 1 is Friedemann’s Life Process of the Human System (1995). This model depicts a schematic drawing of Friedemann’s basic processes that are used by human systems to reach congruence and cope with anxiety. Friedemann points out that the model could be used to explain all social systems and their targets: stability, growth, control and spirituality. How each individual in the system develops and engages in behavior to attain these targets are unique to the individual. The strategies used were obtained from their environment and are organized into the four dimensions: system maintenance, system, change, coherence and individuation (Friedemann).

In Figure 2, Friedemann (1995, p. 147) used a schematic drawing to depict a family in crisis. This drawing provides an example of the structural changes in the family system when in crisis. Friedemann explained that during a family crisis, system maintenance (SM) and coherence (c) are decreased within system congruence (1995). In a mental health crisis (see Figure 4) for example, according to this theory, one could expect structural changes within the family system.
Figure 3, depicts Friedemann’s (1995) model of the “desired family process” (p. 273). In this model, all systems within the family are in balance. All areas are drawn equal in size to indicate that one area is not overpowering the other and in this drawing, the system has adjusted to change, therefore congruence is present. “I” indicates individuation, “C” indicates coherence, “SM” indicates system maintenance, and “SC” indicates system change. In contrast to Figure 2, Individuation and system maintenance are present in Figure 3. Friedemann explained that individuation results when meaningful experiences in the care giving process occur and mastery of the situation exists, with new system maintenance strategies. In this drawing, all members of the family have their needs met, evidenced by all areas being present and drawn equal size (p. 273). Using
Friedemann’s FSO, the findings of this study were compared to the desired family process.

A modified model, based on Friedemann’s FSO (1995) is depicted in Figure 4. This modified model was used in this study to discover the lived experience of family members of those who suffer from mental illness. This model was an interpretation of how this study was conceptualized in Friedemann’s theory. In Figure 4, system maintenance was shown in the drawing to indicate that all of the family’s energies were

Figure 3- Friedemann’s Systemic Organization
Desired family process

focused on trying to cope with their family member’s mental illness. This model was based on the assumption that having someone in the family being diagnosed with mental illness may create a crisis for them and that the family has not yet reached a level of acceptance and developed in this area. Comparing Figures 3 and 4, the desired family process was depicted in Figure 3, whereas in Figure 4, one can note that system change, individuation and coherence are not present. These dimensions are not shown in Figure 4, based on the assumption that the family depicted in the model has not adapted to the change. The dimension of system change according to Friedemann is the family’s ability to adjust to major changes, such as mental illness. The dimension of individuation is how the individual within the system develops. The dimension of coherence refers to emotional bonding and the family’s identity (Friedemann). Assisting patients and families to adapt to mental illness can be facilitated by improved nursing care. Qualitative research on the phenomenon may be able to provide direction for improving nursing care to these patients and their families if research data could be applied to practice.
Figure 4-Chronic Mental Illness
Adapted from Friedemann’s Systemic Organization Model of the Desired family process

Review of Literature

The following review of literature presents a discussion of selected studies that related to the experiences of families of those who are mentally ill. Not only is there a lack of research on this subject matter in nursing, but other mental health disciplines as well. Within this group of studies, only one study by Meadus and Johnson (2000) used the approach of phenomenology for their study of the lived experience of being a family member of someone who is mentally ill. The research studies reviewed here are primarily from nursing, but studies done by other mental health professionals are also included.

The following is a discussion of the literature reviewed. The review of literature was presented according to the common themes found in the literature reviewed which included: caregiver burden, emotional responses, resilience and unmet needs of families.

Caregiver Burden

The most common theme found in both recent and earlier literature relates to the caregiver burden suffered by these family members (Ferriter & Huband, 2003, Gallagher & Mechanic, 1996; Hatfield, 1978; Johnson, 2000; Levine, Lancee & Seeman, 1996; Marsh & Johnson, 1997; Meadus & Johnson, 2000; Provencher, Perrault, St-Onge, & Rousseau, 2003; Rose, Mallinson, & Walton-Moss, 2002; Silver, 1999). One of the studies by Gallagher and Mechanic (1996) looked at the physical effects of this burden on families who live with members who are chronically mentally ill. Research on the physical burden on those caring for the mentally ill is limited compared to the volumes of research done on the effects of caregivers of physical illness. Gallagher and Mechanic emphasized that research is limited in the area of the physical burden on these families.
Such data is significant since the effects of physical burden on these family members can potentially have a negative influence their quality of life. In Gallagher and Mechanic’s study, probability sampling was used. Their sample included 776 participants who were family members of someone with severe mental illness. Using descriptive statistics, they compared the effects of those living with and without someone who is mentally ill. Three measures of health were used. The participants self-reported health, medical services used, and limitations in activity. The participants who lived with someone mentally ill reported significantly poorer health than those who did not live with someone mentally ill. The use of medical services was higher for those who lived with someone mentally ill compared to family members who did not live with someone who is mentally ill. Activity limitations had also increased. Despite these findings, the results did not support their hypothesis, which was to show that duration and severity of mental illness had a measurable impact regarding the health of the non-ill family member.

Another significant finding in Gallagher and Mechanic’s (1996) study were the findings that supported that the gender of the ill family member did have an impact on the results of their study. For example, this study showed significant health effects on the non-mentally ill family members when the ill family member was male. The results of the study indicated that those living with ill males had an increased number of medical services and activity limitations. They noted that these findings were consistent with previous research that men who were mentally ill tend to “engage in more disruptive behavior than mentally ill women-producing greater distress” (p. 1699).
In Gallagher and Mechanic’s (1996) study, another hypothesis that was supported by their findings was that overall, poorer physical health of the non-ill member was found to be greater when caring for an adult child as opposed to, for example, a spouse. This study provided data that were not found previously. The author concluded and acknowledged the increased burden placed on families since the deinstitutionalization of the mentally ill. Not only are these family members negatively affected physically, but also an additional financial burden is often placed on these families (Gallager & Mechanic).

In the study by Meadus and Johnson (2000), the theme of burden is also present. This was the only phenomenological study found in the literature. The purpose of this study was to gain insight into the experience of the adolescent child who has a parent with mental illness. A limitation of the study was that only 3 participants were used and they were all female. Data were collected using audiotaped interviews. Three themes were identified in the study. One of the emerging themes was the burden that these adolescents struggle with in “coming to terms” with having a mentally ill parent and trying to understand the whole concept of mental illness. The study found that all 3 of these adolescents attributed this burden not only to “coming to terms” with the illness, but also the stigma of mental illness. Common coping behaviors reported from the study for these adolescents were humor, detachment, anger, talking with others and coping with their family member’s mental illness as they would cope with a physical illness. This study is different from the other studies reviewed because most of the studies focused on
one of the children being ill, whereas this study offers a different perspective from the child of a mentally ill parent.

*Emotional Responses*

Various emotional responses were found in the studies reviewed in the literature. The most frequent emotions mentioned among family members of a loved one with mental illness were feelings of loss and grieving the loss of who their family was before the onset of the illness. Ferriter and Huband’s (2003) study included a random sampling of 44 parents of patients with schizophrenia from an inpatient forensic hospital in the UK. Various measurements and interviews and various scales were used in their study. In the transcripts from the Focused Life Story Interview—feelings of loss and of what might have been were found in 91% of the interviews.

The feelings of grief and loss by family members were commonly referred to in the literature (Bland & Darlington, 2002; Ferriter & Huband, 2003; Hatfield, 1978; Meadus & Johnson, 2000; Riebschleger, 1991; Rose, Mallinson & Walton-Moss, 2002; Rose, 1998). The feelings of grief and loss experienced by these family members were supported in Riebschleger’s (1991) qualitative study involving 20 adult siblings of chronically mental ill family members. Eight questions were used in the interviews. One of the questions was, what was their initial response, as the sibling, when they realized their brother or sister was mentally ill? All 20 interviewed responded that their reaction was intense grief. “Siblings reported that they grieved the loss of the formerly healthy person who would perhaps never be the same as before the onset of mental illness” (1991, p. 96).
Riebschleger (1991) discussed that the loss experienced by these participants is similar to the five stages of grieving that have been previously documented by Kubler-Ross (1969). For those who chronically dealt with the mental illness, this process did not necessarily progress in order from one stage to the next. The study indicated that a common pattern was to move through the stages of anger, bargaining, depression and relief/respite (p. 3). The participants expressed often times they would fluctuate back and forth through the various stages. One of the participants, a sibling of someone mentally ill, discussed what it was like having a healthy brother and watching him, “go from the promising young man to this ghost-this shell of a person-in 18 months” (p. 4). Feelings of grief and loss were major findings in this study. These participants also added that various factors affected how they coped with their grief. These factors included having mixed emotions, particular difficulties if the onset of illness began in adulthood, the unpredictable course of the illness and the lack of information they received from the mental health professionals.

Emotions of grief and loss experienced by the family member were also found to be significant in Rose’s (1998) study, only from a different perspective than Reibschleger (1991). Rose did an interpretive study to determine the meaning of the care giving experience for 15 family caregivers. In depth interviews were conducted with these participants. The findings of this study, indicated these participants also experienced grief and loss, yet said they were able to manage these emotions by helping to motivate their family member to reach goals. This also gave these family caregivers a sense of control over the situation. This author did point out that previous studies have supported the fact
that these caregivers do suffer from a loss and have difficulty “acknowledging the stranger within” (Rose).

Resilience

As stated earlier, caregiver burden is a theme that was prevalent throughout the literature. In contrast, two studies completed by Marsh and Leafy (1996), and Jubb and Shanley (2002) provided a different perspective, which was the theme of resilience in family members of those who are mentally ill. A literature review by Saunders (2003) had also focused on resilience in these family members.

Though Marsh and Leafy’s (1996) study focused on resilience, they acknowledged the difficulties and burdens placed on the family because of chronic mental illness. In fact they describe that it is a “catastrophic event for families” (p. 1). They quote one of the family member’s as saying, “This terrible disease colors everything, a family cannot escape” (p. 1). Marsh and Leafy expressed that much of what had been published regarding families is related to the negative burden of these families, to the point that it has become part of the defining characteristics. They wanted their study to include a different perspective of the family experience in addition to burden, resilience. They defined resilience as the “ability to rebound from adversity and prevail over the circumstances of our lives” (p. 2).

Marsh and Leafy’s (1996) qualitative study included 131 participants who were family members of people with mental illness and recruited through the National Alliance for the Mentally Ill (NAMI). The sample was predominantly older family members, the majority of the participants were white, and less than 3 % were of another other race. This
study also provided the percentages of family members with various diagnoses. This information was not provided in the other literature reviewed. For example, the primary diagnoses of their relatives included 53.4% had been diagnosed with schizophrenia, 13.7% with schizoaffective disorder and 16% with bipolar disorder. Other diagnoses of mental disorders were the remaining percent. Some of the ill relatives had more than one mental disorder diagnosis. Open ended questions relating to family resilience were used to explore the family member’s experiences (Marsh & Leafy).

The results were both significant and surprising in comparison to those studies on the burden of mental illness within the family. Marsh and Leafley (1996) reported that family resilience was reported by 87.8% of the participants. The dimensions of resilience included bonds and commitments, family strengths and resources, family growth and development, family contributions and family gratification. Of these dimensions, 58% of the participants related resilience to the bond and commitment to the ill member. Several vignettes from this study demonstrated that resilience is part of the family’s experience. One mother was quoted: “I thought my son’s tragedy would completely ruin our lives because it broke our hearts. But we’ve learned-finally, painfully not to let this tragedy totally dominate our lives” (p. 6).

Yamashita’s (1998) study can be contrasted with Marsh and Leafley’s (1996) study. This was the only other study reviewed that looked at mental illness within the family from a perspective other than burden. In Yamashita’s study, the term “resilience” was not used, although a similar concept was used but was referred to as a, “transformation process,” based on the “unitary transformative paradigm” from Newman’s theory (1998). This study
had been conducted in Japan and Canada. One may also note that this was the only study in the literature reviewed that used a theoretical framework within nursing for their study. In contrast to Marsh and Leafley’s study, the sampling was significantly smaller and from different countries. Yamashita’s participants included 12 Canadians and 14 Japanese family members. In addition, in Yamashita’s study, all the ill family members had the diagnosis of schizophrenia.

The methodology was similar in both studies. Both studies conducted interviews to obtain their data. The frequency of the collection differed. Yashamita (1998) interviewed both the Canadians and Japanese once during a 2-week interval and then 1 year later, as opposed to Marsh and Leafley’s (1996) study, who did not include a follow-up interview. However, though there are notable differences in both studies, the results are similar.

These studies are similar in that the participants in both studies, Yashamita (1998) and Marsh, and Leafley (1996), were able to view caring for their mentally ill family member as more than a burden. Yashamita’s study showed that despite society’s view of mental illness, these participants viewed caring for their ill family member as something other than a burden and viewed the experience as one that was transformative and that had strengthened the family bond. Yashamita acknowledged that the participants did express negative aspects, such as burden, but this was not the prominent theme in their findings.

Unmet needs of families

Numerous studies reviewed in the literature discussed the needs of the family members of the mentally ill, from the family member’s perspective. Unfortunately, the majority of the studies reviewed (Bland & Darlington, 2002; Corring, 2002; Dixon, 1999;
Doornbos, 2001; Ferriter & Huband, 2003; Jewell & Stein, 2002; Johnson, 2000; Jubb & Shanley, 2002; Meadus & Johnson, 2000; Provencher, Perreault, St-Onge & Rousseau, 2003; Riebschleger, 1994; Rose, Mallinson & Walton-Moss, 2002, 2004) provided a family member’s perspective, regarding their needs not being met from mental health care professionals. The most common unmet needs expressed from family members found in the literature were, lack of communication, lack of involvement in the treatment plan, receiving limited information regarding the diagnosis, how to cope with the illness and available community resources.

Two significant studies by Ferriter and Huband (2003) and Doornbos (2001) support the existence of unmet needs of family members. In Ferriter and Huband’s study, the participants were the parents of 22 patients diagnosed with schizophrenia. All of the patients were in a secure forensic setting. Taped interviews were conducted with these parents. The results of the study indicated family members found other family members and friends to be most helpful and supportive. The participants expressed the strongest negative emotions regarding their interactions with the mental health professionals. Out of 22 parents, 21 expressed that they felt neglected. Of the 21 parents, 10 felt neglected by the psychiatrist and five felt neglected by the nurses. The participants reported feeling angry with the psychiatrist and nurses. The participants experienced the most difficulty in obtaining information regarding their son’s or daughter’s diagnosis. The participants also commented on the fact that they had received limited information on what to expect from their mentally ill family member. Results indicated that these family members needed direction in caring for their family members with mental illness. In the participant’s responses, with strong
emotion, they had expressed that the great stress and burden of mental illness, was not alleviated by their interaction with mental health care professionals.

In comparison, the study by Doornbos (2001) also focused on the unmet needs of family members with mental illness. This study used a convenience sampling of 126 participants, recruited from NAMI chapters from across the United States. The Professional Support Questionnaire was administered with the participants rating the various items on the scale. The scaled items were relevant to the support received from mental health professionals. One of the results reported had indicated that 30% of the participants felt the communication regarding their role, as a caregiver was not respected. The results suggested that high percentages of family caregivers did not receive supportive information.

Doornbos (2001) suggested that supplying a family with information regarding illness, treatment, referrals, resources, giving support and respect are basic to the role of professional nurses (p. 43). Both of these studies, and those listed earlier, provided supporting evidence that mental health professionals may not be providing families with the support they need. Further knowledge of the lived experience of these families could provide nursing with an increased understanding of this phenomenon so that they are better able to meet the needs of their mentally ill patient’s family members.

Summary

Provided in this chapter is an overview of Friedemann’s (1995) Framework of Systemic Organization theory and how the study was conceptualized within this theory. Using this theory, the impact of mental illness within the family was explored. In this study, the family member’s experience was discovered and provided valuable
information regarding how the mentally ill family member affects the family system in their struggle for congruence.

The review of literature provided a foundation of knowledge for exploring the lived experience of family members who suffer from mental illness. Though there are studies related to the effects on the family, they are limited in the area of nursing. This was supported in Saunders (2003) literature review. Saunders discussed the need for further research that assumes a holistic approach, including common stressors and health consequences of the role of the caregiver. Saunders stated, “Currently the literature comes from broader social science literature, not nursing literature” (p. 191). Nursing literature is limited, yet as nurses, we have the greatest opportunity to provide the support these families need. The literature supports the importance of the family’s role to improve outcomes for those who are mentally ill. As mental health care is changing, and funding is dwindling, the families of the mentally ill are their primary supports. Since nursing strives to provide a holistic approach in their care of patients with mental illness, there is an obligation to increase knowledge and understanding of what the meaning of this experience is for these family members. Such knowledge is imperative if it could ultimately improve the quality of life for those who are mentally ill and their loved ones.
CHAPTER III

Method

The purpose of this study was to explore the experiences of individual family members who have lived with a family member who suffers from chronic mental illness. This chapter provides an explanation of the study design, selection of participants for the study, and the procedure that was followed to protect the participant’s rights. Also included in this chapter is a description of the materials that were used in the study, along with the method for data collection and data analysis.

Design

A phenomenological research design was used in this study to explore the lived experience of family members of those who suffer from chronic mental illness. A holistic approach is fundamental to nursing practice. To provide a holistic approach when caring for those who suffer from mental illness, nursing needs to include family members in the plan of care. To effectively include family members in caring for those who are mentally ill, it is essential that nursing obtain the knowledge and understanding of the lived experience of family members who have a loved one who suffers from chronic mental illness. To add to nursing’s knowledge and understanding of this phenomenon, the research design chosen for this study was phenomenology. Using phenomenology allows the researcher to obtain the meaning of a phenomenon from those who are truly living the experience. Phenomenology is the study of the meaning of what is experienced in everyday life in the world (Van Manen, 1990). The research question is: “What is the lived experience of family members of those who suffer from a chronic mental illness?”
Participants

In qualitative research studies, one cannot predict the precise number of participants prior to the onset of the study. The researcher ceases the search for further participants for the study when saturation is achieved (Burns & Grove, 2001). Saturation as defined by Morse (1994), cited in Speziale and Carpenter (2003), “refers to the repetition and confirmation of previously collected data” (p. 25). In this study, this researcher predicted that saturation would not be reached due to the limited number of participants in the study related to the limited time frame permitted for the study. Using a purposive sampling, there were 5 participants in this study. Purposive sampling was defined as, “conscious selection by the researcher of certain subjects or elements to include in the study” (Burns & Grove, p.376). The participants were members of a volunteer organization, identified as The National Alliance for the Mentally Ill (NAMI). NAMI is a non-profit, consumer support and advocacy organization for families and friends of those who suffer from chronic mental illness. Representatives of the local NAMI chapters were informed of the study and permission obtained to seek volunteers for the study. Participants for this study were voluntary and gave a verbal consent so this would be the only connection the researcher would have with the participant. The interview for the study was conducted with the participants in a “natural setting,” a location of the participant’s preference and agreed upon by the researcher. According to Burns & Grove, the natural setting refers to the environment in which the study is conducted, that has not been altered in order to accommodate the study. The location
selected for this study maintained a natural setting for the participants, for their convenience and protection of their privacy.

Along with being NAMI members, inclusion criteria were used in obtaining participants for the study. Inclusion criteria referred to characteristics or conditions of the participant that must be met in order to be a part of the study (Burns & Grove, 2001). Participant criteria for inclusion were: (a) they were a family member of an individual treated by a psychiatrist or at some time was treated by a psychiatrist and diagnosed with a mental disorder that is listed in the Diagnostic and Statistical Manual of Mental Disorders IV-TR (b) they were able to speak and understand English (c) they were 18 years of age or older (d) agreed to be tape-recorded, and (e) agreed to participate in the study.

Materials

One of the techniques used in qualitative research to obtain data is through an open-ended, unstructured interview. Each participant in this study will have one open-ended, unstructured interview 60-90 minutes in length. Van Manen (1990) explained how this type of interview was advantageous by stating, “it provides greater latitude in the answers provided” (p. 28). In an unstructured interview, open-ended questions are used. Open-ended questions are those questions that require more than a one-word answer (Egan, 2002). Examples include, what has been your experience of living with your family member who has a chronic mental illness? Or, tell me about what it is like to have a family member with mental illness. Both verbal and non-verbal prompts were used in the dialogue. Verbal prompts used included, “uh-huh,” “I see,” “oh,” “um” (Egan). Using
prompts helps to engage the participant and encourages them to continue talking about their experience. Non-verbal prompts refer to body gestures, movements, nods and eye contact (Egan). This researcher used open-ended questions and probes to encourage and prompt the participant to provide a further description of their experience. Such an approach provided direction and focus to the interaction. With verbal consent from the participant, the interview was audiotaped. Each participant was informed that the interview was going to be audiotaped. Their continued participation reaffirmed their consent to participate. This researcher then transcribed each of the audiotaped interviews. For all of the participants, the first portion of the interview was obtaining demographic information. Demographic information obtained included age, sex, race, marital status, education level, employment status, relation to patient, diagnosis of family member, length of time family member has had the diagnosis and their role in caring for the family member. During the remainder of the interview, the participant was asked, “What is your lived experience living with someone who suffers from a chronic mental illness?”

Data Collection

During the initial contact of potential participants at the NAMI site, the researcher arranged the interview date, time and location. Ideally, scheduled follow-up interviews would have been desired to obtain additional information from the family member and review the data with the participant. However, to protect the confidentiality of the participant, this researcher did not contact the participant after the initial interview. The participant was asked to contact the researcher in 2-4 weeks after the initial interview. The researcher could then clarify any areas of the interview that were unclear to the
researcher and this would provide an opportunity for the participant to add any information. The participant was provided with the researcher’s contact number. None of the participants contacted the researcher after the interview.

Protection of Human Rights

To protect human rights, the Institutional Review Board of the Medical College of Ohio approved this study. Verbal permission and a written consent (Appendix A) inviting NAMI members to participate in this study was obtained from the NAMI Ohio Board representative and president of the NAMI chapter in northwest Ohio. The participants were informed prior to obtaining their consent, that involvement in the study was voluntary and that they could withdraw their participation in the study at any time without consequences. The researcher provided each participant with written and verbal information about the study. Participants were given time to ask any questions regarding the study and their involvement in the study. The researcher obtained verbal consent and completed an information sheet that was reviewed with the participant at the time of the scheduled interview. The information sheet did not have the participant’s signature. In addition, to preserve the participant’s confidentiality, identifying information was not on field notes or other documentation that could have been connected to the participant. This researcher followed the guidelines and regulations for Human Participant Research, as defined by the National Institutes of Health, in order to protect the rights of the participants in this study.

The audiotapes, transcripts and information sheets were kept in locked files located in the principal investigator’s office during the study and then for another 7 years.
After the seven years, the data will be shredded and destroyed. As stated earlier, the participant’s names will not appear on the transcripts or field notes. The researcher will assign a number code (1, 2, 3...) to each of the participants to preserve anonymity. To ensure accuracy and clarity of the participant’s response, the researcher plans to clarify with the participant their responses while the interview is in progress.

Data Analysis

Prior to this researcher gathering data from the participants, it was essential for the researcher to put aside any prior preconceived ideas or biases related to the research topic. Speziale and Carpenter (2003) referred to this concept as bracketing. Bracketing allows the researcher to approach the research phenomena with an open mind and minimal bias (Speziale & Carpenter). Prior to initiating this study, this researcher believed that chronic mental illness may have a significant impact on the family member’s quality of life. This researcher believed mental health care professionals have often overlooked this crucial aspect of care. Knowledge about this population is extremely important for the simple reason that these family members are often the mentally ill patient’s primary and only support. The research data obtained from this study, and further research in this area, could be beneficial if applied to nursing practice. Applying this knowledge to practice could potentially facilitate better nursing care for those who suffer mental illness and their families.

The phenomenological method used for data collection and analysis in this study will be based on Van Manen’s (1990) method. Van Manen described six methodological themes, which will be applied in this study. These themes “offer the kind of practical
approaches that may be helpful in doing hermeneutic phenomenological human science research” (p. 30). Van Manen’s themes include: turning to the nature of the lived experience, investigating experience as we live it, reflecting on essential themes, the art of writing and rewriting, maintaining a strong and oriented relation and balancing the research context by considering parts and whole (p. 31). The following provides a more in depth description of Van Manen’s methodological research activities:

1. Turning to the nature of the lived experience

This researcher conducted an unstructured interview with each participant. Each participant was asked, “Tell me about your experience of having a family member who suffers from chronic mental illness.” This allowed the researcher to learn from the participant the meaning of their experience within the phenomenon of study. These data are particularly valuable and relevant because the true meaning of the experience can only be obtained from someone who is actually living in this context. Each experience is unique and can only serve to enrich what is known or not known about the phenomenon. The phenomenological question for this research study is what is the lived experience of family members of those who suffer from chronic mental illness?

2. Investigating experience as we live it

In phenomenology, the underlying philosophy of the research method is that the researcher seeks to learn about the experience from those living it, as opposed to speculating what it would be like. Based on Van Manen’s (1990) philosophy,
conducting the interview with open-ended questions and prompts allows the participant to give a full description of their lived experience.

3. Reflecting on essential themes

Theme analysis in this study refers to the process of recovering the themes that are buried within the lived experience of being a family member of one who suffers from chronic mental illness. The interviews were transcribed verbatim and the phenomenon analyzed. Van Manen (1990) explained, “The insight into the essence of a phenomenon involves a process of reflectively appropriating, of clarifying and of making explicit the structure of meaning of the lived experience” (p. 77). Once the researcher transcribed the participant interviews, the researcher then searched for the “essences” within the themes. Van Manen explained essence in phenomenology, “as a universal which can be described through a study of the structure that governs the instances or particular manifestations of the essence of that phenomenon” (p. 10).

To explain what was meant by themes in phenomenology, Van Manen used metaphors, referring to themes as,

knots in the webs of our experiences around which certain lived experiences are spun and thus lived through as meaningful wholes. Themes are the stars that make up the universes of meaning we live through. By the light of these themes, we can navigate and explore such universes (p. 90).

One can infer from these metaphors that the themes found within the responses of the participants are only a portion of the whole experience of the lived experience of having a
family member who suffers from chronic mental illness. In other words, the themes are only a part of the complete lived experience, a portion of the phenomenon that we are studying.

4. The art of writing and rewriting

Once the themes were developed from the data, according to Van Manen’s (1990) methods of phenomenology, the researcher begins to engage in phenomenological writing. The researcher writes about the common themes to capture the essence of their meaning. Van Manen described how this process helps the researcher to analyze and extract the meaning of the lived experience of family members of those who suffer from chronic mental illness. He proposed that, “writing distances us from the lived experience but by doing so it allows us to discover the existential structures of experience” (p. 127). The process of writing and rewriting is the art of the method used in the study. Van Manen explained that, “the process of writing and rewriting (including revising or editing) is more reminiscent of the artistic activity of creating an art object that has to be approached again and again…” (p. 131). Through this process, the researcher develops a narrative text of the lived experience of family members of those who suffer from chronic mental illness.

5. Maintaining a strong and oriented relation

To remain true to the research the researcher is absorbed in the phenomenon and does not become distracted. During this stage, the researcher is involved in a thoughtful analysis of the themes, staying focused on the lived experience of the
participants. The researcher does not become distracted and settle for premature speculations or “narcissistic reflections” (p. 33). The researcher determines through data analysis which themes are most essential in presenting the phenomenon of the lived experience. Van Manen (1990) further explained what he meant by maintaining a strong and oriented relation. He stated, “To be oriented to an object means that we are animated by the object in a full and human sense. To be strong in our orientation means that we will not settle for superficialities and falsities” (p. 33).

6. Balancing the research context by considering parts and whole

Common themes from the interviews were extracted in the data analysis. The researcher maintained the focus of the study and persevered in the pursuit of answers to the research question, what is the lived experience of family members of those who suffer from chronic mental illness? It was necessary for the researcher to take a step back, look at the larger picture along with the parts that make up the whole.

Summary

One of the main topics discussed in this chapter was the study design used in this research study. Van Manen’s (1990) phenomenological research method was used to explore the lived experience of family members of those who suffer from chronic mental illness. Along with study design, the selection of participants for the study, the research study setting, materials used, data collection and data analysis was discussed.
CHAPTER IV

Results

The purpose of this study was to explore the lived experience of family members of those who suffer from chronic mental illness. In this chapter, the results of this study are presented. Five essential themes were discovered from the reflection of the transcribed interviews with family members as they shared their unique lived experience as a family member of one who suffers from chronic mental illness. Although these themes alone could not provide a comprehensive description of this phenomenon, the themes discovered in this study provide valuable data in building the structure of this phenomenon. The essences of these themes will be elicited in excerpts taken from the participant’s interviews as they described their lived experience of a family member of one who suffers from chronic mental illness. Themes are at an abstract level conceptualized in a theoretical framework and at the level of the discipline. Van Manen’s (1990) method of phenomenology was used as the method for data collection and analysis in this study. For further explanation of Van Manen’s method the researcher recommends the reader refer to Chapter III. Friedemann’s FSO (1995) theory was used to guide this study.

Participants

Five participants volunteered from a local consumer support organization identified as NAMI (National Alliance for the Mentally Ill). Table 1 identifies the demographics of the participants in this study. Three of the participants were female and two were male. All participants were married and Caucasian. All of the participants had
at least some college education. The participant’s relationship and role in caring for their ill family member included: 2 participants were fathers, 2 participants were mothers and 1 participant was the sibling of the mentally ill family member.
Table 1

Participants Demographic Data

<table>
<thead>
<tr>
<th></th>
<th>Participant #1</th>
<th>Participant #2</th>
<th>Participant #3</th>
<th>Participant #4</th>
<th>Participant #5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
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<td>68</td>
</tr>
<tr>
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</tr>
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<td>Graduate School</td>
<td>College Graduate</td>
<td>Some College</td>
</tr>
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<td>Employment Status</td>
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<td>Part-time</td>
<td>Unemployed Housewife</td>
<td>Retired</td>
<td>Part-time</td>
</tr>
<tr>
<td>Relationship to Patient</td>
<td>Father</td>
<td>Mother</td>
<td>Sibling</td>
<td>Father</td>
<td>Mother</td>
</tr>
<tr>
<td>Diagnosis of Ill Family Member</td>
<td>Bipolar disorder</td>
<td>Paranoid Schizophrenia</td>
<td>Bipolar disorder</td>
<td>Schizophrenia, Residual Type</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>Length of time family member has been diagnosed with mental illness</td>
<td>4 years</td>
<td>37 years</td>
<td>16 years</td>
<td>9 years</td>
<td>20 years</td>
</tr>
<tr>
<td>Role in caring for mentally ill family member</td>
<td>Father</td>
<td>Mother</td>
<td>Sister</td>
<td>Father</td>
<td>Mother</td>
</tr>
</tbody>
</table>
The participants reported their mentally ill family member as having a chronic mental illness according to the *Diagnostic and Statistical Manual of Mental Disorders-IV*. The participants in this study had family members who had a diagnosis of bipolar disorder or schizophrenia. It is important to note that the ill family members of these participants were not coping with a recent diagnosis of mental illness. The length of time the participant’s family member had been diagnosed with a chronic mental illness ranged from 4 to 37 years.

**Findings**

Following Van Manen’s (1990) method of phenomenological reflection, five themes were identified as structures of the lived experience of family members of those who suffer from chronic mental illness:

**Theme One:**

The participants experienced negative emotions regarding unmet needs, the stigma of mental illness and the incongruence within the environment including the community mental health resources.

**Theme Two:**

In the midst of system change, the participants experienced coping with multiple stressors that stemmed from the unpredictable and somewhat overwhelming symptomatology and behaviors. The participants experienced emotional burden, financial burden, anticipatory fear, worry and lack of trust.

**Theme Three:**

Family members of those who suffer from chronic mental illness identified the
effects of system change on the family system when a family member suffers from mental illness.

Theme Four:
Family members of those who suffer from chronic mental illness identified a lack of control over changes occurring within the system; lacking knowledge of what was going on with their family member or what it meant for their family member to be diagnosed with a mental illness.

Theme Five:
The process dimensions of coherence and individuation led to spirituality, which provided the strength, faith, courage, and resilience that facilitated the ability of family members of those who suffer from chronic mental illness to endure and reach a level of acceptance of the mental illness.

The essence of the lived experience of a family member of one who suffers from chronic mental illness was portrayed through their responses when asked by the researcher to describe their experience. Each theme will be presented along with supporting verbatim data from the participants. The names of the participants and identifying information used in this chapter have been changed by the researcher to protect the privacy of the participants. Each participant was assigned a fictitious name to protect his or her privacy.
Theme One:
The participants experienced negative emotions regarding unmet needs, the stigma of mental illness and the incongruence within the environment including the community mental health resources.

The participants expressed feeling frustrated with the lack of support received from mental health professionals. This included frustration with the psychiatrists, the mental health professionals and overall lack of support from their local community mental health system. The participants also thought that the stigma of mental illness was partly responsible for the lack of support they received.

Jan, a 73-year-old mother of a son who suffers from paranoid schizophrenia, expressed the frustration with the psychiatrists that her son has been to see. Jan experienced additional burden because she was unable to find a psychiatrist for her son. She stated:

Because of the stress, is really at times, you think to yourself, you just can’t stand anymore. But when you don’t have a good, qualified psychiatrist to lean on, then, it means that you have to take the bull by the horns.

Jan shared her experiences of taking her son to his psychiatrist appointments. Jan had taken her son to a local psychiatrist after the initial diagnosis of paranoid schizophrenia was made during his first hospitalization. Jan described her son’s response to his first appointment. She relayed what her son had said to her, “Mom I think that guy, that doctor needs a psychiatrist.” She agreed with her son and after taking him to a few different psychiatrists her impression was, “I think some psychiatrists need two or three
psychiatrists. Who are they trying to be, God?” Frustrated with the local psychiatrists, Jan has sought mental health treatment for her son from a primary care physician. The primary care physician has been prescribing her son’s antipsychotic medication since he was diagnosed with schizophrenia 37 years ago.

Tony, a 53-year-old father who has a son diagnosed with bipolar disorder, discussed what it was like for him when he accompanied his son to an office visit with his psychiatrist. He had difficulty understanding the reasons why the psychiatrist was using the particular treatment approach regarding his son’s medication management.

It was interesting in dealing with the psychiatrist, the whole medication issue gets interesting and how they end up deciding what medications to try or not try when to increase things. There would be times when I…he’d ask my son or he’d ask me if he needed an increase in dosage and stuff, so at times he’s asking for our opinion which surprises me. And there are other times when we’ve expressed our opinion and then it’s like “no, no…this is exactly what he needs and we’re not going to change things.” So that’s been kind of interesting how that goes.

Of the 5 participants, Jim expressed the strongest feelings regarding the frustration that he has experienced. Jim is a 70-years-old father, whose son suffers from schizophrenia. He expressed feeling resentful that it had taken years to get an accurate diagnosis for his son and then the appropriate treatment. He attributed most of the frustration to the difficulties experienced in getting cooperation from the mental health professionals. He was disappointed in his hospitalizations and expressed that the mental
health care professionals did not listen to him when he tried to tell them about his son’s
behaviors. Jim shared his experience of his son’s first hospitalization:

We had him committed when he was 18yrs old to a psychiatric ward and a… he
was sleeping all day, up all night, maybe he was on drugs. I didn’t like the kids
he was hanging around, things were missing from our house all the time. And
a…found out later on…that even though he was going to a psychiatric hospital,
and he was under lock and key, he was sneaking in drugs [into the hospital] in
his shoes. We found out later on. He was even getting by the staff at the
hospital. It became a joke; the whole situation did because he never did improve
as a result of it. And I regretted it…and he was never officially diagnosed with
anything at that time.

Jim discussed numerous times when he and his wife had attempted to seek treatment for
their son from psychiatrists, courts and counselors. Feeling frustrated and resentful he
stated, “I couldn’t get help from anybody! Not the professional people, not the doctors,
courts….” For years, Jim tried to work with various agencies and mental health resources
and felt he did not get the cooperation or support he needed. The most recent episode
prompted Jim to have the courts appoint a guardian for the care of his son. He stated:

It ended up, he kept getting worse. Then I noticed things missing out of the
house…finally, I got a hold of the counseling center in [town] and we finally got
something going about January of 2004. Even though we had pleaded with the
psychiatrist and counseling center and it took them a while to acknowledge
that.
Jim first began seeking help for his son when his son was in the second grade. Jim stated, “We had him at the doctors various times since the second grade. They never felt there was anything wrong with him.” Many of the difficulties Jim and his wife had in getting help for their son were in part due to the fact they needed his [son] consent since he was over the age of 18 years. Jim stated, “Until we could get him to consent that he needed help, we couldn’t help him…. The privacy act was the killer, I think.” Jim discussed that his son had experienced repeated psychiatric hospitalizations, numerous arrests and a 3-year sentence in prison before he was given an accurate diagnosis. He stated:

We got very little information from the medical professionals. They would not release any information to us as parents. Then we got him into a facility in [county], like a half-way house, we thought it was a good place for him. He was down there for 2 days. The first day he got his money stolen. The money he got from prison release was stolen when he was taking a shower, right from the shower. I was finally able to get some help here locally, finally…from that we were able to get him evaluated. That was in, he was released in 1995, and we had him evaluated in early 1996. That’s when it was determined he had schizophrenia.

Jim attributed much of his anguish from the length of time it took the mental health professionals to find out what was wrong with their son. He had known that his son had problems with chemical dependency, but he believed there was more. He said:

Why is he doing this, is there something wrong with him? Some of the opinions we’d get from the doctors would be…an attitude that he just likes drugs. Not
knowing at the time that his drugs were his escape from his disease….Well, I think it took us about 19 years to find out that he had a serious mental disease.

Lack of support from the CMH had been frustrating and disappointing for 4 of the 5 participants. Jan talked about one instance where she had arranged for a caseworker to come out to the house. He had never shown up to do the evaluation. She expressed her frustration and felt she was not getting cooperation from them. Referring to the CMH caseworker she said, “I could tell you just how worthless he was.” She had attempted getting help from another CMH facility. She heard positive things about a different facility, but her son was denied assistance because he had lived in a different county. This lack of support from the CMH has been an issue for Jan since her son was diagnosed with paranoid schizophrenia 37 years ago. As a result of her frustration and the lack of support she received from the CMH, her son is currently not linked with the CMH. Consequently, Jan continues to pay for her son’s medication and oversees all of his care.

The participants attributed their unmet needs to the lack of support received from CMH resources. The participants also felt that the stigma associated with mental illness has been an obstacle in getting what they needed for their mentally ill family member.

Jan discussed trying to find a place where her son could live safely. She expressed being concerned about his care, in case she would no longer be able to provide care for him. Jan had searched for housing for her mentally ill son. She discovered that because he has mental illness many residential facilities would not accept him. She felt that if her son had another diagnosis, she would be able to place him.
If my son was declared MRDD, there’s all kinds of places he could go to get housing. But because he’s mentally ill, they discriminate big time! He couldn’t even go down to the County Home; they won’t take him….The housing sucks! Big time! [italics added].

Jan expressed her frustration and shared that if her son was physically disabled or declared to have mental retardation, that she would have been able to find housing for her son. Her son is currently living in a house owned and maintained by Jan. She lives in another home with her second husband, but this has resulted in her maintaining two homes. “I keep my house and it costs me dearly…because of my son. If it wouldn’t be for him, I would rent my house out and I would have money coming in, instead of money going out.”

Four of the 5 participants expressed that they were dissatisfied with the resources that were available for their ill family member. Some were able to recognize the progress that was made over the years with improvement in the diagnostic process of mental illness and newer medications. One of the participant's had prior connections with the CMH system and is a school counselor, which he attributed as the reason his son had less difficulty in getting treatment. Another noteworthy aspect was that one of the participants had discussed the difficulty in finding treatment for an individual who suffers from dual diagnosis. This participant and his wife had gone as far as seeking help at a nationally recognized rehabilitation facility. He stated:

My wife went to the Betty Ford Institute in the early 90’s and even back then, the Betty Ford would never recognize the dual diagnosis. They would only recognize
one or the other and treat one at a time, and in that particular case, it was drugs first.

Four out of the 5 participants expressed a lack of involvement with the mental health professionals in the care and treatment of their family member. They were not included in the plan of treatment, however, 3 of the 4 were supporting their family member financially, providing them with housing and had taken over the responsibility of their care. Only 1 participant expressed that the psychiatrist had actively pursued their involvement as a family member. In fact, the psychiatrist had relied heavily on them for information regarding how the patient was doing in terms of the stability of symptoms and medication response.

A finding also worth noting was that the participants discussed their experiences with the psychiatrists, but spoke in terms of generalities when referring to mental health professionals. The participants did not mention experiences with nursing professionals or if nursing had any influence in their family member’s recovery.

Theme Two:
In the midst of system change, the participants experienced coping with multiple stressors that stemmed from the unpredictable and somewhat overwhelming symptomatology and behaviors. The participants experienced emotional burden, financial burden, anticipatory fear, worry and lack of trust.

Common to all of the participants were the various stressors that they have experienced since their family member began developing the symptoms of a mental illness. Some of the hallmark symptoms of the mental illnesses created an emotional
burden for these family members. The following contributed to the emotional burden experienced by the participants, the initial onset of behaviors and symptoms, financial burden, feelings of fear, lack of trust and persistent worry.

For some of the participants, the initial onset of the illness was most difficult for them. One of the participants, Tony, has a son who had been diagnosed with bipolar disorder 4 years ago. He described his son’s first psychiatric admission to the hospital as being one of the most stressful times since he became ill:

The hospitalization was tough and just having him so far out of it … that was probably the most stressful time. Just going up there and seeing what he was like. Wondering how long it was going to take or what was going to get him back to normalcy at that point.

Jan had described that the onset of her son’s schizophrenia had eventually gotten to the point that she felt she could no longer manage him at home. Initially the only symptoms her son experienced were that he was neglecting his basic hygiene, not doing things for himself and would not follow her instruction. She had realized at that point that she needed to seek treatment for him.

Well, when this all started, he was like just didn’t want to listen to me, he just would not do things for himself that he should do… his own personal care or anything. It got so bad, that I just said to my husband, “I just can’t deal with this any longer and we’ve got to do something for him.” So, had to get my other two sons, who are till this day okay and get him and my husband. We got him in the car. I was so desperate at that point, I said we’re going right to the
hospital…and take him up there and tell them I can no longer deal with this and I gotta have some help. I don’t know what it’s going to cost or anything about it. It’s got to be done. We had an awful time getting him into the car. He surmised that this was not a fun venture. So I took him up there. The doctor said, “Who referred him etc, etc.?” I said, “I’m his mother and I’m referring.” I said I have to have some help with this young man. I have no idea what is wrong with him. I cannot deal with this anymore. Then he told the doctor that he heard voices in his head, telling him things…I mean it was just something I try to block out of my mind, because it seems so horrid that one person living on this earth could possibly have all those problems with this disease.

Prior the diagnosis of her own son’s schizophrenia, Delores had experienced mental illness within her husband’s family. Her husband has four siblings who were diagnosed with schizophrenia years ago and had been institutionalized. She remembered her husband’s family always placing blame for the mental illness in the family on other outsiders and called them “nasty people.” When her own son was diagnosed with schizophrenia she said, “Initially I could feel some of the pain that other people felt. But I certainly wasn’t going to blame anybody else.”

One of the findings in this study, which was one of the biggest stressors for all of the participants, was the financial burden they experienced since their family member had become mentally ill. The participants identified that financial burden had begun with the onset of the symptoms of the mental illness and has continued to be a major concern. All of the participants expressed the experience of some financial loss that resulted from the
mental illness. According to the participants, their financial burden has been the result of the high cost of medications, treatment, or related to the mismanaging of money, such as theft and overspending. Overspending is often a symptom associated with the diagnosis of bipolar disorder. Two of the participants attributed the inexplicable excess spending on the purchasing of illegal drugs.

Jan made a general reference to others who think their lives are stressful. “People talk about stress. People don’t know what stress is…a lot of people don’t know…well till you don’t have any money.” Not only did Jan experience financial burden as a result of her mentally ill son, but also she had experienced an additional financial burden when her husband was injured and unable to work.

Tony discussed how the symptoms of his son’s bipolar disorder have created financial difficulties for him and his family during phases of the illness when he was, as he referred to as “manicky.” Tony said,

We would be just waiting for the phone call. What’s happened lately? What creditors are bugging us that he hasn’t paid? He didn’t pay any bills. He never opened his bills. There was a whole span of time where he just wasn’t doing anything…bills that weren’t getting paid that we had to take care of. There was that kind of stress. Him being down there, how do you deal with the system when he’s 3 hours away? You know the strain was on the whole family. He was writing checks on his brother’s account, so it took them a while to understand what was going on with him. There was a lot of he didn’t really understand. Some of this was the bipolar; some of this may be medication or self-medication. I’m
not sure how much money he eventually spent. We are probably talking $1,000 to $2,000 dollars over the span of time. He really seemed to have trouble remembering what he had spent the money on. I kept thinking maybe he had a stash of money somewhere, hoarding it. At this point, I really don’t think he did, but I don’t think he remembers. His recollection of his manicky stuff is usually real fuzzy and he doesn’t seem to remember that.

Tony’s experience of financial burden was a result of his son’s symptoms of bipolar disorder. For Tony, financial burden resulted from having to support his son and the amount of money his son had spent during manic episodes. In addition, Tony has had to pay off debts that his son had incurred during the initial phases of his illness prior to his diagnosis.

There’s been financial effects …things have probably cost us $6,000-$7,000 just from paying off debts, paying off new debts, supporting him, so there’s been the financial impact. But if we hadn’t spent $6,000-$7,000 maybe we wouldn’t have moved. Its not like I’m bitter or resentful, just kinda what we had to do and we did it. But there's been a financial impact.

Jim expressed that the overall stress caused by his son’s illness and the financial losses incurred were some of the most difficult aspects of his son’s mental illness.

Well, I think over the course of the years, stress would be number one.

Financially yes, he stole $ 2,000 plus out of my account once. I made up for it because I was advised by some people in the religious field to forgive, and I did, obviously, it didn’t really help him any, it just postponed him going to jail.
Jim described his son’s behaviors and how he has mismanaged his money when he was trying to work part-time.

If he had a paycheck, it didn’t last 2 weeks. Never lasted, he could never handle money. Whether that has something to do with schizophrenia or not, I’m not exactly sure. And give it away or drugs probably. He was a soft touch. If somebody gave him a hard luck story, he’d give him his paycheck or most of it.

Jim explained that his son was not paying his bills and had excessively charged up his credit cards.

He went through bankruptcy once, because he could get a credit card with a $1,000 limit. When it got to $2,000 they demanded he pay it back all at once immediately, he made about a $1,000 a month, just can’t do. They would never want to talk to me on the phone, they only wanted to talk to him and he would never be at home or he would refuse to answer the phone…he had about a half a dozen at one time.

Enduring over 10 years of such behaviors, this year Jim has had to obtain a legal guardian for his son. “I got guardianship because I didn’t think I could handle him and he was putting tremendous stress on my life, asking me for money everyday.” Jim’s son no longer resides with him, he currently lives in a residential facility and has been assigned a court appointed legal guardian.

Besides financial burden as mentioned above, another aspect of financial burden experienced by the participants was the financial stress related to the high cost of the medications used to treat the symptoms of mental illness. For instance, Jan’s son was not
eligible for Medicaid and has had to pay out of pocket for her son’s medications. He would not take the prescribed medication in a pill form so he had to take Prolixin injections. Jan explained:

So he said you can get this medicine Prolixin at the drug store, I’ll write a prescription for it and he’s got to have this every 2 weeks. So I went to the drug store and they said okay that will be $185.00… I said, “really, can I see the bottle?” About maybe an inch high. I said, “How long is this gonna last him?” Well he said, “I’m going to recommend he get so many milligrams…” Anyway he had said, “I recommend he takes this shot every two weeks.”

So I thought maybe he could take it for awhile and then he’d be better and he wouldn’t have to take it anymore.

Jan continues to pay for her son’s Prolixin injections every 2 weeks 37 years later.

Tony expressed concern that his son wouldn’t be able to afford to pay for his medications. He is currently receiving his medications free of charge through various indigent programs provided by the pharmaceutical companies. His son’s symptoms have been controlled with his medication compliance and he has been able to return to work. Tony’s concern now is that his son’s returning to work has meant that he loses all of his Medicaid benefits. In addition, his son no longer has health insurance. If his son continues to work at his job and makes more money, he may no longer be eligible to receive assistance from the pharmaceutical companies. Tony stated,

One of the biggest concerns becomes as you become well enough to work and if you make too much money you lose Medicaid, because he was self-employed, we were able to do some income averaging and keep the Medicaid up through last
December. If he would have been on a straight salary, then I think he would have lost the Medicaid earlier, because for the year he hadn’t made a lot of money…he’s got $1500 in medicine bills, if you work, $1500…you’d have to be making $30,000 to make a living wage and pay for your meds….A year ago that was a big concern on my part, of how is this going to shake out. He’s starting to sell houses. He’s making enough money and loses Medicaid and then what happens?

Fear had been an element of the emotional burden that was experienced by all of the participants in this study. Delores expressed her initial reaction to her son’s diagnosis of schizophrenia:

I felt at that time the diagnosis was being made at the [name of hospital], I felt everything was right. Eventually…it was scary…it was scary because I had seen what could happen with people with schizophrenia, I knew that it surfaces at early adulthood or the onset, so the timing was perfect with my son. That’s exactly what it was.

The participants identified experiencing emotions that added to their burden such as, feeling fearful and feeling responsible for protecting their mentally ill family member from self-harm. Jan discussed her fear of her son’s driving and felt forced to take his driver’s license away.

I took away his driver’s license. I wouldn’t let him drive anymore. Okay, here’s the stop sign up here [gesturing] he stops back here. I said, “Dan you gotta go up there, how are you going to see if any cars coming?” “Oh, I’ll get there….” I
wouldn’t let him drive because he was driving so poorly. He did have a car and he wrecked that.

Tony described how he has been afraid that his son will become noncompliant with taking his medications as prescribed. In the past, his son was self-medicating to relieve his symptoms of his bipolar disorder. Tony described how on one occasion his son had taken an excessive dose of his prescribed mood stabilizer.

The stress of trying to keep track of everything, catch things before they got too bad, and try to make sure it didn’t get to the police. I guess just sort of the watchfulness, stress, not paranoia, but just what is coming next…He still was having some problems. Some self-medicating again with the anxiety. He had a mindset if medication helps, then more medication will help more. So they were starting to switch him from Depakote to Lamictal. He took like 2 weeks worth of Lamictal in 3 days…so with Lamictal…was pretty scary.

In addition to being afraid his son would harm himself, Tony also feared that his son would suffer legal consequences to his behaviors that were triggered by his bipolar disorder.

I think the scariest part was when there was some of the painkiller abuse things going on. That was the scary part, if you’re dealing with the mental illness and you’re dealing with dependency, that was scary, that was the scariest thing. I think there was the fear that eventually he was going to do something where the police are going to get involved and having to go through that, yes you can say you're bipolar but you're still going to have to be responsible.
Delores had expressed being afraid that her son may relapse because he has taken himself off medications. He quit taking the medications for his symptoms of schizophrenia due to unwanted side effects of the medications. He has sought alternative treatment and is following a vegan diet. She discussed that presently he is not experiencing symptoms of his illness. She expressed feeling fearful for him to be off the medications and referred to a conversation that she had with her son.

He has assured me; because that is the one thing I’m concerned. “[Son] if you’re off your meds I’m really scared.” “Mom, I know what the symptoms are, I know if I need my meds. I know I know, don’t worry!” So I have to believe him.

Jan’s son with schizophrenia had initially been prescribed medication in pill form, but he admitted later that he had not been taking the medication. “He tells me now that he used to put it in the back of his mouth and I would think he was swallowing it. He’d swallow it and make believe he took it, but he never took it.” Since then her son receives his medication by injection.

Jan also has worried that at some point the medication her son is taking for schizophrenia will no longer be effective or that he may suffer from harmful effects. So then I became worried that when you stay on a medicine for such a long time, that it can sometimes have reverse effects. That’s what I’ve always believed and I don’t know if that’s right terminology, but anyway I was worried that he took this so long, that it might be not good for him.

Jim expressed a history of feeling afraid that his son’s symptoms of mental illness would interfere with his ability to be able to function at his place of work. His son
required frequent direction and this became very stressful for him and his wife. “We’d be constantly dogging him to get to work on time.” Jim said that he and his wife would be, Reminding him, making sure he would be all right. He would have a lot of panic attacks when he was younger….and we think that was part of the problem later on. Of course, his bosses would threaten him too, if you’re late were going to fire ya, and that would lead to panic attacks.

Tony expressed fear that his son may relapse and the acute symptoms of his bipolar disorder would return. At times, he has had difficulty deciphering what are normal behaviors for him versus what may be signs that he may be having a relapse of his bipolar disorder. Tony stated:

At times, it makes me more nervous because, you know some of the behaviors are normal behaviors and is this normal behavior or is this bipolar behavior?

That gets a little nerve racking at times too.

Tony also expressed that he tended to be more vigilant with his other children. He fears that one of them may also develop a mental illness. He states he is often more observant of their behaviors for “fear that someone else will have it.”

Jan explained how initially she and her family did not understand mental illness and questioned how her son had developed schizophrenia. Jan feared where the mental illness came from. She also feared that someone else in the family would develop a mental illness. Jan stated:

Well they explained some, but I think it’s a shock to the whole family, that this person has this…and that affects the whole family maybe I’ll get it. Where did
this come from? Whose hereditary thing is this? Is it hereditary? Those are the kinds of questions that went through my mind. It does make me nervous regarding the other kids in the family, is there some predisposition that we don’t know about. Is one of his brothers going to end up going the same way and that is kind of a scary thing.

Two of the participants had expressed the stress and added burden they experienced when they had difficulty trusting their mentally ill family member. This added additional emotional burden for these participants.

Jim’s son had lived with him and his wife, but had numerous episodes in which he had stolen things from their own home. “All the time we were afraid for all our possessions. We had so many robberies over the years. We tried to take what precautions we could to prevent it, but a… sometimes we were just outsmarted.” Jim assumed his son was using the money to obtain drugs. Jim reflected:

We pleaded with him and he got in trouble for shoplifting twice in 2004, one in February and May 2004 from department stores. What we found out he was doing he would be getting some merchandise from us, then he would take it back to the store and get credit for it and use the money to purchase drugs. Not large amounts but some amounts. Things got so bad that in May, he was so obnoxious with me, that I had him committed. Basically, he sold all his possessions and he doesn’t have any.

The most recent episode for Jim was when his son sold his new TV and VCR that Jim had bought him for Christmas. Jim stated:
The last time he [son], about 4 weeks ago, he got rid of his latest television and VCR that I gave him for Christmas. He seems like he can last about 3 months without doing something stupid. He claims he wasn’t taking the medication. They said well we’re giving it to you. ‘Oh, but I was spitting it out.’ The last urinalysis they did on him, they knew that he faked it, with water or something. But he’s done that more than once with the court too.

Tony had also talked about the difficulty he had trusting his son to manage his own finances and medications. “It’s been different trying to keep an eye on his finances, paying bills for him, not trusting him to take his own medication. He’s always been real compliant; he’s not been argumentative….”

Theme Three:

Family members of those who suffer from chronic mental illness identified the effects of system change on the family system when a family member suffers from mental illness.

The participants expressed their experience of how having a family member with mental illness has affected their family. Jim acknowledged the stress on the entire family and suspected that his son’s behaviors may have influenced how others viewed the family. The family’s reputation was particularly important because Jim had been in political office during the earlier years of his son’s illness. Jim stated that his son’s illness affected the whole family by the “…stress and family’s reputation… I don’t know, the other children have done well and have shooen it off, but it bothers them. A lot of time he wouldn’t participate in family activities.”
Tony discussed the reaction of the other family members in response to his son’s diagnosis of bipolar disorder. He expressed that his wife’s experience of having a mentally ill son was much different from his and he is unsure if she, until this day, has accepted her son's mental illness.

It’s been a lot different for myself than my wife. Part of it is my psyche background...a little more understanding on my part. Kind of the hard part is that its part of the mental illness, the weird behaviors and that’s something she never really seemed to process and I’m not sure she still really has. That he’s doing some of those things and he really does not remember what he did…guess in some respects matter of fact like, you know its something we need to deal with, at times it became a keeping his mom out of the picture, because she didn’t really seem to buy into the realization of what was going on. So there’s some conflict there…where I would be the one dealing with him…she’s kinda turned off on just the idea that she never really understood why he was the way he was and that it wasn’t his fault so…you know just trying to keep the family dynamics going. I’ve done it partly because those two just didn’t get along and she wasn’t accepting…partly what I did was insulate her so she couldn’t complain. If she wasn’t dealing with it, shouldn’t complain and her attitude toward it was just not helpful. So I kinda had to do that or it would not have gone well. It would have definitely been more problematic.

Jan has always lived and cared for her son with schizophrenia in her home. Her first husband had died and she has since remarried. She has moved in with her second
husband, and her ill son lives in her house. Her second husband does not want her son with schizophrenia to live with them. Jan stated, “He [current husband] won’t let him come here and live. No! No! No! He just can’t deal with anyone that’s sick like that.”

Jim lost his wife a few years ago and wondered how much the stress of their mentally ill son contributed to her poor health and ultimately her death. He had expressed that he suspected his wife had a harder time than he did in coping with the constant stress of their son’s illness and behaviors.

Well, I think it affected the wife many years ago, she felt that it was her fault as a mother. It was probably a little easier for me because I was out in the business world and other things to occupy my time. But she was a stay at home mom. And of course, whether that had anything to do with her eventual death, you just don’t know.

Jim explained that his wife had been a little stricter on the other children as a result of the one son’s illness. He also discussed how the other children in the family were affected living with the constant chaos created by the son who suffers from mental illness. One of his sons will not interact with the mentally ill brother and does not understand the illness. Another son makes an effort to visit him. Jim stated, “My one son won’t do anything. My other son comes to the meetings, goes and visits once in awhile. [The other son] is mad at him for what he’s done with his life. So he hasn’t totally acknowledged the disease.”

Carol reflected on what effect her brother’s mental illness had on her family. She spoke of her childhood, when her brother was younger. She had expressed that the family
had always focused on helping the ill brother. It was often difficult for her to observe the emotional toll it had taken on her mother.

Well it affects you, you see your mother upset, you see your mother crying and again, I tried to do the best that I could and I helped him, coach him through his reading. It put a stress on the whole [italics added] family. It was just added, it was just one chunk, but it just added with everyone else’s stuff. The illness has made him…he’s not the little boy, the brother I grew up with.

Theme Four:

Family members of those who suffer from chronic mental illness identified a lack of control over changes occurring within the system; lacking knowledge of what was going on with their family member or what it meant for their family member to be diagnosed with a mental illness.

All of the participants expressed that at some phase during their loved one’s illness, they had experienced feelings of not knowing what was going on with their loved one. They had questioned how they developed the illness and how they should cope with it.

When Jan heard the diagnosis of paranoid schizophrenia, she did not know what mental illness or schizophrenia was. Jan stated, “I thought...where did this come from? Why, why me Lord?”

Jim discussed various situations in which he had reached a point of not knowing what to do anymore. After he and his wife experienced several failed attempts at trying to find out what was wrong with their son and seek treatment. It had taken years to get a
diagnosis for their son. For years, they had wondered what was wrong with their son. Years had gone by without, “Never really understanding where all this was coming from.” There were times, “We knew he was going downhill, but we didn’t know what to do about it.” Again, the fact that his son was over the age of 18 left Jim and his wife powerless because they could not get information from the mental health professionals, even though he resided with them and were the ones who cared for him and supported him. “We got very little information from the medical professionals. They would not release any information to us as parents.” Jim went on to describe a situation where he had felt that he could not get information and desperately wanted to understand what was going on with his son.

…I think a lot of the problems with my son is that we got no knowledge from the judges or the medical profession [italics added]. We were trying to get his medical history and background, why is he doing this, is there something wrong with him. Some of the opinions we’d get from the doctors would be like, he just has a very, an attitude that he just likes drugs. Not knowing at the time that his drugs were his escape from his disease…This is the problem as parents, you don’t have rights, you can’t force an issue because he’s over the age of 18 and he’s 44 today.

Tony reflected on the initial onset of his son’s symptoms of bipolar disorder. His son had gone away to college. When he left home he was not having any symptoms of the illness. After a while, he began to question what was happening with his son. He explained that his,
[Son] began at X University for his BA degree had no real symptoms at all until senior year, when he started talking about burning out a bit and he was living away from home. He did graduate. He was going to school; he was working, probably too many hours. Started talking about some sleep disturbance things, somewhere along the way, I'm not sure of the time limit, eventually he graduated, moved to …managing a shoe store. Did that probably 6 months off and on, working a lot of hours and more strange behavior sort of things. He got his BA. I thought it may have been manicky stuff. Then we weren't sure if he graduated. We weren't sure if he graduated, we were hearing all this stuff from him, is it true? Is it not true? When he was up in [location], more sleep problems started, getting into the manicky spending kind of things.

Carol’s brother has been diagnosed with bipolar disorder for approximately 16 years. As she had reflected on the past, she explained how her family did not talk about her brother’s suicide attempt, the mental illness, nor did she feel the family was involved in his treatment.

She said:

His wife mainly took care of the details. There were times over the years where there was very brief information or I was brought in to sit with a counselor or a therapist, but looking back there was not a whole lot of information given or involvement by the rest of the family…we came from…our family didn’t talk very much. So I don’t know all the dynamics that was going on. We didn’t know what was going on. We knew a little bit. But we didn’t know everything. I do
have to probably qualify this episode. He had been hospitalized, the first time we knew something was definitely wrong…he tried to commit suicide. I don’t know how, nobody told me.

Theme Five:

The process dimensions of coherence and individuation led to spirituality, which provided strength, courage, and resilience that facilitated the ability of family members of those who suffer from chronic mental illness to endure and reach a level of acceptance of the mental illness.

Though the participants described their experiences in terms of emotional burden, they were able to find the strength they needed to cope with the stress of having mental illness in their family. They reflected on how they found the strength to cope with all the problems associated with their family member’s mental illness. All of the participants spoke of having gained strength through their connection with the NAMI support group. Some of the participants had an overall attitude of optimism that has helped them cope with their family member’s mental illness. Three of the 5 participants found that their faith in God had given them the strength and courage they have needed.

Jan did not know what NAMI was when she had gone to her first meeting, but has found the meetings and her involvement in the meetings a tremendous support. She described her first encounter with NAMI.

So I went over to this NAMI, I didn’t even know what NAMI meant. They didn’t do a very good job of explaining the basis for all this. Then I got connected with
that Jim, oh my, he’s one of my favorites. What trouble he’s had with his son…it’s almost like a group therapy for parents.

At times Jim had suffered embarrassment from his son’s behaviors. His son has had multiple arrests and imprisonment. His involvement in NAMI has provided an outlet for him to talk about his mentally ill son. Being a member of NAMI has motivated him to become an active member in the organization so that he can contribute to helping others who have a family member suffering from mental illness. Through active membership, he can help to advocate for improved care and improved resources for those who suffer from mental illness.

Well certainly, it's an embarrassment for the family, it was less of an embarrassment after I was able to talk about it and that’s why I got involved with NAMI, 7 years ago. I felt something had to be done. Even though it’s a slow process. Its one of the first organizations that I ran into that acknowledged that one was the crutch for the other. Of course, in the last 6 to 7 years. I learned a lot more about schizophrenia and drugs that go with it.

Despite the many stressors and burdens the participants have experienced by having a family member with mental illness, their attitudes were generally optimistic. They expressed feelings of gratitude, recognizing that their experience could have been worse. They were proud to share that even though their family member had a mental illness; they were able to appreciate their positive attributes and were able to make the best of their situation.
Tony felt fortunate that his son’s diagnosis of bipolar disorder had been made within 2 years of the onset of his symptoms.

I’m just glad it didn’t take as long as I’ve heard it could take to get that kind of diagnosis. He was actually pretty lucky in that. And he actually never had a full psychotic episode until he was already in treatment. And that was more the product of changing meds, getting the dosages up.

Jim is able to recognize the progress that has been made in the field of mental health since his son first became ill. “Today I think people are getting diagnosed much earlier.” He reflected on his reaction after his son was finally diagnosed with schizophrenia. “I think we adopted a more proactive attitude. Now what can we do to help, instead of thinking he’s just a bad kid. And I think we started moving positively in the right direction.” Jim also expressed that he thought that his ill son’s behavior had a positive influence on his youngest son.

I think there was one good thing out of the whole thing, looking back, I think my youngest son was experimenting with marijuana in high school and he straightened out about his senior year and he went on to do well. And I think his older brother messed up and I think it helped him straighten out.

Delores, who also cares for her a son with cerebral palsy, has viewed her son’s mental illness as a challenge.

With what I know about schizophrenia being a chemical imbalance in the brain, if it is treated, should be able to live okay. Oh, I was glad it was diagnosed and then I see it as a challenge for treatment... now we know what it is and you take steps
to treat it or at least lessen the effects of it…in a way it was almost a relief that it was schizophrenia, because schizophrenia is treatable. Thank God, it’s treatable! And people can function. The more I’m aware of people who are successfully in the workforce and they have schizophrenia. So in my mind there’s no excuse to have a mental illness and not be a functional part of society. We’re fortunate in a way that…as disheartening as it was, sad as it was, I can look at him now and really be proud, you know. But I don’t know I’ve always been busy, I’ve worked. I don’t have time to dwell on problems. I kinda like to see the good side of problems rather than the bad side.

Tony works in the school system as a school psychologist and recognizes the positive aspects of this experience with his son’s mental illness. 

Professionally, it’s been nice because I’ve learned a lot about bipolar. So it’s given me some information and I’ve done some extra seminars that have been put on, partly just so I can see how it can help me and my son and partly just professionally and that’s been kind of a nice side effect. Some of that’s the psychologist in me. If you don’t make the best of things, you’ll go crazy.

Three of the participants attributed their spirituality as a means of strength to cope with their family member’s mental illness. Jan reflected on how she found the strength:

It’s been a rough way to go…with my son. And I did not expect anything like this to ever happen, but when it comes, you have to deal with it. The first thing I do is pray to the Lord that He will give me the strength, that He will give me the know how to know what to do and all I can say is He certainly didn’t shortchange
me there. He gave me all kinds of ideas of things I could do and I just tried to carry the ideas out, to help my family and to help my son, and to help myself and to help my sanity. Because the stress is really at times, you think to yourself, you just can’t stand anymore.

Carol expressed that her faith had gotten her through difficult times with her mentally ill brother. “I have a lot of personal Christian faith which has probably helped me on that. I've done what I can do and all I can do is pray for the ill brother and for everyone.” Currently her relationship with her brother has become estranged and she attributes that to his inaccurate perceptions, which she believes resulted from his mental illness.

The essence of resilience was evident with all of the participants. Jan, whose son suffers from paranoid schizophrenia has worked with her son’s limitations and is able to focus on his strengths. She was able to share the positive experiences she has had with her son. Jan has reached a level of understanding and acceptance of her son’s mental illness.

Well I got him interested in washing dishes for me and he does dishes for me and he does a pretty darn good job. He mows my lawn for me and he will feed the cats. He will run the sweeper and dry his clothes, but he can’t wash his clothes. Sometimes he puts too much soap in to do the dishes and stuff like that but I try to keep explaining it to him, but its repetition, repetition same ole thing….As long as he has a supervisor he can do very well. He gets crazy ideas, like he’ll put a board underneath of the sink drainer thing, where you put the dishes after you
wash them so they can drip. He’ll put a board under there and then go get a bath
towel and put it under there too to catch the water. I mean, these things that he
does, his mind is just not working properly. Then when he does something
really nice for me, then I’ll say, “Dan I just don’t know what I’d do
without you helping me and he’ll say, “that’s okay mom” and he’ll give me a
big hug and then I’ll say “how about if I bring you a tub of ice-cream?” The
son replied, “that’d be good ma.”

Jan also added that she has a close relationship with her son. He is frequently suspicious
of others, due to the paranoid schizophrenia and keeps the shades pulled down in the
house. He is suspicious of others and fears that others are watching him. Jan explained
that he is not suspicious of her. She stated, “Oh ya, if mom says it alright, Ya, then its
okay. And he says, “Mom I love you.”

Jim’s active involvement in NAMI has been motivated by his desire to help others
so that they do not have to experience the same difficulties that he has with his son. In
looking to the future, Jim expressed the need for further research in the area of mental
illness. “I think one of the problems is, I think we need more research, cuz that’s my own
personal thing.”

From this whole experience, of having a brother with mental illness, Carol would
like to reach out and help others.

Oh, from this whole experience, what I’d really, really like to do is, help
somebody not go through what I’ve gone through. I can take a negative into a
positive and help other people. I’ve always been one to help other people. Put
things aside for myself and help other people, especially for the parents out there. It made me a real advocate for any kind of people with mental illness. I just want everybody to be aware.

Delores, whose son was diagnosed with schizophrenia, is actively involved in the ADAMS (Alcohol Drug Addiction and Mental Health Services) board and in NAMI. She had prior involvement with these advocacy groups since her husband’s family had several members who also had suffered from chronic mental illness. She stated,

When Bob was diagnosed, then it made me a bigger fighter. It just made me more aware of people. I guess I like to just take every opportunity I can just to educate people on mental illness, the symptoms, and the availability of treatment. I want mental illness to be on the same level as Diabetes, Heart Disease. So our concerns are probably the concerns of any other parents, that they are happy. That they have enough money.

Lastly, Jan’s resilience is inspiring for all family members of those who suffer from chronic mental illness.

The big thing to do is, you cannot give up and when you think all the cards are against you. You gotta get the brain a working and figure out what you may be able to do and don’t be afraid to try it! Believe me more than one night I would cry myself to sleep just wondering how I was going to make it the next day. How can I get through this? What can I do? And seems like you sleep on this. When you wake up in the morning, try to think what you have on your mind because often times I believe the angels help you and put stuff in your head, go do
this, go do that. That’s my faith, but what can you do? You gotta live on. You gotta try to help one another. That’s all I try to do.

Despite all of their obstacles, all of the participants demonstrated resilience in their struggle to reach a level of acceptance in dealing with their mentally ill family member. Their inspirational strength, faith and courage have led them to their resilience.

Summary

This chapter presented the findings of the phenomenological study on the lived experiences of family members of those who suffer from chronic mental illness. Van Manen’s (1990) method of phenomenology was used to analyze the data. The data presented in this chapter were direct verbatim excerpts from the transcribed interviews of 5 participants. After phenomenological reflection, writing and rewriting, five essential themes were discovered that revealed the structure of the lived experienced. Verbatim statements of the participants were provided to support the essential themes.

CHAPTER V

Discussion

The purpose of this study was to explore the lived experience of family members of those who suffer from chronic mental illness. Five family members were interviewed regarding what this experience has meant for them. Friedemann’s FSO (1995) was the
theoretical framework used to guide this study. Van Manen’s (1990) method of phenomenology was used to collect and analyze the data from this study. Five themes were identified to be the “structure of the experience” for these participants. These themes included:

Theme One:
The participants experienced negative emotions regarding unmet needs, the stigma of mental illness and the incongruence within the environment including the community mental health resources.

Theme Two:
In the midst of system change, the participants experienced coping with multiple stressors that stemmed from the unpredictable and somewhat overwhelming symptomatology and behaviors including emotional burden, financial burden, anticipatory fear, worry, and lack of trust.

Theme Three:
Family members of those who suffer from chronic mental illness identified the effects of system change on the family system.

Theme Four:
Family members of those who suffer from chronic mental illness identified a lack of control over changes occurring within the system; lacking knowledge of what was going on with their family member, or what it meant for their family member to be diagnosed with a mental illness.
Theme Five:

The process dimensions of coherence and individuation led to spirituality, which provided the strength, faith, courage, and resilience that facilitated the ability of family members of those who suffer from chronic mental illness to endure and reach a level of acceptance of the mental illness.

This chapter presents a discussion of the themes identified in this study as they relate to Friedemann’s (1995) theory and the research literature. The study conclusions, limitations, implications for nursing and recommendations for further research are presented.

Discussion of Findings Related to Literature and Theory

Though each of the responses of the participants were unique to their own experience, some commonalities did exist among the 5 participants as they described what it was like for them being a family member of one who suffers from chronic mental illness. All of the participants provided valuable data that led to the themes that were discovered in this research study.

Theme One:

The participants experienced negative emotions regarding unmet needs, the stigma of mental illness, and the incongruence within the environment including the community mental health resources.
As mental health care providers, nurses need to understand the lived experience of family members of those who suffer from chronic mental illness. Friedemann (1995) emphasized the importance of nursing’s knowledge and understanding of the family’s experience, “A nurse needs to fully grasp the wealth and depth of each family’s experience before being able to enhance its health” (p. 33). By conceptualizing this study within Friedemann’s FSO, it becomes apparent that nursing must gain the knowledge and understanding of the lived experience of family members of those who suffer from mental illness in order to advocate and promote congruence within the family unit and enhance health. Friedemann supported the application of her theory in caring for those who suffer from mental illness. Friedemann refers to various research studies that support her systems theory. Friedemann stated, “Even though families may not be the initiators of problems, these research findings suggest that family reactions and interactions may be predictive of the patients’ long-term adjustment” (p. 253). The studies referenced by Friedemann supported the notion that relationships within the family and the family’s ability to adapt to change can influence the prognosis of the individual and their symptoms. This provides further evidence of the important role of family members in the lives of those who suffer from mental illness and provides support for this research study and further research to better understand this phenomenon.

All 5 participants expressed some frustration with the lack of support they received from mental health professionals. Four of the 5 participants specifically discussed difficulties with the psychiatrist who had treated their family member. Such difficulties included lack of clear information from the psychiatrist regarding the
diagnosis and lack of consistent involvement in the treatment plan. Such experiences with several psychiatrists often led the participants to feelings of frustration, feelings of not being heard and a lack of confidence in the mental health provider and health care system in general. Two of the participants expressed taking the initiative to advocate for their family member without relying on the psychiatrist in order to seek treatment for their loved one. Along with this lack of support from psychiatrists, the participants had experienced lack of cooperation from other mental health care providers. In addition, they had difficulty with the judicial system. The participants viewed the court system and current laws as obstacles in getting the help they needed for their family member who suffered from mental illness.

In this study, the participant’s experience of unmet needs and lack of support were supported in the research. For example in Doornbos’ (2001) study, similar findings regarding the lack of support experienced by family members of those who suffer from mental illness were found. Doornbos’ study showed the importance of the role of family members in the care of the mentally ill; a role that has often been overlooked. The study findings provided evidence and implications for mental health nursing to support the family’s role in caring for their ill family member. In Doornbos’ study, the lack of support that caregivers received was found to accentuate the experience of burden suffered by their participants who were family members of one who suffered from chronic mental illness. The results of this research study indicated that a large percentage of family members never received the crucial support they needed from mental health professionals (Doornbos). The results of Doornbos’ study support the findings of this
study and the important role of nursing in providing much needed support to families of those who suffer from chronic mental illness.

In the study by Johnson (2000), a lack of support from mental health professionals was identified. Though their findings did not support previous research findings which had shown that mental health professionals were blaming family members for a patient’s mental illness, the findings did indicate that mental health professionals did not include the participants in their family member’s care. The participants of Johnson’s study reported feeling, “disregarded by staff at crisis centers and hospitals and by psychiatrists in all settings” (p. 130). These participants reported feeling excluded from their family member’s treatment plan, despite the fact that “they were often expected to fulfill housing and case management functions…” (p. 130) for their family member upon discharge from the hospital.

In this current study, 4 participants had expressed disappointment in the lack of support they had received from community mental health (CMH) system. The participants had identified their dissatisfaction with the CMH system as a reason for discontinuing their services or not utilizing them. As a result, only 2 participants are currently involved with their local community mental health system. In addition, all 5 participants had discussed their concerns regarding the stigma of mental illness that prevails in our society and had identified that the stigma of mental illness contributed to the lack of support they received.
According to the World Health Organization (WHO) (2001), the stigma of mental illness is considered a hidden burden experienced by those with mental illness and their families. The WHO defines stigma:

Stigma can be defined as a mark of shame, disgrace or disapproval, which results in an individual being shunned or rejected by others. The stigma associated with all forms of mental illness is strong but generally increases the more an individual’s behavior differs from that of the ‘norm.’

It has been difficult to measure or quantify the amount of burden actually caused by stigma (WHO). The stigma of mental illness can have an impact on all areas of one’s life. Those who suffer from mental illness are often rejected by others, including family members, employers, and they are often denied equal access to mental health care and the resources needed in their recovery (WHO). The consequences of the stigma of mental illness reaches beyond the individual with the illness, affecting family members and loved ones. Such rejection by society can lead to feelings of isolation and humiliation (WHO). Consequently, one who suffers from mental illness may be reluctant to seek treatment or comply with their treatment regimen.

The concept of the stigma that surrounds mental illness has been explored and numerous articles on the phenomenon have been published, but few research studies have been published and even fewer have been published on the family perspective of the stigma associated with mental illness. The research study by Muhlbauer (2002) explored the experience of stigma from a family member’s perspective. The findings identified in Muhlbauer’s study indicated that stigma was experienced by the participants in both the
private and public sector. The stigma experienced by the participants was classified as internalized, interpersonal or institutional and had often times progressed through various stages. The participants shared their experience of having to cope with stigma on a daily basis with their mentally ill family member. Participants had experienced stigma or the consequences of stigma even from the mental health professionals. One of the participants in the study reported stigma by the psychiatrist. The psychiatrist had refused to treat their family member because he “considered people with schizophrenia lazy” (p. 80). The participants in Muhlbauer’s study identified having to cope with various aspects of stigma that they experienced as a result of having a family member who suffers from mental illness. In addition, strategies to conquer the detriments of stigma were identified by Muhlbauer. The stigma of mental illness and its consequences reaches beyond the scope of this study and demands further research to determine how it impedes the care of those suffering from mental illness.

The concept of stigma was also a finding in Corring’s (2002) study. Corring explored the quality of life of family members who cared for their mentally ill family member. The findings indicated that the participants perceived being viewed differently than those caregivers of patients with physical disorders such as cancer, heart problems or stroke. Participants expressed that caregivers who had family members with a physical diagnosis such as those mentioned, were considered a “hero…but when you have mental illness you’re a second class citizen and those of us who care for those people feel it too...”(p. 354). Corring’s findings also supported the findings of this current study in regards to the difficulties the family member encounters in dealing with the court systems
and the laws. Corring’s findings suggest that professionals who are employed in the legal system need additional education regarding mental illness. Much of the stress experienced by Corring’s participants was due to the lack of support they received in dealing with their family member. Corring’s findings indicated that lack of support and discrimination-surrounding mental illness influences not only the recovery of the ill family member, but also the quality of life of the family member who cares for the ill member.

Theme Two:

In the midst of system change, the participants experienced coping with multiple stressors that stemmed from the unpredictable and somewhat overwhelming symptomatology and behaviors including emotional burden, financial burden, anticipatory fear, worry, and lack of trust.

According to Friedemann (1995), system change can occur as a result of various triggers within the family system, such as illness or trauma. Applied to this study, mental illness in the family would prompt system change. According to Friedemann, in order for system change to occur “a person experiences pressure from within the environment” (p. 11). This discontent from within the system prompts the individual to make a change. The behaviors and actions that one engages in response to the pressures within or outside of the environment lead to the targets of control and growth. It is within these processes that nursing can intervene with families by assisting them in reaching the targets of control and growth and promote congruence and health within the family system.
Friedemann stated, “The client is helped most by a nurse who fully acknowledges the pain and difficulty associated with system change” (p. 43).

Common to all of the participants was the emotional burden created by the various stressors that they had experienced since their family was diagnosed with mental illness. Four of the participants discussed their emotional burden that had occurred with the initial onset of the symptoms of their family member’s mental illness. Two of the participants indicated that their family member’s first psychiatric admission to the hospital was particularly stressful for them in comparison to subsequent hospitalizations. The findings of the current study indicated financial burden, anticipatory fear, lack of trust and persistent worry had contributed to the emotional burden they have experienced.

Emotional burden experienced by family members is supported in the literature. An earlier study by Hatfield (1978) summarized the effects of caring for a family member with mental illness. Hatfield concluded that these family members are often compromised physically and psychologically. Consequently, the non-ill family member has difficulty meeting their own needs and the family unit becomes threatened. Later studies have also found emotional burden to be prevalent in the family members of those who suffer from mental illness.

Findings in the nursing study by Ferriter and Huband (2003) supported the experience of emotional burden. Their study of 22 biological parents who had a child that was diagnosed with schizophrenia, found that stress, fear and loss were frequently reported. Another finding was the amount of emotional distress the parents experienced in caring for a son or daughter who was diagnosed with schizophrenia. Ferriter and
Huband noted that all 22 of the participants had discussed experiencing major stress as a result of the mental illness. Overall, emotional burden was found in 77% of the participants and financial burden found in 45%. Participants reported that this burden “at times was more than could be coped with” (p. 557). Their findings also supported that mental health professionals had been the least helpful resources in dealing with their family member’s mental illness. The findings of Ferriter and Huband’s study support the present study findings and the desperate need for nursing intervention.

The participants of the present study reported that financial burden accounted for a portion of their overall emotional burden. These findings were supported in the research. For example, Dore and Romans (2001) studied the impact of bipolar disorder on families and partners. In their study the participants reported financial burdens related to the family caregiver’s reduced income and that their family member “frequently had difficulty managing their finances during an episode of illness and almost half (49%) took on significant responsibility for the patients finances at those times” (p. 152). The study findings showed that 29% of caregivers had incurred costs for hospitalization or related to the behaviors of the individual. Overall 46% of the participants in this study perceived these financial burdens as major stressors (Dore & Romans).

The consequences of financial burden have been shown to have negative effects on the family member’s health. This was supported in Gallagher and Mechanic’s (1996) study. Their findings demonstrated that the burden of family members of those with mental illness negatively affected their health, which can add to the financial burden. Gianfrancesco, Wang and Yu (2005) had also concluded from their study that living with
a person who suffers from serious mental illness significantly increased the overall health care costs of the family, in particular mental health care costs.

The participant’s experience of anticipatory fear found in this study were similar to the findings in Corring’s (2002) study. Corring found that participants experienced feelings of frustration and fear. Corring’s study explored the quality of life of family members of those who suffered from mental illness. Family members experienced anticipatory fear in regards to their family member relapsing, and becoming symptomatic again. At times, the participants had described this as feeling as if they were “walking on egg shells” (p. 353). Jones’ (1997) research also supported the experience of anticipatory fear and worry. Findings in Jones’ study indicated that family members not only worried but also feared the future regarding such things as who would manage the care of their mentally ill family member if something had happened to them. In addition, Jones’ findings suggested that the perception of burden experienced by the family member could be influenced by the role of the family member. Jones emphasized and provided support for the importance of mental health professionals to understand the various perceptions of burden and how it may vary depending on the relationship and role of the non-ill family member.

In this study, the lack of being able to trust the ill family member added to their experience of emotional burden. Two of the participants in this study reported a lack of being able to trust their ill family member. The lack of trust experienced by these participants related to behaviors such as theft and noncompliance with their medications. Support for the experience of lack of trust was supported in the research by Rose,
Mallinson and Walton-Moss (2002). In Rose et al.’s study, the participant’s responses were categorized into three common themes. One of the categories was that the families had experienced uncertainty and lack of trust with their family member. One participant had expressed that they could not trust that their family member would be able to care for him or herself. The participants expressed feeling overwhelmed with having to be vigilant in watching their mentally ill family member (Rose et al.).

Theme Three: Family members of those who suffer from chronic mental illness identified the effects of system change on the family system.

Friedemann’s FSO (1995) is a systems model, which specifies that when one member of the family system is affected, such as with mental illness, other parts of the system are also affected. Despite current research supporting the etiology of mental illness as biological, it is still believed that the family process can influence the ill member’s symptomatology (Friedemann). Such data supports the need for mental health professionals to involve families in the care of those who suffer from mental illness. The nurse’s role with the family is to provide “support to a life process through which individuals derive satisfaction, meaning and congruence” (p. 246). According to Friedemann, “the manifestations of the patient’s condition are intimately interwoven with the processes of the family and the larger environment, people of contact and messages received from the society” (p. 254).

In this study, the interrelated processes of the family are substantiated in the responses from the participants. All of the participants commonly reported that the mentally ill family member had impacted the lives of the remaining members of the
family. When exploring the effects of the illness on family members, it may be necessary to also consider the role of the family member and the role of the ill family member. In the present study, 2 participants were fathers of a mentally ill sons, 2 participants were mothers, and 1 participant was a sibling. Specific concerns reported by two of the participants were how mental illness had affected their marriage; one participant thought that the mental illness affected the entire family in terms of the family’s reputation and overall family dynamics. This participant suspected that his son’s illness and behaviors may have contributed to the poor health of his deceased wife. One participant, whose brother had bipolar disorder, expressed that having a brother with mental illness had created increased stress and tension within the entire family. This same participant expressed that she and the remainder of the family had always made accommodations for her mentally ill brother.

The effects of system change on the other members of the family system can be supported in the literature. The studies reviewed provided data regarding the effects on the family members. The study by Provencher, Perrault, St-Onge, and Rousseau (2003) explored the effects and relationships of the stressors of mental illness on family members. Their findings indicated the many ways the non-ill family member’s lives are affected as a result of a mentally ill family member. Provencher et al. (2003) had noted that the participants reported that mental illness in one of the members of the family had created, “disruptions in the family routine, restrictions in their social and leisure activities…” (p. 602).
Similarly, Corring’s (2002) quality of life study on family members of those with mental illness, found that families are “vulnerable to disruption in physical well-being, development and activity, and emotional well-being…” (p. 357). Hatfield’s (1978) study was the most comprehensive research study found on the specific effects of mental illness on the family. Hatfield had explored the family members and specific areas affected by the illness. The findings indicated that the effects of the mental illness on family members included, causing hardship for siblings, posing a threat to the parent’s marriage, disruption in the family’s social and personal life and the fact that the burden of the ill member frequently tends to fall on one member of the family. Common findings among children were that, “other children in the schizophrenic’s family suffered hardship and frequently were neglected” (Hatfield, p. 336). Other common responses reported from the siblings of schizophrenics were that they could not understand the bizarre behaviors and often blamed the mentally ill family member for misbehaving, which left them resentful toward their parents for their lack of discipline (Hatfield). The findings in Hatfield’s research supported that other family members are affected by the mental illness and the stress on the other children and the parents can cause marital relationships to suffer.

Theme Four:

Family members of those who suffer from chronic mental illness identified a lack of control over changes occurring within the system, lacking knowledge of what was going on with their family member or what it meant for their family member to be diagnosed with a mental illness.
The participants in this study had commonly reported experiences related to the loss of control. Earlier stated, an illness, such as mental illness, can promote system change. During system change, a loss of control may be experienced. According to Friedemann’s FSO (1995), the target of control within the system is necessary to maintain structure and organization within the family. Through system processes, the family strives to reach the targets (e.g. control) and find congruence. According to Friedemann’s FSO, “control needs to be achieved in order to regain congruence” (p. 208). In order to gain control, the processes of system maintenance and system change needs to be present within the system. System maintenance is the traditional behaviors and activities, which are the foundation and the basic operations of the family system. System maintenance strategies are activities of every day life and include those activities in care giving (Friedemann). System change leads to “the incorporation of new knowledge and the assumption of new family behaviors, structure, values and therefore, encompasses culture transformation” (p. 27). To facilitate system change the family is open to the environment and takes in new information, adjusting the system accordingly. The “outcome of system change process is a decision about the acceptance or rejection of certain values that can be made through channeling and absorbing knowledge and information” (p. 27).

All of the participants in the present study reported that during some phase of their family member’s mental illness they had experienced feelings of not knowing what was going on with their loved one. They questioned how their family member could have developed this mental illness, experienced feelings of not knowing what the illness was
all about or what to do about it. Having adequate knowledge and information regarding their family member’s diagnosis and an overall understanding of mental illness may have helped to lessen the participant’s experience of feeling they had lost control over the situation.

The following literature supported these findings. In Nystrom and Svensson’s (2004) study, their aim was to explore the lived experience of fathers of adult child with schizophrenia. The authors emphasized the great expectations being placed on parents as a consequence of psychiatric deinstitutionalization, which they concluded has resulted in turning “many parents into long-term care providers for adult children with schizophrenia” (p. 363). They described that the unpredictable nature of mental illness and symptoms are added stress for the caregiver. Similar to the present study, Nystrom and Svensson’s findings showed that fathers had experienced various phases during the course of their child’s mental illness and that they too had experienced a sense of lack of control. Interviews of their participants included statements that “appeared to follow a time continuum, from losing control to successively regaining it” (p. 368). The participants experienced a feeling of loss of control and powerlessness when they had to observe their own child having symptoms such as hallucinating and behaving in frightening manner and not knowing how to handle this. This perception of the loss of control had often times left them feeling powerless to help their own child (Nystrom & Svensson).

Rose, Mallinson, and Walton-Moss (2002) studied families over a 2-year period and found that the participants had many questions. They had experienced confusion
regarding the mental illness of their family member. The participants reported a sense of urgency initially in the illness. They wanted to find the answers to their questions and be able to manage the crisis. The study found that the participants pursued normalcy for their ill family member. One of the steps in this process was being able to “regain control over the illness, to lessen the impact on the patient, and to influence its course” (p. 527).

The current study findings of feeling a loss of control was related to the participants’ experience of lacking knowledge regarding what was happening to their family member and an overall lack of knowledge and understanding of the mental illness. The study by Yamashita (1998) supported the current study of the family member’s experience of not knowing what the mental illness was all about. A predominant theme in Yamashita’s study was that the family members reported not knowing about the illness or felt confused regarding the diagnosis, its severity and the prognosis of the illness (Yamashita). Similarly, one of the themes found in Meadus and Johnson’s (2000) study also related to the participants lack of knowledge and understanding of their family member’s mental illness, which ultimately increased their fear and worry.

Theme Five:

The process dimensions of coherence and individuation led to spirituality, which provided the strength, faith, courage, and resilience that facilitated the ability of family members of those who suffer from chronic mental illness to endure and reach a level of acceptance of the mental illness.

In this current study, it was important for family members to reach a level of acceptance in dealing with their family member who suffers from chronic mental illness.
Nursing interventions involve the entire family system and support their process dimensions of system maintenance, coherence, system change and individuation that eventually lead to health (Friedemann, 1995). According to Friedemann, “the emotional aspects of acceptance seem to be embedded in the search for meaning” (p. 229). The participants in this study used their unique process dimensions of coherence and individuation to reach a level of acceptance of their family member’s mental illness. In Friedemann’s FSO, the process dimensions of coherence and individuation lead to the target of spirituality. Acceptance of illness occurs through the target of spirituality. It is this “activation of the target of spirituality that results in subsequent shifts within the control target and movement toward a new balance” (p. 229). Within this theory, when family members have reached a level of acceptance of the illness, their focus is not on the ill member’s limitations, but their ability to focus on the ill family member’s strengths and help the ill member to build on these strengths (Friedemann).

Common to all of the participants in this study is the strength they had developed in order to cope with the multitude of stressors that they were faced with as a result of having a family member who suffered from chronic mental illness. The participants reported that they obtained strength through their involvement in the NAMI support group, their spirituality and for some just having an optimistic attitude. Though the participants experienced burden in various forms, all of the participants were found to demonstrate resilience. The essence of resilience was a common finding noted by the researcher in all of the participants. The following provides a discussion of what had
given the participants the strength they needed to cope with their family member’s mental illness and literature to support these findings.

All of the participants had reported that their connection with an advocacy support group, specifically NAMI, had given them the ability to cope with their family member’s mental illness. The participant’s involvement in NAMI provided them with what Yalom (1995) referred to as “universality.” The therapeutic effects of the group experience allows one to recognize that they are not unique in their experience, that others have had similar experiences and the group provides validation of their experience and benefits from the “catharsis and from ultimate acceptance by other members”(p. 7).

The literature provides evidence that support groups can be beneficial for family members of those who suffer from chronic mental illness. For example in Corring’s (2002) study, findings suggested that the “services that will support, educate and involve family members as well as the person with a mental illness are likely to improve quality of life for families of people with mental illness”(p. 357). Citron, Solomon and Draine (1999) studied self-help groups and characteristics of the group that families found helpful. Similar to the current study, the participants of Citron et al.’s study were from an advocacy group, but the study had taken place in a different state. Using descriptive statistics for a Group Benefits Scale, they measured what areas of the group that the participants found to be most effective. The results indicated that the most beneficial aspects of the support group were gaining more knowledge regarding the mental illness, learning more about available resources, and feeling less alone with their concerns. The authors contended that participating in support groups were a positive approach for
families who need to cope with caring for their mentally ill family member. The need for support groups have become more important with the changes in mental health services, the limited financial resources and the increase of family members caring for their mentally ill family member. Citron et al. explained one of the main reasons for limited resources for mental health by stating, “Mental health has always been regarded as the ‘step-child’ of the health care system” (p. 27). Implications from Citron’s et al. (1999) study demonstrated that the utilization of support groups are one of the most cost effective ways to provide education and support for families. With these findings, Citron et al. anticipated that the role of support groups could become much larger in the future.

Some of the participants had an overall optimistic attitude regarding their experience and were able to make the best of their situation. Some of the participants shared the positive attributes of their family member despite their diagnosis of mental illness. One of the participants, whose son was diagnosed with schizophrenia and had another son with cerebral palsy, reported that she viewed the mental illness as a challenge and had expressed feeling grateful that her son had mental illness as opposed to an illness which was untreatable. Not only did she feel it was a treatable illness, but that if given the proper treatment the individual could live successfully. The strength and courage to cope with mental illness in a family member related to the participant’s optimism and positive outlook, as opposed to focusing on the burden. The study findings of Rose et al. (2002) supported various aspects of burden that were reported over a two-year period. In addition to burden, the results indicated that the participants in the later phases of the illness had “adopted a stance of possibilities and realities” (p. 525). Unlike previous
studies, which focused on burden, the participant’s responses also included positive statements and future oriented statements as they reportedly strived for growth (Rose et al.). Results indicated, “some families were able to achieve a goal of being positive about the future for themselves and their relatives” (p. 532).

Three of the 5 participants found that their spirituality had given them the strength and courage they needed to deal with the overwhelming stressors of caring for their family member. The participant’s spirituality helped to provide the participants with strength, faith, courage and the resilience. The following research supported these findings. In Johnson’s (2000) study, participants reported faith, family and obligation were what had given them strength to keep going. Johnson found that those who felt supported by the religious community were more optimistic and more competent in managing problems (Johnson).

Bland and Darlington’s (2002) findings were similar. In their study they had explored the sources of hope for caregivers of people with serious mental illness. Religion or spirituality was reported as a major source of their hope. They reported that their faith in God had helped them to find the strength to get through the illness. The participants also had included that their religious practices and being a member of the church community had also provided support and strength.

As mentioned previously, all of the participants in this study expressed an essence of resilience and their responses had indicated a level of acceptance of their family member’s mental illness. This theme was supported in the literature. Marsh and Leafy’s (1996) study explored the theme of resilience in family members of those with mental
illness. The results of their study were similar to the present study regarding resilience. Their participants included members from NAMI. Family resilience was reported by 87.8% of the participants. In this study, resilience related to family bonds and commitments; family strengths and commitments; family growth and development; family contributions and family gratifications (Marsh & Leafy). Though burden responses were included in the study, the predominant theme identified was resilience. Implications from the study indicated that the public would need to expand their idea of the family experience to include resilience as well as burden (Marsh & Leafy).

Yashamita’s (1998) study found that in the course of dealing with their family member’s mental illness, the participants had reached a “turning point.” The participants described their turning points as the point at which they began “understanding and accepting the illness, accepting the uncertainty of the situation, understanding the relative’s behavior as part of the illness and accepting their relatives as they are” (p. 521).

Conclusions

This study explored the lived experience of family member’s of those who suffer from chronic mental illness. The lived experience was revealed through verbatim responses of the 5 participants. The changes in mental health care since the beginning of deinstitutionalization has resulted in greater responsibility for family members to provide care for the mentally ill. Though one may suspect that the family members of the mentally ill have experienced predominantly burden, the five participants in this study had learned to cope with mental illness with inspiring strength and were able to reach a level of acceptance of their family member’s illness. All of the participants had reported
that their involvement in the support group, National Alliance for the Mentally Ill had provided them with information and support that they had not often found elsewhere.

An additional finding in this study worth noting is the responsibility and care of the ill family member had often fallen on the shoulders of one individual in the family. Though other members in the system were affected by the ill member, the participants reported being the main primary care giver of their ill family member. This was also found in Hatfield’s (1978) study in which some of the participants reported the main emotional burden and responsibility of caring for the ill member fell on one individual in the family (Hatfield). Another finding worth noting that was not supported in the literature reviewed, was 2 participants had reported concern and disappointment that their ill family member would most likely be unable to find a partner and would end up living their life alone. This finding is similar to the family member’s experience of emotional burden of worry as described in Theme Two, but further research would be needed to explore this aspect of burden experienced by family members of those who suffer from chronic mental illness.

Though most of the findings of this study were supported by the literature, few studies were available from nursing. In addition, the majority of literature reviewed had focused on the various aspects of burden experienced by these family members. An important similarity between the findings in the literature reviewed and the current study were the participant’s experience of feeling unsupported in caring for their loved one with mental illness. The literature had supported this theme and has provided evidence of the importance and effectiveness of education and support for family members who care
for their mentally ill family member. Despite this need, a recurrent theme found within the literature (Corring, 2002; Doornbos, 2001; Dore & Romans, 2001; Gianfrancesco, Wang, & Yu, 2005; Jubb & Shanley, 2002; Gallagher & Mechanic, 1996; Greenburg & Greenley, 1997; Hatfield, 1978; Marsh & Lefley, 1996; Provencher, H. L., Perreault, M., St-Onge, M., & Rousseau, M., 2003; Rose, Mallinson & Walton- Moss, 2004; Tryssenaar & Tremblay, 2002; Yamashita, 1998; Ostman & Hannson, 2001) was that family members continue to experience a lack of support, lack of education, and a lack of needed resources to provide better care for their mentally ill family members. Such an experience expressed by family members becomes even more important as society continues to move away from the idea of institutionalizing those with mental illness, mental health care resources are limited due to budget cuts and families are given the primary responsibility to care for their ill family members. Meeting the needs of families could not only have a profound impact on the quality of life for the family members, but also their family member who suffers from chronic mental illness. Providing support to family members could promote a healthy environment, which could empower these families to focus on their strengths and reach a level of acceptance of the illness. “A healthy family may represent an oasis within an overwhelming and largely uncontrollable environment in which members feel acknowledged and provided with the necessary support to venture out and apply themselves in the community” (Friedemann, 1995, p. 17). Findings of this study lead to important implications for mental health nursing and their role with families.
Limitations

Limitations of this study can be identified. The researcher was not able to reach saturation due to size of sample and limited timeframe of the study. Additional findings may have been obtained if true saturation had been obtained. A second limitation was the inexperience of the researcher in doing qualitative research. A third limitation was all of the participants were from the same NAMI support group and lived in the same rural county. This may have created bias in terms of motivation of the caregiver and their perception of the illness. A fourth limitation was being logistically unable to review raw data with the participants. It would have been preferable to have a second interview with the participant to validate the reported findings.

Implications for Nursing

The findings of this study and supporting literature provide evidence of an increasing demand on family caregivers and the education and support that family member’s need from mental health professionals. Nursing’s role in the care of family members of those who suffer from chronic mental illness has become increasingly important, as the country’s mental health care has been in a state of transition. “A patient’s rehabilitation does not take place in a therapist’s office, it occurs in the situation in which he or she lives” (Hatfield, 1978, p. 358). For many of those who suffer from mental illness, the situation in which he or she lives is now with family members and not in an institutional setting. As nurses, we need to adapt our care to the changes and limitations in our current health care delivery system to meet the needs of patients and their families. Nurses who are working in community mental health or in a hospital
setting should use every available opportunity to teach families how to cope effectively with mental illness in their family and provide them with the desperately needed support and guidance in their family member’s rehabilitation process.

Understanding the lived experience of family members of those who suffer from chronic mental illness should be a priority for mental health nurses in the care of the mentally ill and their family members. Such information is necessary to be able to provide care for patients and their families and to be able to meet their needs for education and support. More than any other profession, the discipline of nursing has one of the most opportunistic roles to meet the needs of those who suffer from chronic mental illness and the families that care for them. Allowing family members to express their needs and emotions regarding their mentally ill family member, providing support and available resources could positively influence the patient and their family member. By providing professional support, the family member’s burden could potentially be reduced and consequently improve the quality of life of the patient and their family member (Doornbos, 2001).

An important implication for nursing, which was supported by this study is the need to attend to the obstacle of stigma that continues to exist when one is diagnosed with a mental illness. The stigma that accompanies mental illness has detrimental consequences and often prevents an individual from seeking the treatment they need. Nursing and other mental health professionals can play a powerful role in extinguishing stigma, by enhancing their own knowledge, staying informed regarding new research and examining their own biases and beliefs about mental illness and seek assistance to
overcome them. Nursing and other mental health professionals who are providing care in the mental health profession do themselves, their patients and their families a disservice by harboring inner prejudice and bias and being uninformed regarding mental health.

In this study, the participants expressed stress and frustration emotions regarding their unmet needs. This area has been identified in this study and supported throughout the literature. Nurses and mental health care providers have an obligation within the scope of their practice to educate patients, families, other health care professionals and the public regarding mental illness. Through education regarding mental illness, nursing could potentially reduce the emotional burden experienced by family members. Providing families with verbal explanations and written literature could help educate families regarding mental illness and alleviate some of their burden. Explaining to families what to expect and how to handle crisis could help to alleviate some of the family’s fear and worry. The family members would be better prepared to cope with the unpredictable symptoms and crisis, which frequently occurs in the course of chronic mental illness.

From this study, the researcher found that the experience of the first psychiatric hospitalization was a great stressor for family members. Providing adequate information and support to families during this difficult experience could influence their willingness to seek treatment in the future. Informing family members that their concerns are not unusual and providing families with access to a support group early in the treatment of the mental illness could be effective in decreasing anxiety, stress and overall burden that family members experience during their ill family member’s first psychiatric admission. Providing added support early in the diagnosis or during the first psychiatric
hospitalization could promote positive outcomes for the patient and the family. Examples of interventions during an acute psychiatric admission may include weekly educational groups for families and including families in treatment team meetings. Nurses could take an active role in assessing the family member’s needs and educate family members by providing accurate information regarding the diagnosis, symptoms, treatment, effects of mental illness and relapse prevention. Nurses should provide family members with referrals to outside agencies, such as NAMI, that may provide a great source of support, as evidenced by the findings in this study.

It is part of the role as mental health care providers to dispel the myths about mental illness, counter the negative stereotypes and to advocate for the mentally ill when they are exploited or misrepresented in the media or in political agendas. Nurses can have great influence on mental health advocacy through various political avenues by their active involvement in organizations that advocate for the mentally ill and support funding for mental health care resources. A current advocacy issue in many states is the fight for Mental Health Parity, which would prohibit the insurance companies from applying limitations of coverage on the treatment of mental illness.

The Advanced Practice Nurse’s role in mental health could have a profound impact on family members by implementing such things as teaching and evaluation tools with families that could be used in both the private and public sector. Increasing the family member’s knowledge may help to lessen the emotional burdens experienced. The participants in this study were able to reach a level of acceptance of their family member’s mental illness. Mental health nurses could make a remarkable difference for
families of those who suffer from chronic mental illness by helping them on their road to
acceptance. This research study provided valuable knowledge about the family member’s
lived experience that can be applied to practice. The nurse can use the knowledge and
understanding in educating and supporting families. The nurse can provide direction and
the essential resources that empower family members to build on their own strengths and
problem solving skills. Empowering the family promotes better care for their mentally ill
family member and improved self-care in their effort to achieve congruence within their
system. As indicated, the findings of this study demonstrate important implications for
nurses that could potentially influence the future care and quality of life of those who
suffer from mental illness and their families.

Recommendations for Further Research

The findings of this study provide valuable knowledge for nursing and other
mental health professionals. Despite the valuable data obtained, a more in-depth
understanding regarding the lived experience of family members of those who suffer
from chronic mental illness is needed, especially within the discipline of nursing. The
literature reviewed provided evidence of the lack of current nursing studies on this
phenomenon. In addition, further nursing research conceptualized within a nursing
theoretical framework is needed. Though research has indicated that mental illness
influences family members, further research on how mental illness affects specific roles
in the family would also provide valuable data. Financial burden was found to be an
experience of family members, yet there were few studies to explore this issue. With
changes in insurance coverage and increasing costs of medications for mental health
problems, further knowledge gained through additional research could potentially be useful for advocates to present in the political arena. Research on family members who are from various demographic areas and diverse ethnic background would provide increased data from a larger population of family members of those who suffer from chronic mental illness. Further research is also indicated to explore the stigma of mental illness. Specific areas to be researched may include stigma within the mental health professions and stigma experienced by families of those who suffer from chronic mental illness. Though much progress has been made in the last decade regarding the neurobiology of mental illness and the pharmacological treatment of mental illness, a great deal is yet to be explored about those who provide most of their care and are living the experience.

Summary

This chapter discussed the essential themes and essences of the structure of the lived experience of family members of those who suffer from chronic mental illness. Within this chapter, the themes discovered in this study were applied to Friedemann’s theory and literature was identified to support the findings of this study. The study conclusions and limitations were discussed. Implications for nursing were identified along with recommendations for further research. These study findings provide nurses with knowledge to apply to practice and teach families how to care for their family member who suffers from chronic mental illness. As nurses, we have the opportunity to improve the quality of life for those who suffer from mental illness and their families who care for them.
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ABSTRACT

The purpose of this study was to discover the lived experience of family members of those who suffer from chronic mental illness. Van Manen’s method of phenomenology was used for data collection and analysis. Five participants described their experience of being a family member of one who suffers from chronic mental illness. The nursing framework used to conceptualize this study was Friedemann’s Systemic Organization (1995).

Five essential themes emerged to reveal their lived experience: (a) participants experienced unmet needs, stigma and incongruence within the environment; (b) coping with multiple stressors that stemmed from the unpredictable overwhelming symptomatology and behaviors; (c) the effects of system change on the family system; (d) a lack of control over changes occurring within the system; and (e) spirituality provided strength, faith, courage, and resilience that facilitated the ability of family members to endure and reach a level of acceptance of the mental illness.